Sara Sanders Stacey R. Kolomer Cheryl Waites Spellman Victoria M. Rizzo *Editors* 

# Gerontological Social Work and the Grand Challenges

Focusing on Policy and Practice



Springer

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For all Hartford Faculty Scholars and Doctoral Fellows, AGE-SW Pre-dissertation Fellows, Hartford Partnership Program for Aging Education Practitioners, and NADD Gerontology Task Force. We are grateful for your everlasting commitment to mentoring the next generation of gerontological leaders and transforming social work education.

#### **Preface**

#### **Background and Overview**

The Grand Challenges for Social Work initiative was developed in 2012 by the American Academy of Social Work and Social Welfare in collaboration with leading social work researchers and academics to address some of the largest social challenges of the century (Padilla & Fong, 2016). It strives to "anticipate society's greatest problems, identify opportunities for social change, locate resources for change, develop success scenarios for social work, and raise vital scientific questions" (AASWSW, 2015) and aims to address primary issues that impact overall well-being and social environment, including "identity and recognition, love and nurturing, nutrition, shelter, family responsiveness, social protections, public health, medical care, education, opportunities for life experiences, information, employment, economic resources, financial services, systems for safety and justice, meaningful participation in society and personal fulfillment" (Sherraden et al., 2015, p. 5).

Grand challenge initiatives are designed to tackle a limited set of broad problems that have solutions that are within reach (Uehara et al., 2015). The focus is on both internal and external impacts of societal change that take place for an extended period of time. Internal impacts are related to the field of social work directly, including changing the identities of social work, impacting social work education, and working collaboratively with national organizations and social work educators and leaders. External impacts of the Grand Challenges include the development of strong, interdisciplinary research agenda and programs, public education about social work, increase funding for social initiatives, and strengthening the pool of future social workers and social work educators. During the next 10 years, the Grand Challenges for Social Work aim to ensure healthy development for all youth, close the health gap, stop family violence, advance long and productive lives, eradicate social isolation, end homelessness, create social responses to a changing environment, harness technology for social good, promote smart decarceration, reduce extreme economic inequality, build financial capability for all, and achieve equal opportunity and justice.

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#### **Aging in America**

In the United States, there are over 46 million people age 65 and over. In 2016, there were 27.5 million older women as compared to the 21.8 million older men with that disparity increasing as people age (Roberts, Blakeslee, & Rabe, 2018). Today, most older Americans identify as white with nine percent reporting as black and eight percent identifying as Latino (Roberts et al., 2018).

Physical and mental health issues are a challenge for many people over 65. Obesity rates in older adults between ages 65 and 74 have risen 40% (Mather, Jacobsen, & Pollard, 2015). A quarter of older adults live with multiple chronic health conditions such as hypertension, diabetes, and arthritis. Five million people are living with Alzheimer's disease (Mather, Jacobsen, & Pollard, 2015). By age 85, 55% of women and nearly 41% of men report having a physical limitation (Anderson et al., 2012). In addition to the impact on the older adults themselves, family and friends can be physically and economically burdened by the stress and strain of caregiving for an impaired older adult.

Financially, older adults today are doing better than previous generations of seniors. However, there continue to be economic challenges for some, particularly for women and persons of color. Twenty-one percent of married couples and 43% of single people rely on 90% of their income from Social Security. Eighteen percent of Latinos and 19% of African American older adults live in poverty (Mather, Jacobsen, and Pollard, 2015). Due to time off for caregiving and lower-wage work, women are more likely to be struggling financially in later years than men. Most concerning is that after meeting monthly expenses, one third of older adults have no money left. Nearly three million senior households or approximately 23% of 65+ households live with food insecurity (Fernandes et al., 2018).

The aging of our society is a critical social issue as we move deeper into the twenty-first century. Demographic trends indicate that the number of adults age 65 and over will increase to about 80 million by 2040, representing 21% of the US population (Administration on Aging, 2012). It is also projected that the older adult population will be more racially and ethnically diverse (Vespa, 2018). By 2035, more people in the United States will be over age 65 than under 18 (Vespa, 2018). With the changing demographics, there will be significant health and economic challenges for society to address. For example, Alzheimer's disease could triple by 2050 impacting 14 million people (Mather, Jacobsen, & Pollard, 2015). The increasing number of older adults in the United States, as in most places across the globe, poses challenges to families and caregiving, healthcare systems, mental health services, communitybased support programs, long-term care, housing, transportation, employment, poverty, retirement, and economic security. It also presents opportunities to craft and implement policy, strategies, and best practices to serve and support our now diverse and aging society. Gerontological social work must be at the forefront and lead in this arena by addressing these and other remerging societal challenges.

The Grand Challenges for Social Work provides a framework for exploration and action using a gerontological lens. As the Grand Challenges were presented, the

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majority did not have an aging focus and, in most circumstances, completely ignored aging and older adults from any discussion. Social workers utilize a systems approach for understanding individual, family, and community experiences. Older adults play a critical role in the lives of individuals, families, organizations, and communities. Eliminating older adults from the discussion for addressing the most pressing issues in society for social work to address seems disconnected. With current demographic trends, this in fact seems to support ageism that remains in society. Social work researchers, policy advocates, practitioners, and educators must assume a leadership role by addressing current societal challenges among older adults and our aging society. It also calls for active attention to the implementation of science-based research, policy, and practices to promote health and well-being.

The book is divided into 12 individual chapters, each addressing one of the Grand Challenges for Social Work through the lens of gerontological and gerontological practice. The chapters are structured to provide an overview of the issues associated with the Grand Challenge, a case presentation, discussion of assessment and intervention strategies, and finally future steps for practice, policy, and research.

Chapter 1 tackles the topic of healthy development for all youth, with a specific focus on how older adults in the lives of youth can contribute to their development. Many of the interventions and programs designed for ensuring healthy emotional, mental, behavioral, and physical development for youth only mention inclusion of parents while not including grandparents, siblings, or other close family members. Attention in this chapter will be given to how older adults contribute to healthy development of youth in our society. This chapter describes the range of custodial and co-parenting households including grandparents and the related risk and protective factors for youth and identifies interventions that have demonstrated effectiveness with these families.

Chapter 2 focuses on the health gap that exists with the United States. Older adults are a large consumer group of healthcare services for both acute and chronic health conditions. "Closing the Health Gap" will outline the current state of healthcare research and policy for older adults, specifically focusing on populations that are disproportionately impacted due to poverty, immigration status, environment, or other factors. Examining the social determinants of health and how they contribute to older adults maintaining overall health and well-being across multiple healthcare systems will also be explored.

Family violence, regardless of the type of violence, impacts the entire family system and can create trauma for generations. Chapter 3 examines stopping family violence, particularly violence that impacts older adults. Elder abuse is a prevalent type of family violence that has gained substantial attention by clinicians, policymakers, and researchers as a major issue affecting the aging population. The chapter on *stopping family violence* will examine the impact of abuse on the older adult's mental and physical health. Specific focus will be on elder abuse and the generational transmission of family violence onto older adults.

Chapter 4 looks at strategies for advancing long and productive lives in older adults. The development of interventions associated with *advancing long and productive lives* takes into account the full life course of individuals and their families

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as they age. Increasing attention towards the areas of diversity, socioeconomic conditions, environmental factors, and public policy is important to be addressed for older adults as well. With our aging society and increased longevity, the prevalence of chronic diseases, dementia, health, and economic disparities calls for innovative evidenced-based practices, actions, and services provision to support healthy aging. This chapter will bring together these concerns and expand the meaning of productivity to include caregiving and volunteering as a means of staying engaged and active.

Chapter 5 has been written on social isolation which has been discussed in the literature on older adults. The literature has looked at the link between social isolation and depression and other mental health consequences. Social isolation reduces opportunities to engage with others and advance productive living. With the magnitude of losses older adults face, coupled with the change in functionality, determining strategies of eliminating social isolation and keeping people engaged at their personal level of choice is essential. This chapter will examine the issues associated with social isolation and older adults and the strategies for reducing it at all levels of the system.

Chapter 6 is dedicated at examining the issues of homelessness among older adults.

Homelessness is a growing concern among gerontologists as approximately one third of all individuals who classify as homeless are over age 50. The combination of issues associated with homelessness, including mental health, historic trauma, and substance abuse coupled with physical changes associated with aging such as reduced mobility and a need for assistance with daily activities, calls for creative solutions. This chapter identifies practice strategies for gerontology professionals to use in direct practice but also at the macro level with necessary policy considerations to better address the factors that lead to homelessness for older adults.

Chapter 7 looks at the role of social workers in responding to the changing environment, with a lens on environmental justice. Catastrophic events such as 9/11 and Hurricane Irma have taught that disaster planning for older adults and their caregivers necessitates interprofessional collaboration and coordination. When considering disaster preparedness, special consideration needs to be given to people with Alzheimer's disease and visual or hearing impairments and to individuals who are bedbound or confined to a wheelchair. This chapter will focus on the organization of preparedness plans of national and regional organizations for older adults.

Chapter 8 examines the role that technology can play in the world of older adults and can be a tool in addressing isolation, health, and mental health challenges. Additionally, how technology can be a resources in helping older adults maintain functional independence is also discussed. Computer technology has the potential to assist in maintaining independence by supporting the everyday tasks of older individuals, as well as by aiding caregivers and family members. This chapter will explore how technology can be harnessed to support older adults in aging in place and how to engage older adults, families, and service providers to use these resources.

Chapter 9 discusses the graying of the correctional system in the United States.

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With longer and stricter sentencing guidelines, offenders are aging in place and dying in the correctional system. With not all states allowing for compassionate release and not all offenders having a place to go if released, considering how to meet the needs of older adults who are living and dying behind bars is essential. This chapter highlights the practice and policy issues currently being examined to assist in addressing the needs of older offenders.

Chapter 10 examines the economic inequality that exists in the United States, with a particular focus on the policy issues and programs that are designed to address the discrepancy between populations. *Economic inequality* permeates the United States, and yet much of the focus regarding balancing wealth is concentrated on addressing the needs of children and families; however, millions of older adults are considered economically insecure. With rising costs of medication, housing, food, and transportation being economically insecure can cause physical, mental, and emotional harm to older households. This chapter will discuss the financial insecurity of older adults as it currently exists, existing programs and services in communities that can help older Americans become financially secure and independent, and development of policy reform that tackles income inequality in older adults.

Chapter 11 looks at building financial capacity for individuals as they reach older adulthood as many individuals are facing financial insecurity. There is a specific focus in this chapter on the lack of financial income, scams and fraud, and engaging the older adults in financial management. Aging families are threatened by several challenges with regard to building financial capability, including limited savings and lack of retirement plans. Interventions and opportunities for educating families about financial capability for older adults will be discussed.

Chapter 12 examines equal opportunity and justice with a specific focus on transgendered older adults. Older adults face multiple jeopardies regarding equal opportunity and justice shaped by ageism and the lack of knowledge regarding aging. Perceptions and recognition regarding how ageism and ageist attitudes influence employment discrimination, housing, economic security, retirement, nursing homes and continuum of care facilities and services, healthcare provision, and disparities that impact racial, ethnic, and LGBTQ communities are important in effecting a just multigenerational society. This chapter will address how to enhance the recognition and understanding of justice issues as it pertains to transgender older adults and how to advocate and promote justice.

**Keywords** Grand challenges; Gerontology; Older adults; Aging; Social work; Twenty-first century; Health; Well-being; Families; Aging initiatives; Communities; Aging in place; Diversity; Social justice; Disparities; Homelessness; Technology; Social isolation

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## **Chapter 1 Ensure Healthy Development for All Youth**



1

James P. Gleeson, Qiana R. Cryer-Coupet, and Tyreasa Washington

#### **Grand Challenge: Ensure Healthy Development for All Youth**

To address the Grand Challenge of ensuring healthy development for all youth, the American Academy of Social Work and Social Welfare has adopted two goals to achieve within 10 years through widespread implementation of tested and effective preventive interventions:

- 1. Reduce the incidence and prevalence of behavioral health problems in the population of young people from birth to age 24 by 20%.
- 2. Reduce racial and socioeconomic disparities in behavioral health problems, also by 20% (Grand Challenges for Social Work, 2018 GC Fact Sheet No. 1).

#### Overview

Behavioral health problems compromise a young person's mental or physical well-being and impede healthy development. Thirty years of scientific evidence demonstrate that behavioral health problems can be treated and also prevented (DeVylder, 2015; Hawkins et al., 2015). Missing is a focus on implementation and the effectiveness of programs and interventions in grandparent-headed households and families engaged in parent-grandparent coparenting relationships.

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While the majority of children and youth in this country reside with at least one biological or adoptive parent, more than 2.8 million children (3.8% of the U.S. child population) live in households with neither of their parents present (U.S. Census Bureau, 2016). Point in time statistics reveal that nearly 1.6 million (2.1%) of these children reside in the home of a custodial grandparent (also known as grandfamilies). More than 5.6 million (7.7%) live in three-generation households that include grandparents and parents, 2.4 million (3.3%) in households that include a grandparent and both parents, nearly 2.8 million (3.8%) in households that include a grandparent and the child's mother, and 437,000 (0.6%) that include a grandparent and the child's father (U.S. Census Bureau, 2016). Cumulative estimates indicate that nearly 30% of U.S. children co-reside with a grandparent at some time in their childhood, and this is most common during the child's first year of life (Amorim, Dunifon, & Pilkauskas, 2017).

In nearly two-thirds of three-generation households, the grandparent is the head of household. The grandparent is the child's primary caregiver when no parent is present; however, noncustodial parents may maintain a coparenting relationship (Gleeson, Strozier, & Littlewood, 2011). In most three-generation households, the child's parent or parents maintain the primary parenting role. In other households, the grandparent is the primary caregiver or shares parenting responsibilities. Threegeneration co-residence is most common among Asian families, followed by African American, Hispanic, and White families (Amorim et al., 2017). Grandfamily arrangements are most common among African American families. African American children are nearly twice as likely to ever live in grandfamily arrangements compared to Hispanic children, three times as likely as White children, and six times as likely as Asian children (Amorim et al., 2017). Providing services (i.e., case management, counseling, parenting classes, and education about navigating school systems) to three-generation and grandfamily households is essential in achieving the goal of reducing racial and socioeconomic disparities in behavioral health problems (i.e., under-/overdiagnosis of mental health problems and inadequate/inappropriate medication prescription and management) since children and youth of color are more likely to be raised or coparented by a grandparent compared to White children.

*Grandfamilies* Grandfamilies form for a variety of reasons related to parents' inability to care for their children, including parental substance abuse/addiction, child neglect or abuse, parental incarceration, parental mental or physical illness, homelessness, or general lack of stability (Gleeson et al., 2011). Mandatory sentencing policies have contributed to mass incarceration and the need for grandparents to step in to raise their grandchildren, disproportionately affecting people of color and those living in poverty (Children and Families of the Incarcerated Fact Sheet, https://nrccfi.camden.rutgers.edu/files/nrccfi-fact-sheet-2014.pdf, retrieved 1/9/19).

#### **Informal kinship**

Grandfamily arrangements vary by degree of involvement with the public child protection system (CPS). Approximately 39% of children living with a grandparent or other relative with no parent present in the household are in private "kinship care"

arrangements with no involvement of CPS (Testa, 2017). In some of these families, the kinship caregiver may have assumed private guardianship, but in many families the caregiver has no legal custodial relationship to the child. Another 32% of children in kinship care with no parent present are in voluntary arrangements. Like private kinship care, CPS does not have custody or guardianship of the child and the relative may or may not have private guardianship or custody. Unlike private kinship care, these children and families have had some involvement with the child welfare system, and slightly more than half of these have open cases with the public child protection system. Both private and voluntary arrangements are often referred to as *informal kinship care*.

More than 40% of caregivers without CPS involvement do not have legal custody or guardianship of the child(ren) in their care, and since they are not engaged with the child welfare agencies or courts, they may see little need for legal permanency. The lack of a permanent legal status may leave children vulnerable in the long term either from a troubled parent who retains legal custody or from instability due to inadequate access to supports and services. Grandparent caregivers are often ineligible for certain financial supports when they lack legal status as foster parents, adoptive parents, or legal guardians.

#### Formal kinship

Approximately 9% of children in kinship care with no parent present are in public kinship care arrangements, also known as *formal kinship care*, which means CPS has custody or guardianship of the child. CPS has legal responsibility to oversee the living arrangement and to develop and implement a case plan to ensure the child's safety, well-being, and movement toward a permanent legal living arrangement. Children in public kinship care generally are in the custody of the child welfare system due to abuse, neglect, or abandonment by the child's parents. An estimated 20% of children living with kin with no parent present are in legally permanent arrangements through adoption (Testa, 2017).

Risk factors On average, children raised by their grandparents are at greater risk of academic, socio-emotional/behavioral, and mental health problems compared to their peers in the general population and peers raised by their mothers in similar socioeconomic conditions (Pilkauskas & Dunifon, 2016). Higher levels of risk have been attributed primarily to the trauma associated with the reasons that led to living with a grandparent. Other contributing factors are higher rates of family poverty and lack of access to financial supports and services (Caliendo et al., 2017; Testa, 2017). Nonetheless, the research on kinship care suggests that children living with kin display more favorable behavioral and mental health functioning and greater improvements in behavioral functioning over time than children in the custody of CPS and placed with nonrelated foster parents (Gleeson, 2012; Washington et al., 2018; Winokur, Holton, & Batchelder, 2018). There are a couple of exceptions that suggest increased risk of adolescent substance abuse and pregnancy (Sakai, Lin, & Flores, 2011) as well as delinquency among African American and White adolescents (Ryan et al., 2010) in public kinship care compared to their peers in foster care.

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Children in public kinship care arrangements have been identified as sufficiently at risk to require CPS to assume legal custody. Children in voluntary kinship care arrangements may also experience high levels of risk exposure. Bramlett and colleagues' (2017) analysis of national survey data focused on children in nonparental care found that children with current or past CPS involvement, who were not in the custody of the child welfare system at the time of the survey, were at particularly high risk. These children displayed higher rates of adverse family experiences compared to children in private kinship care with no history of CPS involvement. They were more likely to have experienced violence in the home or neighborhood, lived with a person who experienced mental illness or struggled with addiction, or been impacted by parental incarceration. Children in private kinship care with no history of CPS involvement tended to have better health and academic outcomes, but had poorer prospects for legally permanent relationships with their adult caregiver.

While grandfamilies tend to have more material and financial resources than the noncustodial parents, the children in these family are much more likely be living in poverty than their peers in the general population (Pilkauskas & Dunifon, 2016). Children living in poverty are more likely to experience disruption of their living arrangements than other children living with kin (Lee, Choi, Lee, & Kramer, 2017). Although most grandparent caregivers intend to raise their grandchildren until they are grown (Pilkauskas & Dunifon, 2016), not all situations are successful. Stability of the kinship care living arrangement is also affected by the number of children in the home, the age of the children, and the age of the caregiver (Lee et al., 2017). There is evidence that children living with older grandparents are more likely to experience stable living arrangements compared to children living with younger grandparents; however, the likelihood of disruption of the living arrangement increases with the number of children in the home. Disruption is also more likely for infants and adolescents.

Custodial grandparenting exposes caregivers to a number of health risks as well. Grandparent caregivers tend to neglect their own health and well-being (Kelley, Whitley, & Campos, 2010). Raising a grandchild tends to disrupt grandparents' life plans, thrusting them into a parenting role once again and depriving them of the joys of grandparenting without the responsibilities of parenthood. Assuming primary care of a grandchild is often accompanied by strained relationships with spouses or intimate partners and isolation from friends and other grandchildren because of parental responsibilities (Hayslip Jr, Blumenthal, & Garner, 2014). Caregiver stress is further exacerbated when there are conflicts with the grandchild's parents, if CPS is involved, and if there are legal challenges related to custody of the child. Grandparent caregivers experience additional burden, stress, and strain when the parents are unable to raise their child due to drug abuse, severe mental illness, or involvement with the criminal justice system. They may also have additional complex caregiving responsibilities for an aging spouse or other family members (Peterson, 2018). Lack of financial and material resources is also associated with caregiver stress (Gleeson, Hsieh, & Cryer-Coupet, 2016). Housing instability, which is common for many low-income grandparent caregivers, is a major contributor to caregiver stress (Fuller-Thomson & Minkler, 2003; Kolomer & Lynch, 2007).

Despite the stress and burden, many grandparents derive satisfaction and meaning from raising grandchildren (Waldrop & Weber, 2001). Grandparents and other kinship caregivers are often motivated by their desire to keep the children with family and out of the foster care system, to keep them safe, and ensure their well-being and a sense of belonging (Gleeson et al., 2009). Some kinship caregivers are motivated by a sense of obligation and love, while others describe a spiritual influence.

**Protective and promotive factors** Recent research has identified protective factors that buffer risk, as well as promotive factors that contribute to positive outcomes for children. Denby and colleagues (2017) found a direct inverse association between kinship caregiver stress and perceptions of child well-being. Kinship caregivers of children with special needs experienced higher levels of stress and reported lower levels of child well-being. The association between caregiver stress and child wellbeing was partially mediated by the caregiver's parenting skills and attachment to the child, which was moderated by the caregiver's level of motivation and ability to sustain care of the child. The direct effect of risk factors on well-being was moderated by the degree of extended family involvement and support in the care of the child. More involvement of extended family meant less effect of the risk factors. Washington and colleagues' (2018) systematic review of studies of children in kinship care and foster care found positive parenting practices and healthy family functioning had positive effects on behavioral health, with higher levels of functioning generally displayed by children in kinship care than in foster care. Healthy family functioning and good quality relationships between children and their biological mother and father were predictive of higher levels of children's competence (Washington et al., 2014; Washington, Gleeson, & Rulison, 2013).

Financial and material resources and family competence are protective factors for kinship caregivers. Adequate financial and material resources moderate the association between family competence (i.e., the family's ability to problem-solve, adapt, and express appropriate emotions) and caregiver stress (Gleeson et al., 2016). Family competence has a greater impact on reducing caregiver stress when family resources, including financial and material resources, are adequate.

Three-generation households and co-parenting Three-generation households vary considerably with regard to how and why they are formed. For the purposes of this chapter, the focus is on households in which grandparents are primary caregivers or play a significant coparenting role. Children in many three-generation households experience risks similar to those that precipitate grandfamily living arrangements. However, compared to custodial kinship care arrangements, three-generation households are more likely to form because of financial need, parental divorce, or the parents' work or school responsibilities (Gleeson et al., 2011). It is also common for teen mothers to continue to live with their parent(s) and rely on them to help with the care of the child, as new grandparents help their child continue to negotiate their adolescent development and simultaneous transition to a parenting role (Dallas, 2004).

Cultural and racial patterns in the formation of grandfamilies, three-generation households, and coparenting relationships reflect cultural views, strengths, and helping traditions (Gleeson, 2012; Gleeson et al., 2011). Particularly in African American and Latino families, grandparents often play a coparenting role or, through their support, strengthen young parents' coparenting relationships (Poblete & Gee, 2018). A broad coparenting framework is helpful in understanding cultural patterns of shared caregiving, in response to a number of environmental conditions (Jones, Zalot, Foster, Sterrett, & Chester, 2007). Rather than defining parental roles by marital status or household composition, broader definitions of family that incorporate a number of different family members who may be involved in parenting, regardless of whether they live in the home with the child, more accurately reflect the child's experience, and the experience of those who are key in influencing the child's development.

A coparenting framework is useful in understanding who is involved in parenting the child in all families, including grandfamilies. This is important when engaging key family members in treatment or services to ensure the child's healthy development. Analysis of data collected from the Fragile Families and Child Well-being study demonstrates nonresident parents visit their children frequently, an average of two to three times per week (Pilkauskas & Dunifon, 2016). In some of these families, the parent plays a coparenting role. Parent-grandparent coparenting in grandfamilies is more common in private than public kinship care arrangements (Gleeson et al., 2011). Research involving two-parent families has demonstrated positive associations between the quality of coparenting relationships and child outcomes, but research on multigenerational coparenting is relatively new and primarily descriptive of the variety of coparenting arrangements. These arrangements vary in a number of ways, including the degree to which child rearing responsibilities are shared, whether the child's parent or grandparent takes the primary role, how responsibilities and tasks are determined and by whom. A number of coparenting quality assessment mechanisms have been applied to parent-grandparent coparenting relationships, with much of this work focused on mothers in jail or prison and the child's grandparent caregiver as well as in three-generation households with coresident grandparents. An interesting study conducted in Pakistan with mutigenerational families, involving a child, two parents, and a grandparent, revealed a positive relationship between parenting quality and the child's self-reported social competence, with the child's emotional closeness to grandparents demonstrating a moderating effect between less desirable parenting and the child's social competence (Akhtar, Malik, & Begeer, 2017). The following case presentation, shared by Ms. Brown, describes her experience coparenting as a custodial, and as a noncustodial, grandparent over the first 17 years of her granddaughter's life.

#### **Case Presentation**

Ms. Brown has always played a major role in raising her 17-year-old granddaughter, Kmama. When her middle son, Myson, was released from prison after serving a sentence for selling drugs, he entered into a relationship with CeCe, who was

addicted to drugs and raising children from previous relationships. Ms. Brown and her husband allowed them to live rent-free in the two-flat building they owned. Ms. Brown and her husband lived on the first floor. Myson had difficulty finding steady work and qualifying for financial support and was regularly short on cash, frequently requiring Ms. Brown and her husband to give him money for food, clothing, and other necessities.

Shortly after Kmama has born, Myson and CeCe separated. Myson returned to selling drugs, CeCe continued to do drugs, and both had repeated episodes of arrest and incarceration. Ms. Brown took Kmama in, continuing to care for her even after her husband died. Ms. Brown relied upon her mother and sister who lived close by to help with childcare so she could go to work. CPS was never involved.

I didn't want to become her guardian. I wanted and expect my son to raise his own child, but I also could not live with my grandchild going into the CPS System.... I was not going to let that happen.

Myson kept his daughter for a full year after marrying another woman. He moved out of state with "his new family". However, when CeCe was released from prison, Myson gave Kmama to her, which lasted only a short time since CeCe began using again. As Kmama was shipped back and forth between her father, mother, and maternal grandmother (who also used drugs), Ms. Brown continued to check in on her and provide support. Every week, she received a call that her granddaughter did not have shoes, clothes, and other essentials.

I still feel like he's holding me hostage. I feel like if I don't give the \$100 or \$200, I fear my granddaughter is going to be homeless or have no food. I still go ... twice a month to make sure my granddaughter is OK.

At several points during her adolescence, Kmama returned to live with Ms. Brown, sometimes displaying behavior that she found challenging. However, Ms. Brown describes her greatest challenge as "trying to let my grandbaby know that she is loved... make sure that she knows that I love her and that she is safe". Ms. Brown struggles with "trying to hold my family together," while meeting her own developmental needs.

I get angry. I get mad. I raised my children. We took them places and gave them things. I am hurt that he sells illegal drugs but I am more angry that he doesn't take care of his child...I have 5 grandchildren and she is the only one I ever had to care for.

I don't want to give up on my son. He is not a bad person. He hurts because I know that he loves his daughter. He is in his mid-30s...I wish there were policies that support parents coming home from prison.... I just wish there was more support for the transition to be more successful after prison. Both parents were incarcerated in this situation....

I don't want to be a mom, I just want to be a grandma. I can't go anywhere and ask anybody for help...There are things I cannot have because I am supporting my son and his daughter, this can cause me to be homeless, stressed, and I have nowhere to go for help. Need systems of support.... support is support, if this means supporting extended families to support families...grandparents should not have to do this...

#### **Assessment and Intervention**

There are a number of family-child interventions with at least some empirical support that are relevant to achieving the goals related to the Grand Challenge. These interventions target key protective factors identified in the research on grandfamilies, including access to resources, caregiver parenting skills, coping with stress, and family engagement. Several of these interventions may have been helpful to Ms. Brown and her family at various points in their life, had they been available.

Kinship navigator programs (KNP) assess the needs of grandfamilies and other kinship caregiving families and assist families in identifying resources and services to which they may be entitled as well as navigating bureaucratic eligibility criteria and procedures to access these resources and services (Rushovich, Murray, Woodruff, & Freeman, 2017; Schmidt & Treinen, 2017). Navigator programs are particularly important for grandfamilies providing private kinship care, like Ms. Brown, since these families are less likely to be connected with formal social service systems. Other interventions show promise in helping grandparents and other relatives involved in public and voluntary kinship care negotiate the child protection bureaucracy, including Kinship Liaison and Kinship Support (Gleeson, 2012; Wheeler & Vollet, 2017). Kinship Liaison interventions pair caregivers who are new to involvement with the child welfare system with experienced kinship caregivers. Kinship Support interventions assist voluntary, as well as public kinship caregivers who are not licensed as foster parents, access services needed to ensure the safety, permanency, and well-being of children in their care.

Family Group Decision Making (FGDM) is a promising practice in engaging extended family members that has been tested in a number of child welfare and juvenile justice settings with grandfamilies and other formal and informal kinship care arrangements (Gleeson, 2012). FGDM is a decision-making process involving members of the family group, members of their informal network, community groups, and CPS or other agencies involved in the family's life. FGDM is derived from family group conferencing, which was developed with the indigenous Maori population in New Zealand, based on their traditional practices. With the assistance of a coordinator, families lead the decision-making process, consistent with their cultural values and traditions (American Humane Association and the FGDM Guidelines Committee, 2010).

It is possible that FGDM could have been helpful to Ms. Brown in convening members of the paternal and maternal extended family, along with Kmama and her parents, to develop a more stable long-term plan for Kmama. FGDM can be implemented in conjunction with Navigator and/or Kinship Liaison programs, which may be useful in bringing formal social services to the table in combination with informal family support. Feldman (2017) demonstrated positive, but statistically insignificant trends in reducing parenting stress, increasing social support, meeting family needs, and child well-being among a sample of families involved in informal kinship care (mostly grandfamilies). Clearly, more research is needed to determine the full potential of FGDM for families involved in a variety of grandfamily and coparenting arrangements.

McLaughlin, Ryder, and Taylor's (2017) systematic review of studies of the effectiveness of interventions for grandparent caregivers identified an Australian randomized controlled trial (RCT) evaluating the efficacy of a behavioral intervention designed specifically for grandparents (Grandparent Triple P) who provided 12–30 hours of informal childcare for a grandchild (Kirby & Sanders, 2014a, 2014b). Short-term effects were demonstrated in grandparents' parenting confidence, levels of depression, anxiety and stress, relationship satisfaction with the biological parent, and self-efficacy in communicating difficult parenting topics with the parents.

McLaughlin et al.'s (2017) systematic review concludes that compared with other approaches, cognitive-behavioral interventions with grandparents are supported by the highest level of evidence. In addition to Grandparent Triple P, other cognitivebehavioral interventions demonstrate positive effects on the grandparent's resourcefulness, stress, depressive symptoms, and quality of life, all relevant to the grandparents' ability to sustain their caregiving role. Promising results have also been found for (1) support groups in reducing symptoms of depression; and increasing caregiving mastery and access to formal supportive services and resources; (2) psychoeducation to improve grandparent caregivers' knowledge of physical healthrelated needs, parenting, and child development; (3) interdisciplinary case management to improve grandparent mental health outcomes, social functioning, family coping, and physical health and reduce psychological distress; and (4) home visitation by registered nurses and social workers and other support services to improve the health outcomes of grandparent caregivers (McLaughlin et al., 2017). Interventions that improve the health and well-being of grandparent caregivers are likely to contribute to their ability to continue to care for their grandchildren, increasing the likelihood of enhancing the well-being of the youth in their care.

A multisite RCT based upon the Family Stress Model demonstrates the effectiveness of a behavioral parent training (Triple P Positive Parenting) and a cognitive-behavioral intervention (Coping with Caregiving) compared to an information-only comparison group, with custodial grandparents (Smith et al., 2018). Both interventions were more effective than information only in reducing grandparent caregivers' psychological distress, improving parenting practices, and lessening the grandchild's psychological difficulties. Consistent with the Family Stress Model, this study's findings demonstrate that targeting parenting practices improves these practices while simultaneously reducing caregiver stress, and, targeting caregiver coping reduces caregiver stress while simultaneously improving parenting practices.

Multiple studies demonstrate effectiveness of interventions with families to manage and improve serious behavior problems displayed by some youth in kinship care and foster care. For example, a recently published systematic review reported a number of well-designed studies that tested the effectiveness of *Keeping Foster Parents Trained and Supported* (Project KEEP), an intervention designed to equip foster and kinship caregivers with the parenting skills necessary for managing challenging child behavior problems, with children who are placed in public kinship care and nonrelative foster homes (Washington et al., 2018). KEEP has been found to be effective in decreasing children's behavior problems and sustaining these

gains over time compared to children in control groups, reducing behavior problems of more than one child in the household, and in reducing parental stress associated with children's behavior problems. Although Ms. Brown's family was not involved with CPS, there were a number of times when managing Kmama's behavior was challenging, and interventions such as KEEP may have been helpful.

Washington and colleagues (2018) identify an RCT that tested the effectiveness of Child Directed Interaction Training (CDIT) and found the intervention was associated with decreased externalizing behaviors. CDIT is the first phase of Parent-Child Interaction Therapy, an evidence-based treatment for preschoolers with histories of child abuse and neglect. CDIT enhances the caregiver-child attachment relationship by providing caregivers with concrete skills to increase emotional reciprocity in caregiver-child interactions while using differential social attention to manage child behavior. A recent pilot study of CDIT with young children in kinship care demonstrates more positive caregiver relationships with children, decreased caregiver parenting stress and depression, and fewer child externalizing behavior problems compared to a wait list control group (N'zi, Stevens, & Eyberg, 2016).

A number of creative interventions have been developed by Strozier and colleagues (Gleeson, 2012). Their school-based intervention shows promising results in increasing the self-esteem of children in kinship care and reducing the caregiver's burden related to dealing with the child's education. Their computer-based training program enhances kinship caregivers' self-efficacy and confidence in educating the children in their care.

In addition to the interventions that have been evaluated and described in the published literature, there are a number of creative programs that are being developed by service programs around the country. One such program is Helping and Lending Outreach Support (HALOS) in Charleston, South Carolina. This agency is solely dedicated to meeting the needs of abused and neglected children by assisting and advocating on behalf of their kinship caregivers. Understanding the demands that are often placed on kinship caregivers with minimal resources, HALOS provides a coaching model and delivers most of their services in-home. Caregivers are assisted with financial resources to obtain primary material needs. They are also assisted with the process of establishing legal guardianship to ensure that they can enroll their relative child in school and receive medical care. Eligible families also receive enhanced case management for an additional 12-18 months, working with a success coach to develop and carry out a family action plan. HALOS provides monthly caregiver networking events, legal workshops, parenting (second time around) classes, and courses on how to support their relative children with the multiple transitions they are facing.

Another program which is listed in the California Evidence-Based Practice Clearing House, but has not yet been rigorously evaluated, is Grandparent Family Connections, a multifaceted, community-based service program that works with grandfamilies in their homes and in the context of their neighborhoods to help them meet the basic needs of the children in their care and prevent child maltreatment. The program uses an ecological developmental framework, community outreach, individualized family assessment, and tailored interventions to address the special

needs of grandfamilies, increase protective factors, decrease risk factors, and target child safety, well-being, and permanency outcomes (http://www.cebc4cw.org/program/grandparent-family-connections-gfc/detailed).

#### **Future Steps**

**Practice** To ensure healthy development for all youth, Hawkins and colleagues (2015) recommend implementing and sustaining universal, selective, and indicated programs. Universal programs are designed to benefit all children and youth, while selective programs focus on young people who have been exposed to elevated levels of risk but do not yet display behavioral health problems. *Indicated* programs are for youth who evidence early symptoms of behavioral health problems. Kinship Navigator Programs have the potential to identify resources and link families to programs that address universal needs, such as income and housing assistance, healthcare, legal services, and to identify selective and indicated programs and link families to these services when levels of risk are high. However, Kinship Navigators are not currently available in all states and localities. A working group of scholars and practitioners who met for a 3-day summit on kinship care in 2016, identified the need for systems of care, with KNP as the central point of contact and entry point for kinship caregiving families, particularly those involved in private kinship care arrangements with no established relationships with service providers to help them access resources and services to meet their needs (Caliendo et al., 2017). Ensuring the availability of kinship navigators in all states and localities could go a long way in disseminating universal, selective, and indicated services to meet the needs of families headed by grandparents and those in which grandparents play a key coparenting role. Navigator programs should be charged with maximizing access to and utilization of services that address the specific needs of grandfamilies, particularly those involved in private and voluntary kinship care. However, these services should also be made available to other families not currently connected to social service systems. For some families, information and referrals are all that are needed. However, aggressive outreach is necessary for some of the hardest to reach families, including those who fear that formal social services are primarily in the business of removing children from families and placing them in foster care. Given the high level of need and the low level of utilization of supports and services among grandfamilies and many three-generation families, it is important for navigator programs to actually create demand and facilitate uptake and utilization of essential universal services, as well as selective and indicated services.

Beyond navigator programs, it is critical that helping professionals have a broad view of family and understanding of diverse parenting and coparenting arrangements. Social workers and other helping professionals encounter grandfamilies and multigenerational coparenting families through the doors of all major service systems, such as CPS, the justice systems, health care, and educational settings. Without

specific focus on caregiving responsibilities and arrangements, and a broad view of family, professionals may not be aware of the relevance of these responsibilities and arrangements to the stated presenting problem. For example, the primary care physician may not be aware that an older person's high blood pressure and other health problems are related to stress associated with caring for grandchildren or conflicts with their own children related to coparenting grandchildren. The school psychologist, social worker, or special education teacher may not realize that engaging the grandparent, uncle, aunt, or other relative may be as essential as engaging the child's parent in a plan to address the child's behavioral and mental health or academic challenges. It is clear from the existing research that supporting caregivers to help them cope with and reduce stress, access healthcare and other services, and live healthy lives, benefits the caregivers and tends to have positive effects on child behavior and functioning.

Bonecutter and Gleeson (1997) describe four practice principles that provide a guide for practice with grandfamilies and families involved in various coparenting arrangements. First, adopt a broad view of family to include extended family, kinship networks, and multiple households. Second, continuously strive for cultural competence using a strengths-based approach and an appreciation for various forms of shared caregiving. Third, adopt a collaborative approach with families in all phases of assessment, intervention, and decision-making. Finally, build the case management capacities of families to ensure their stability into the future, planning for secondary caregivers should current caregivers become incapacitated. These principles can be applied to a variety of situations and encounters with grandfamilies and families involved in other coparenting arrangements. For example, a broad view is helpful when assisting grandparent caregivers in identifying family members who may bring particular strengths and resources to developing and implementing a long-term plan for ensuring a stable living arrangement and healthy development for grandchildren in their care. A collaborative approach is necessary to identifying and engaging these family members, incorporating their wisdom in the development of the plan, and ensuring their commitment to implement the plan over the long haul. A strengths-based approach and respect for families is essential to identifying ways the family has solved problems successfully in the past, and traditions that they can draw on to manage transitions, such as caring for children when parents are incarcerated or adjusting to changes when they are released from prison and return home. Ms. Brown shared a recommendation for helping professionals who come into contact with grandparents involved in raising or coparenting their grandchildren: "Listen carefully to what the caregivers say are their needs rather than just putting in what you think are their needs."

**Research** Research is needed at local, state, and federal levels to identify barriers and challenges to accessing essential universal, selective, and indicated services. More research is needed about the effectiveness of a variety of universal programs such as KNP, FGDM, Kinship Liaison programs, support groups, as well as selective and indicated interventions such as case management, Project KEEP, and Grandparent Triple P. In addition, research is needed to adapt and test the effectiveness of other promising interventions with grandfamilies and coparenting families.

Testing the effectiveness of various community-wide collaborative interventions to increase the uptake/utilization of universal services and evidence-based interventions with youth reared or coparented by grandparents is needed. Addressing risk factors that may differ across communities such as differential exposure to social determinants of health as well as protective factors that may be unique to specific communities is essential. Identifying existing resources and services as well as evidence-based interventions that are needed for children/youth and their caregivers/families in each community is also important.

Research is also needed that considers racial, ethnic, and cultural factors when adapting and testing the acceptability, utilization, and effectiveness of various universal, selective, and indicated interventions with grandfamilies and three-generation families (American Psychological Association, 2008; Hayslip, Fruhauf, & Dolbin-MacNab, 2017). For example, a number of scholars argue that to improve the efficacy of interventions with African American families, the role of racism and other racial/cultural factors such as racial socialization should be considered (Coard, Foy-Watson, Zimmer, & Wallace, 2007; Snowden, 2001). Additionally, culturally relevant interventions increase the attendance, participation, and satisfaction of African American participants (Coard et al., 2007). This is likely true for other cultural groups as well.

**Policy** A number of policies facilitate or impede access to necessary universal, selective, and indicated services for grandfamilies, three-generation households, and families engaged in a variety of shared caregiving and coparenting arrangements (Gleeson et al., 2011). In large part, access to financial support and other services for grandfamilies is influenced by whether the arrangement is public, voluntary, private, or permanent. Families in public kinship care arrangements have access to more financial support, particularly if the family's home is licensed as a foster home. Access to foster care payments is prohibited if the child's parent lives in the home, and in some cases, this is also true for Temporary Assistance for Needy Families (TANF), thus inhibiting some otherwise healthy coparenting arrangements or limiting access to financial support. Caregivers receiving TANF child-only grants (often less than \$7 per day) are obligated to provide the state information to help facilitate collection of child support. This may be stress-inducing for caregivers who may put their own children at risk of arrest for nonpayment. Given state child support pass through laws, caregivers who receive TANF may only receive a portion of the child support order as the state retains the remainder to recuperate the cost of administrating the TANF program. Half of the state, have no policies allowing pass through of child support payments without reducing the family's TANF assistance (NCSL, 2017). This dynamic can add tension to the coparenting relationship if the parent believes they are sending a larger amount than the caregiver is receiving to meet the child's needs.

There are policies that provide some limited support for grandfamilies. The National Family Caregiving Support Act provides some funding for support groups and respite care as well as "warmlines" that provide information, referrals, and support to grandparent caregivers by phone. The Fostering Connections to Success and Increasing Adoptions Act allows states to use Title IV-E funds to support sub-

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sidies to kin who assume guardianship of children as an exit from the custody of CPS, if the child had been living with the family and the home is licensed as a foster home. The Family First Prevention Services Act (FFPSA) allows states to use Title IV-E funds to provide up to 12 months of mental health services, substance abuse treatment, and in-home parenting training to families with a child at risk of entering the custody of CPS, including grandfamilies. FFPSA allows states to apply for federal matching funds for up to 50% of their expenditures to provide *Kinship Navigator programs*. KNP is a partial solution to helping families access needed services and supports. However, further work is needed to address the fragmentation of policies, which results in complicated eligibility criteria, service gaps, and access barriers.

#### Conclusion

Reducing the incidence and prevalence of behavioral health problems in the population of young people from birth to age 24 by 20%, within 10 years, through widespread implementation of tested and effective preventive interventions, requires engagement of the families that care for all youth, including those families headed by grandparents and those in which grandparents play significant coparenting roles. Reaching these families to ensure their access to state-of-the-art preventive and treatment interventions requires an understanding of diverse family forms, a broad view of family, beyond nuclear one- or two-parent-headed households. An appreciation for cultural traditions of shared caregiving across generations and adaptation of prevention and intervention programs to ensure their acceptability, usefulness, and effectiveness with various parenting and caregiving arrangements is also required.

Considering the relationship of ensuring the healthy development of all youth to other grand challenges that are particularly relevant to grandparent caregivers and

#### **Discussion Questions**

- 1. How would you explain the importance of a Family Group Decision Making approach when working with grandfamilies and families engaged in parent-grandparent coparenting?
- 2. Compare and contrast the factors that may contribute to differential experiences of caregiving stress among those with private and public grandfamily arrangements and three-generation households.
- 3. What is the connection between policies that have led to mass incarceration and the rise of the prevalence of grandfamilies and parent-grandparent coparenting relationships?
- 4. Explain how social workers can involve youth and their grandparents in the process of advocating for the development of universal, selective, and indicated services to enhance grandfamily and three-generation household well-being.

their families is also important. These include eradicating social isolation, reducing extreme economic inequality, advancing long and productive lives, closing the health gap, and promoting smart decarceration. Practice, research, and policies related to each of these grand challenges have implications for ensuring the healthy development of all youth, particularly those who are raised in grandfamilies or other coparenting relationships involving grandparents.

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### Chapter 2 Close the Health Gap



Tamara Cadet, Shanna L. Burke, and Adrienne Grudzien

#### **Grand Challenge: Close the Health Gap**

Having access to health care is critical to achieving the Healthy People 2020 goals. The US Department of Health and Human Services has identified the main goals of Healthy People 2020 as (1) attaining high-quality, longer lives, free from premature death, preventable illness, disease, and disability, (2) improvement of health across all populations and elimination of health disparities, (3) creating social and environmental conditions that ensure good health for all, and (4) promotion of health behaviors and development (Centers for Disease Control and Prevention (CDC), 2019) across the life span. Being healthy is a state of well-being that flourishes when economic, social, and environmental barriers are removed. The "Close the Health Gap" Grand Challenge for Social Work posits that the development of "a socially-oriented model of healthcare that breaks down and removes the root causes of health inequity and promotes upstream interventions and primary care prevention will eradicate the gap that exists for marginalized populations" (American Academy of Social Work and Social Welfare, 2018). This model suggests that addressing the social determinants of health is part of effective healthcare instead of only employing traditional medical treatment. Health promotion efforts must also extend across the life span with attention to older adults who may be contending with chronic health conditions.

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## Overview

Health disparities become health inequities because of systematic inequality between more and less advantaged social groups. Health disparities exist when one population has a higher burden of illness, injury, disability, or mortality in relation to another population. For example, we expect higher rates of chronic health conditions among older adults when compared to younger adults (Healthy People 2020, Internet). Health equity occurs when everyone has the opportunity to be as healthy as possible. Typically, this occurs by addressing economic and social factors that contribute to inequality.

Disparities for older adults exist in mortality and illness rates, behavioral risk factors for disease, environmental hazards, and the social determinants of health (SDOH). SDOH can include poverty, inadequate housing, structural racism and discrimination, food and housing security, limited education, and exposure to crime and violence (Adler et al., 2016). The intersections of race and ethnicity, socioeconomic status, geographic location, immigration status, age, sexual orientation, gender, and disability influence SDOH. SDOH contribute to individual and group differences in life opportunities, stressors, ability to access preventive and curative care, and quality of care. Thus, it is important to note that gerontological social work in health disparities and inequities varies considerably due to the diversity among older adults, including factors related to their biological, behavioral, physical/built, sociocultural, and healthcare environments.

The National Institute on Minority Health and Health Disparities Research (NIMHD) (n.d.) framework identifies five domains of influence that impact health outcomes: biological, behavioral, sociocultural, physical/built, and healthcare environments. Nested within each domain are four levels of influence: individual, interpersonal, community, and societal. In this chapter, we provide a brief review of gerontological social work literature that includes as many marginalized populations as possible based on selected components of the NIMHD framework with the understanding that these domains of influence are inter-related.

Biological The NIMHD Framework calls for an understanding of how biological vulnerability affects health disparities and health outcomes differences. Genetic variations between race and ethnic groups are foci of research to understand how susceptibility to disease may be moderated by these factors among older adults. For example, Latinos are 1.5 times more likely to have Alzheimer's disease (AD) and other dementias as non-Hispanics. African Americans are two times more likely to be diagnosed with AD than non-Hispanic White older adults (Alzheimer's Association, 2018). There are likely biological explanations for these more adverse outcomes related to health behaviors, sociodemographic status, and community-level effects. Specifically, cardiovascular disease and diabetes, which are more prevalent among African American and Latino individuals, also increase risk for AD. Further, depression is also more prevalent among Latinos, and depression is a risk factor for AD (Burke, Maramaldi, Cadet, & Kukull, 2016a, 2016b, 2018).

**Behavioral** Among behavioral influences of the NIMHD framework are health behaviors. Obtaining cancer screenings is an example of a health behavior. Various psychosocial factors influence cancer-screening behaviors. Maramaldi, Cadet, and Menon (2012) suggest that more present time-oriented Hispanics were less likely to participate in colorectal cancer screening initiatives. Cadet (2015) suggests that breast cancer screenings are positively associated with age and negatively associated with constraints (perceived barriers to accessing services). Findings from a study of urban African American men's screening behaviors also identifies age and access to yearly primary care visits as positive correlates of prostate cancer screenings, in addition to education level (Mitchell, 2011). Many health behaviors, including participating in cancer-screening initiatives, are impacted by older adults' sociocultural environment, which include socioeconomic status and social support.

Socioecultural Environment Socioeconomic impacts on health and well-being for low-income older adults are far-reaching and often intersect with racism, ageism, and ableism to reduce opportunity and access to human services (Anderson, Richardson, Fields, & Harootyan, 2013). Gerontological social work research has explored the significance and extent of demographics, including culture (discussed earlier), literacy, socioeconomic status, and social support in the lives of older adults. Ozawa and Yeo (2008) report that the economic status of older adults was associated with disability rates not race/ethnicity. Further, Mexican-American older adults experience greater disparities in health, the majority of which are explained by socioeconomic status (Villa, Wallace, Bagdasaryan, & Aranda, 2012).

In terms of health literacy, Liechty (2011) notes that research in this area is limited and social workers have an opportunity to do more. Findley (2015) reports that health literacy has been associated with poor health outcomes. Adults 65 and older are among those with the lowest health literacy levels. Finally, findings from Rust and Davis (2011) indicate that participants often face barriers to being fully informed about their health concerns and many did not have adequate financial resources to access all medications.

Social support and religiosity also predict higher life satisfaction scores for minority elders (Roh et al., 2015). Increasingly studies investigating the composition and impact of social support on marginalized older adults' well-being are focusing on lesbian, gay, bisexual, and transgender (LGBT) communities. Early research notes that participants' abilities to be open about sexual orientation increased social support satisfaction levels (Grossman, D'Augelli, & Hershberger, 2000).

**Physical/Built Environment** Physical or built environments (homes, buildings, streets, open spaces, and transportation infrastructure) affect older adults' daily functioning and behavioral choices. Sidewalks, bike paths, and parks in safe neighborhoods increase options for physical exercise, which reduces risk for multiple chronic illnesses, including cardiovascular disease, diabetes, and certain cancers (Centers for Disease Control and Prevention, 2011). Urban or rural settings and transportation access may impact whether older adults have adequate socialization

or are isolated and lonely and whether they make medical or behavioral health appointments. Older adults often seek to age in place and live in their own homes. However, the home environment is typically not appropriate to support their physical needs based on declines in functional capacity (Greenfield, 2012). The lack of home modifications to accommodate the physical needs of older adults may influence whether older adults remain living safely in the communities.

Healthcare Environment Researchers report obstacles to health equity based on racial and ethnic group. Findings from Lai and Chau (2007) indicate poorer health and mental health outcomes are associated with cultural and language barriers. Choi (2015) reports that non-citizens are less satisfied overall with their healthcare and have more difficulty accessing certain types of care. Considerable evidence exists to demonstrate the health disparities and inequities that exist for older adults from various marginalized populations. Given this evidence, there is a need for the development, implementation, and testing of scalable interventions to address health disparities.

### **Case Presentation**

Maria is a 68-year-old Hispanic woman who identifies as Mexican-American. She is a widow and has lived alone for the past 8 years in a first floor apartment. Her husband died 8 years ago from a stroke due to obesity. She does not have any children. She has a cousin who sees her once a week to bring her to church. Going to church and interacting with the church community is important to Maria although she is not particularly close to anyone in the congregation. She has limited financial support. She receives a small pension from her husband's employment as a banker at a local branch. Maria stopped working as a homemaker after her husband died because she just did not have the energy to leave the house. She was very distraught after her husband's death. She said, "He was everything and all that I had." Maria worked as a homemaker because she had just completed 8th grade when she emigrated from Mexico to the United States with her family.

She decided to go to the community health center (CHC) in her town after "feeling funny." She is skeptical and hesitant about the healthcare system. She has heard horror stories about other people's experiences with doctors and at the hospital. She has this saying, "I might get the doctor who graduated last in their class or last in their internship." She has heard that the doctors do not treat older adults well. She frequently expresses that she has heard "they talk to them as if they are machines." But, she "feels funny," so she decides to go to the CHC. Maria does not have health insurance. She "heard" this CHC would see her without any questions.

Maria is immediately overwhelmed when she enters the CHC. She sits in the nearest chair because she is out of breath. Maria is also obese so walking from the taxicab has made her tired. While she can speak English, it is easier for her to talk and read in Spanish. Once Maria is in a clinic room, she explains that she has not

been to see a doctor in years. She explains that she has not had any signs of being sick so she must be healthy. She meets with a physician who explains that her blood pressure is high (150/90); at 5'4" she is obese (weight: 210); her cholesterol is high (302); and she has not had any recommended cancer screenings. Maria does not understand why the physician is telling her all of this. She came because she is "feeling funny." Her physician says that this feeling is just "part of the normal aging process." She leaves the CHC.

Over the next several weeks, Maria continues to "feel funny." She is also having a harder time walking around the house and dressing herself. She is also now experiencing pain in her breasts. Maria decides to return to the CHC. This time she asks to speak with someone other than the physician she saw last time. She meets with a clinician who asks her why she came to the health center. She explains that she is "feeling funny" and it is interfering with her functional abilities. She also has pain in her breasts, she says quietly. Maria is aggravated and dazed by the whole experience.

#### Assessment and Intervention

Because the older adult population compared to their younger counterparts are more likely to have a higher prevalence of chronic diseases, physical disabilities, mental illnesses, and other co-morbidities (Boutayeb & Boutayeb, 2005), a comprehensive assessment that accounts for the person-in-environment and uses a strengths-based perspective is necessary. In addition, assessments should value interprofessional, team-based, person-centered care in community-based and institutional settings where older adults may live, work, and play. These perspectives provide social workers with the foundation to engage older adults and their families, assess their care needs, and develop care plans to meet those needs. Further, these perspectives contribute to conducting a biopsychosocial assessment for older adults and identifying potential disparities and inequities.

The biopsychosocial framework for older adults, which is similar to the NIMHD framework, includes seven domains (Christ & Diwan, n.d.):

- Physical well-being and health assessment can include overall health status, presence of pain, nutritional status, fall risk, incontinence, sleep, substance use, and misuse, oral health, vision, and hearing. For example, poor nutrition habits may contribute to Maria's obesity, which affects her overall health status;
- 2. Psychological well-being and mental health assessment includes, but is not limited to, screening for depression, anxiety, and dementia. These areas are frequently not diagnosed, underdiagnosed, or misdiagnosed because presenting symptoms are attributed to the physical health problems of the older adults and stereotypical beliefs that aging is associated with increased negative psychological effects. For example, Maria may be experiencing depression as evidenced by her "feeling tired" and "overwhelmed" when she is at the CHC.

- 3. Cognitive capacity assessment includes screening for normal, gradual decline in memory and/or progressive, irreversible, global deterioration related to Alzheimer's disease. It is important to note behavioral symptoms, such as agitation and sleep disturbance. For example, Maria is experiencing agitation;
- 4. Functional ability assessment measures an older adult's ability to perform various activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include dressing, bathing, eating, grooming, toileting, transferring from bed or chair, mobility, and continence. IADLs include cooking, cleaning, shopping, money management, use of transportation, telephone use, and medication administration. Given Maria's weight, it will be important to assess these areas:
- 5. Social functioning assessment includes an older adult's social supports and social networks. These include relationships with family members and friends and social activities. For Maria, understanding whom else may be in her life other than church and her cousin will be important;
- 6. Physical environment assessment includes examining the condition of lighting and flooring with particular attention to obstacles or possible hazards for falling (i.e., scatter rugs, extension cords), bathing and toileting appliances with particular attention to a possible need for assistive devices (i.e., handheld shower, tub seat), heating and cooling appliances, access to rooms in the home, and access to the house from the outside. For example, Maria has lived alone for the past 8 years and her home may not be safe; and,
- 7. Caregivers' function assessment examines the level of strain caregivers may be experiencing. Perhaps, Maria's cousin is experiencing caregiver strain, which is why she only sees Maria once a week. Assessing both objective and subjective aspects of caregiver strain provides a more comprehensive understanding of caregivers' needs. An objective assessment includes areas such as financial and family concerns and cultural beliefs and practices. Subjective assessment includes caregivers' perceptions of their caregiving situation.

The domains in the biopsychosocial framework are similar to the domains assessed in comprehensive geriatric assessment (CGA) (Welsh, Gordon, & Gladman, 2014). CGA is a systematic assessment of older adults by an interdisciplinary team of health professionals (including social workers) and consists of six core components: data gathering, team discussion, development of a treatment plan, and implementation of a treatment plan, with monitoring and revision as needed. Evidence-based assessment tools for older adult populations include but are not limited to the following: *LEIPAD*, which assesses the domains of physical, social, and cognitive function, finances, spirituality, environmental domains, and sexuality (De Leo, Diestra, Lonnqvist, Cleirin, & Frisoni, 1998); *Medical Outcomes Study Short-Form Survey*, which measures physical health, mental health, and social domains (Stewart et al., 1992); and *World Health Organization Quality of Life-BREF*, which assesses physical health, mental health, and social and environmental domains. This assessment tool is noted for its cross-cultural competency (Saxena, O'Connell, & Underwood, 2002).

Several assessment tools would be appropriate for use with Maria. To ensure that Maria understands her possible conditions, accounting for her possible cultural beliefs, such as fatalism (Powe & Finnie, 2003), medical mistrust (Rose, Peters, Shea, & Armstrong, 2004), and power distance (Hofstede, 2001) using assessment tools is important. Further, assessing the health literacy level for Maria using a scale, such as the Brief Health Literacy Screen, is critical to providing patient-focused care. To measure possible depressive symptoms, the Center for Epidemiologic Studies Depression scale is commonly used to detect symptoms in older diverse adults (Long Foley, Reed, Mutran, & DeVellis, 2002). To assess cognitive function, the Montreal Cognitive Assessment (MoCA) is a widely used tool (Smith, Gildeh, & Holmes, 2007). To assess Maria's functional ability, the Katz Activities of Daily Living Scale (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and IADL scale (Lawton & Brody, 1969) is appropriate. To assess for Maria's social functioning, the Norbeck Social Support Questionnaire (Gallo, Fulmer, Paveza, & Reichel, 2000) is appropriate.

The importance of providing culturally appropriate assessments cannot be overstated. While some assessment tools that might be appropriate for Maria have been previously identified, not every assessment tool accounts for psychosocial or sociocultural considerations of diverse populations who often experience health disparities and inequities. Because assessment is both a process and a product, it is an intervention in and of itself. Using social work skills, such as establishing rapport, genuineness, acceptance, empathy, and active listening, is one of the ways of engaging older adults. Therefore, utilizing questions that are culturally competent and designed in a way that an older adult, such as Maria, can understand is the first step.

In general, interventions used with older adults should be grounded in individualized assessment. These interventions include: (1) psychoeducation about the aging process and common illnesses that occur in older adulthood; (2) information about community resources for older adults and their families; (3) assistance with applying for services and benefits, such as income related and health insurance benefits (i.e., Medicaid, food stamps, etc.); (4) arrangement of transportation to get to medical appointments; (5) provision of support or identification of possible additional sources of support; (6) assessment of the fit between the older person's capabilities and their home environment; (7) decisional support tools to understand the risks and benefits of specific interventions related to cancer screening and medications; and (8) care coordination. Maria could benefit from several of these interventions, including nutritional psychoeducation regarding obesity, application for Medicaid since she has no health insurance, medical transportation, and culturally competent care coordination.

A particularly relevant aspect of closing the health gap is the consideration that older adults have both non-medical and medical needs that can be barriers or facilitators to positive health outcomes. A thorough CGA can identify these needs. Several social work led interventions include screening and interventions for medical and non-medical needs for older adults. They include the Geriatric Resources for Assessment and Care of Elders (GRACE) (Counsell, Callahan, Buttar, Clark, & Frank, 2006), Programs of All-Inclusive Care for the Elderly (PACE) (Eng, Pedulla,

Eleazer, McCann, & Fox, 1997), and the Ambulatory Integration of the Medical and Social (AIMS) model (Rowe et al., 2016). Findings from studies of these models suggest that they can improve health and healthcare utilization outcomes. For example, Maria would likely benefit from AIMS, a care management model provided by social workers in primary care.

## Future Steps: Research, Policy, and Practice

The intersection of policy, practice, and research cannot be overstated. Evidence-based strategies implemented in practice provide a foundation for developing or changing policy. Within the NIMHD framework presented earlier, we offer some examples of population research that gerontological social workers should consider followed by a discussion of policy with suggestions for advocacy to close the health gap. Finally, we will provide further suggestions about practice interventions, including GRACE, PACE, and AIMS.

**Research** Within the *biological* domain, we discussed Alzheimer's disease (AD). Apolipoprotein E (APOE) 4 is a susceptibility gene most commonly known as a risk factor for AD with alleles expressed as e2, e3, and e4 (Ashford, 2004). These allelic frequencies vary across populations worldwide (Eisenberg, Kuzawa, & Hayes, 2010), which makes APOE a particularly relevant target for health disparities investigations. Given the increased risk of AD in older African Americans, there are limited investigations examining the association between APOE and aging among minority individuals of advanced age. Research that addresses cultural and ethnic differences in AD will be important to contributions to reducing health disparities and increasing inequities. Social workers should have a basic understanding of this biological research and continue to advocate for research that can reduce health disparities and inequities.

While there are a number of descriptive investigations examining the *behavioral* domain that also include the *sociocultural environment* of the NIMHD framework, limited evidence-based social work interventions designed to improve the screening behaviors of older diverse adults exist. Increasingly, decision supports are interventions considered for cancer screening and other healthcare treatments. Current decision supports are often designed for high health literacy adults and older adults (McCaffery et al., 2013). Future research needs to incorporate the perspectives of low health literate adults to modify and/or develop new decision tools so that all populations have access to information to make optimal decisions. Despite the important role of *physical/built environments* in the lives of older adults, disparities-focused gerontological social work research in this domain is limited. Bakk, Cadet, Lien, and Smalley (2017) examined home modification rates and report that older Blacks and Hispanics have lower rates of home modification use when compared to older non-Hispanic Whites. However, much research is still needed to understand

aging in context. In a special edition of *The Gerontologi*st focusing on older adults and aging in context, Pruchno (2018) notes that we need a better understanding of how older people define their neighborhoods, including more research about diverse aspects of contexts including the built environment, the natural environment, and the food environment. Finally, in the *healthcare* domain, research should develop effective strategies to recruit and enroll diverse older adult participants (National Institute on Aging, 2018). Overall, research that includes social workers is needed to address healthcare disparities and health inequities and close the health gap.

**Policy** A number of policy implications for "Closing the Health Gap" for older adults exist. Overall, continuing advocacy and community involvement to create new policies to support access to services, awareness of interventions to increase overall functioning, and coordinated efforts among disciplines that include social workers are needed. Specifically, decision support tools are increasingly recognized as a way to create awareness and the Patient Protection and Affordable Care Act (PPACA) (2010) includes provisions related to the development of decision support (O'Malley, Carrier, Docteur, Schmerling, & Rich, 2011). Findings from studies of interventions, including the Geriatric Resources for Assessment and Care of Elders (GRACE) (Counsell et al., 2006), Programs of All-Inclusive Care for the Elderly (PACE) (Eng et al., 1997), and the Ambulatory Integration of the Medical and Social (AIMS) model (Rowe et al., 2016), suggest that these interventions are effective in addressing social care needs in the healthcare delivery system. This evidence can be used to advocate for the reimbursement of care management services by social workers in both fee-for-service and value-based services environments. Changes in health policy over the last decade (i.e., PPACA, 2010) also provide promising routes for the reimbursement of care management services by social workers (Rowe et al., in press).

**Practice** A number of health disparities affecting older adults and older diverse adults exist, and there are many interventions designed to help them. Shier and colleagues (2013) identify non-medical needs as the major barriers to meeting the medical needs of older adults. As discussed earlier, the AIMS model (see Rizzo, Rowe, Shier Kricke, Krajci, & Golden, 2016 for full description of AIMS model) is a promising intervention that utilizes social workers in primary care to address the social care needs of older adults. In a retrospective study, Rowe and colleagues (2016) report that AIMS has a positive and significant impact on healthcare utilization (emergency department visits, hospitalizations, and hospital readmissions). In a more recent study in which 88% of the participants were non-white, Rizzo and colleagues (2019) report that AIMS reduced symptoms of depression as well as health risk 6-months post-intervention. Documentation of social work activities and skills in the AIMS model, and other similar models, is critically necessary to advocate for the inclusion of social workers as members of interprofessional teams addressing the non-medical and medical needs of older adults to close the health gap.

## Conclusion

Health disparities and health inequities are pervasive social and public health concerns associated with the social determinants of health. As evidenced by the current research, social workers have the skills necessary to address the social determinants of health that create barriers for older adults and contribute to the health gap. As a profession, social work is well positioned to continue to advance the health equity agenda in research, policy, and practice in collaboration with other disciplines as part of the "Close the Health Gap" grand challenge.

## **Discussion Questions**

- 1. How would you explain the possible issues that exist for Maria in terms of patient-provider communication? What assessment questions would be appropriate? What might be some possible interventions? What are the policy barriers?
- 2. Why do you think some populations seem to have access and awareness to some information and others do not?
- 3. What is the connection between non-medical (psychological, social, other) and medical needs in prompting health equity?
- 4. If you had to pick a particular chronic illness that research has shown evidence of inequities across diverse older adult groups, what specific assessment questions and interventions might you consider.

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# **Chapter 3 Stop Family Violence**



David Burnes, Joy Ernst, and Patricia Brownell

## **Grand Challenge: Stop Family Violence**

The "Stop Family Violence" Grand Challenge focuses on child maltreatment and intimate partner violence, noting that these two types of violence often occur together. It also focuses on the disproportionate effect of family violence on women and girls. The description of this challenge notes that violence within the family encompasses many types, including physical violence, emotional abuse, sexual violence, and economic exploitation, which result in damaging consequences, such as serious injury and death. The goal of the Grand Challenge is to promote "healthy, violence-free relationships between partners and among families" and to "bring about a 50% reduction in child maltreatment and gender-based violence (GBV) within the next decade" (American Academy of Social Work and Social Welfare, 2018). Family violence is not isolated to younger individuals. It also may include older individuals, which warrants the inclusion of elder abuse in this Grand Challenge.

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## Overview

Although the "Stop Family Violence" Grand Challenge focuses on child maltreatment and intimate partner violence, it neglects attention on abuse against older adults. This chapter highlights elder abuse as another critical form of family violence requiring urgent attention. Elder abuse is a pervasive social and public health concern associated with devastating consequences to older adults, such as premature mortality and significant costs to society, including higher rates of hospitalization, emergency room visits, and nursing home placement (Dong, 2015). Family violence may conjure images of frightened small children as they listen to the sounds of their parents yelling, screaming, and physically fighting or young mothers appearing at shelters for abused women with their small children in tow. It also encompasses abuse and neglect of children and a comprehensive systemic response to it. Family violence service systems include both child protective services and domestic violence service agencies. However, both these service systems, like this Grand Challenge, and the public have under-recognized that older adults are also victims of family violence. This failure of recognition means that existing service systems do not adequately respond to the needs of older adults, including ageassociated health, cognitive, and psychosocial vulnerabilities.

Elder abuse is a prevalent form of family violence that has gained substantial recent attention by clinicians, policy-makers, and researchers as a major issue affecting an aging population. The Centers for Disease Control and Prevention (CDC) (2016) recently recognized elder abuse as a serious public health problem requiring formal surveillance. The 2015 decennial White House Conference on Aging (2015) designated elder abuse as one of four top-priority issues affecting older adults. The World Health Organization (WHO) (2017) defines elder abuse as "a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person." Elder abuse includes various subtypes, such as financial, physical, psychological, or sexual abuse as well as intentional or unintentional neglect from formal or informal caregivers. Although not formally included as a type of elder abuse in standard definitions, the issue of self-neglect is viewed as closely related and is often addressed by similar service systems. The issue of elder abuse is framed within a discussion of elder justice, which involves efforts to prevent, identify, and intervene to protect older adults while maximizing self-determination.

Aging Issues Related to Stopping Family Violence The WHO (2017) estimates that 15.7% of people 60 years and older are subjected to abuse or neglect. Evidence from large-scale studies in the United States suggests that approximately one in ten older adults experience elder abuse each year (Pillemer, Burnes, Riffin, & Lachs, 2016). A recent study using the National Intimate Partner and Sexual Violence Survey shows that 14% of women over the age of 70 experience some form of past-year abuse (Rosay & Mulford, 2017). Domestic violence research outside of the United States estimates that approximately 28% of older women experience cumulative abuse across the life span (Luoma et al., 2011). Despite the high prevalence

rates of elder abuse found in research, these rates are likely *underestimated* for several reasons. Similar to child maltreatment, many cases of elder abuse go undetected or unreported. Prevalence studies that rely on self-report information also exclude particularly vulnerable older adult sub-populations, such as those living with dementia or in long-term care settings. The absolute number of people who will experience abuse/neglect in later life is projected to increase dramatically with population aging (Pillemer et al., 2016).

Elder Abuse and Family Violence in the Gerontological Social Work Literature Elder abuse has been highlighted as a social problem since the late 1970s with social workers involved in early studies of protective services (Blenkner, Bloom, & Nielsen, 1971). Social workers have provided leadership in responding to elder abuse through work in Adult Protective Services (APS), in programs that respond to family violence involving older adults, and in multidisciplinary health and social service settings. Social work practitioners and researchers have been involved in research that examines prevalence, risk and protective factors, and interventions used in combatting elder abuse and neglect. Much of this research is conducted by multidisciplinary teams, including, but not limited to, social workers, physicians, sociologists, and lawyers (see, e.g., Burnes, Lachs, & Pillemer, 2018; Gassoumis, Navarro, & Wilber, 2014). Social workers represent, by far, the largest profession responsible for delivering and managing services designed to support victims of elder abuse.

At the macro level, members of the social work profession have been involved in efforts to elevate the issue of elder abuse and shape responses to it. The Elder Justice Roadmap (Connolly, Brandl, & Breckman, 2014), authored by two social workers and an attorney, resulted from an effort to organize responses of 750 stakeholders to the statement, "To understand, prevent, identify, or respond to elder abuse, neglect, or exploitation, we need ... (p. i)". The Roadmap identified action needed in the domains of direct service, education, policy, and research. Five major priorities identified are as follows: (1) building public awareness to increase knowledge of the multifaceted nature of elder abuse; (2) increasing research on brain health to elucidate the relationship between cognitive capacity and mental health to elder abuse; (3) supporting and training paid and unpaid caregivers as a means to prevent elder abuse; (4) quantifying the economic cost of elder abuse to victims, families, and society; and (5) increasing resources for service, education, research, and knowledge development.

Research has examined the impact of legislation and policy on elder abuse reporting and response. For example, state requirements that APS investigators have degrees in social work are associated with higher rates of case substantiation (Jogerst et al., 2004). More recent research involving social workers examined the impact of changes in state laws on reported incidents of financial exploitation (Carey, Hodges, & Webb, 2018).

While funds for elder abuse prevention activities have been a part of the Older Americans Act since 1987, the passage of the Elder Justice Act in 2010 brought

national-level attention to the needs of the APS system. Since 2015, the Administration for Community Living (ACL) has made funding available through specific state grants to build knowledge and improve processes related to APS and other response efforts. Many of these grants involve partnerships between APS agencies and university-affiliated social work researchers. ACL has also funded the National Adult Maltreatment Reporting System to collect and examine data on APS processes and outcomes on a national scale.

At the mezzo and micro levels, comprehensive reviews of evidence-based research on interventions aimed at addressing elder abuse have revealed a paucity of high-quality research. The review articles highlight the scarcity of research designs that can provide strong evidence for program effectiveness (i.e., research employing randomized control trials). Ayalon and colleagues' (2016) systematic review notes the lack of evidence-based interventions designed to assist professionals in detecting abuse or working directly with victims. The Cochrane review of elder abuse interventions (Baker, Francis, Hairi, Othman, & Choo, 2016) identifies preliminary evidence that elder abuse interventions impact caregiver anxiety and depression; however, the effectiveness of interventions in preventing or reducing elder abuse occurrence/recurrence remains uncertain. Elder abuse education among social workers across service sectors who work with older adults or potential perpetrators (e.g., discharging adult children from criminal justice or mental health services into family homes) is clearly needed (Moore & Browne, 2017). The following sections provide a case example and highlight important considerations for social work assessment and intervention when working with elder abuse cases.

### **Case Presentation**

Juanita (75) has been married to Fred (80) for 55 years. They have two children, George (53), single, and Josie (47) who is married with two children and lives in a different state. Juanita and Fred have had a volatile marriage, with explosive arguments sometimes accompanied with pushing, shoving, and threats involving money. George has been diagnosed with severe borderline personality and schizoaffective disorders and receives long-term federal disability benefits. George has lived in adult homes and is often hospitalized for acute psychiatric episodes. Afterwards, he moves into Juanita and Fred's home for short periods. George continually badgers his parents for money. Their daughter, Josie, has little contact with the family because of long-standing problems in her relationship with Fred and anger at Juanita for not leaving him. Josie is recently separated and moved into a small rental apartment; she is struggling to support her teenage son and daughter. Recently, Juanita was diagnosed with osteoporosis and Fred was diagnosed with mild-to-moderate Alzheimer's disease. Juanita has always managed the family's finances and is finding herself struggling with George's demands for money. Recently, Juanita gave George more money than the family could afford so he could move out. When George left, he also took some of Juanita's jewelry to sell, something he had done in the past. Fred became angry with Juanita and hit her in the face, causing bruising. Juanita also fell and dislocated her shoulder, resulting in a short hospital stay. Hospital staff raised concerns about her ability to return home safely. However, a local domestic violence shelter would not accept her, as she needed medication and personal care. APS briefly became involved with the family, but Juanita refused services stating she was willing to take the risk of staying with Fred, for whom she was the primary caregiver, and George was for the time being out of the household. APS closed her case as per procedure. Juanita is not eligible for Medicare-funded home health care since she does not need nursing supervision, and a referral to the local area agency on aging for housekeeping services resulted in placement on a waiting list. The family income is too high for Medicaid eligibility without spenddown, and the family budget is too limited for private pay personal care. Juanita refuses to press charges against Fred or George. She is concerned about their behavior and would like them to get help.

## Assessment

In responding to suspected cases of elder abuse, social workers are tasked with two forms of assessment: (1) determining whether mistreatment has occurred and (2) determining the level of risk for victimization. For both forms of assessment, social workers gather information from several sources: interviews with the suspected victim and relevant others (e.g., family members, caregiver); direct observation and physical evidence (e.g., injuries, home environment conditions); and corroborating documentation from other entities (e.g., social services, family physician, financial institution, etc.) (Administration for Community Living (ACL), 2016).

Screening tools have been developed to help determine whether elder abuse has occurred (Gallione et al., 2017). Although screening tools historically assessed elder abuse as an aggregate phenomenon, recent efforts recognize that each mistreatment subtype (financial, emotional, physical, or sexual abuse and neglect) is clinically distinctive and requires separate assessment (National Research Council, 2003). Separate elder abuse subtype assessment also provides an opportunity to identify cases of poly-victimization - cases in which older adults experience more than one type of abuse/neglect, which can carry long-term cumulative burden on victims (Hamby, Smith, Mitchell, & Turner, 2016). Obtained through direct interviewing with an older adult, screening tools typically measure elder abuse based on the presence or absence of specific mistreatment behaviors (e.g., threatening, yelling, pushing, hitting, theft of money, etc.), assessed in binary no (not present)/yes (present) terms. A binary assessment approach provides the necessary information to make an overall substantiation decision. However, this approach can obscure the true range and depth of abuse/neglect experiences, and recent research has proposed a shift toward assessing elder abuse along a continuum of severity (Burnes, Lachs, & Pillemer, 2018).

The ecological-systems framework has become the dominant perspective to understand and assess elder mistreatment (EM) victimization risk (National Research Council, 2003). This perspective captures the complex etiology of EM by recognizing that risk is a function of various domains situated across different levels of social organization. Specifically, elder abuse risk factors are assessed at levels of the individual victim and individual perpetrator, victim-perpetrator relationship, family system, home environment, social environment, and the victim's intersection with broader sociocultural processes. Although many factors across the aforementioned ecosystemic levels are theorized as placing older adults at increased risk of elder abuse, recent systematic reviews have identified strong empirical evidence for the following factors: individual victim (cognitive impairment, functional impairment, poor physical or mental health, behavioral problems, prior trauma or interpersonal violence, absence of a protective spouse); perpetrator (caregiver burden/stress, poor mental health, substance misuse); victim-perpetrator relationship (older adult dependency upon perpetrator for daily care, perpetrator dependency upon older adult for economic resources); family system (family disharmony, conflictual relationships); home environment (victim-perpetrator shared living arrangement, low household income); social environment (low social support, social isolation); and broader sociocultural processes (female gender) (Johannesen & LoGiudice, 2013; Pillemer et al., 2016).

The ecological-systems assessment approach conceptualizes elder abuse as an interpersonal problem interacting with social and environmental factors. The factors indicating elder abuse victimization risk vary widely across cases and are uniquely constellated across ecosystemic levels for any given case. For example, in the attached case vignette, a social work assessment might identify that Juanita is living with functional impairment (e.g., osteoporosis) that may limit her ability to defend herself. She and Fred have a volatile marriage and history of interpersonal violence that may be embedded within unequal, patriarchal gender dynamics, which places Juanita at risk for ongoing patterned abuse. Juanita has a child with psychiatric challenges who is dependent upon her for economic resources (e.g., housing, finances), which can promote underlying fear and resentment toward Juanita in the childparent relationship. In the absence of adequate systemic resources (e.g., shelter, Medicare/Medicaid assistance), Juanita is left in a high-risk family and household dynamic without formal support.

The assessment process informs the development of a tailored intervention plan designed to address salient factors contributing to the risk of revictimization (Burnes, Rizzo, Gorroochurn, Pollack, & Lachs, 2016). In line with the ecosystemic approach, recent elder abuse intervention research suggests that an effective intervention model should have the capacity to work with both the older adult victim and the perpetrator and to strengthen the family and social systems surrounding the victim-perpetrator dyad (Burnes, 2017; Hamby et al., 2016; Mosqueda et al., 2016). An ecosystemic intervention approach also highlights a need for macro-level practice, such as advocating for changes in laws, regulations, and funding to support service systems that are responsive to the specific needs of older adults.

## Intervention

With a paucity of rigorous intervention elder abuse research, it is not possible to identify truly evidence-based intervention strategies. Nevertheless, scholarship has advanced our conceptual understanding about approaching elder abuse intervention, and the preliminary evidence base is useful in identifying promising strategies. This section describes key concepts and principles characterizing the elder abuse intervention practice paradigm and common types of response interventions that currently exist in the community.

Key Conceptual Considerations The overall objective of elder abuse intervention is to reduce the risk of revictimization and improve the older adult's safety and quality of life in accordance with their expectations and preferred resolution outcomes (ACL, 2016; Burnes, 2017). Generally, elder abuse intervention work is guided by core practice principles of voluntariness, self-determination, and the imperative to pursue the least restrictive intervention path. Unlike child protective services, unless an older adult lacks capacity, elder abuse intervention services are voluntary. Older adults can choose to accept services completely, partially, or refuse services altogether. Indeed, refusal or underutilization of services is a major problem, with the vast majority of elder abuse victims never receiving formal support (Burnes, Acierno, & Hernandez-Tejada, 2019; Ernst et al., 2014).

Parallel to voluntariness is an older adult's right to self-determination. Elder abuse victims have the right to determine a course of action and parameters of case resolution that align with their own expectations, rather than an externally defined benchmark of success. Older adult clients have the right to make their own decisions, even if these decisions impede or counteract the goal of safety (ACL, 2016). Very few clients choose to pursue an absolute standard of case resolution defined by the elimination or cessation of revictimization risk or complete safety. Such a standard would typically require older adults to sever their relationship with an offspring or spousal perpetrator and/or relocate to a different living setting. Rather, the majority of elder abuse victims choose to pursue a case plan that results in a reduction of revictimization risk – one that increases safety to some degree yet also preserves family relationships, maintains a sense of status quo, and/or does not expose a familial abuser to legal/justice systems. Indeed, many victims of elder abuse prioritize interventions that provide support for a familial perpetrator. Perhaps the greatest moral challenge faced by social workers in elder abuse interventions is the act of balancing the pursuit of safety with the client's right to self-determination. Related to this balance is an imperative to pursue the least restrictive intervention path. An intervention plan ought to reflect a course of action that limits the older adult's rights/freedoms to the least extent possible (ACL, 2016). Thus, a clientcentered, constructivist, harm-reduction framework characterizes the elder abuse intervention paradigm. This framework allows social workers to collaborate with a client to understand the unique circumstances of their case and co-construct a tailored intervention plan to reduce revictimization risk in accordance with their wishes (Burnes, 2017). Over the past several decades, two major forms of community-based elder abuse response intervention have emerged across the country: Adult Protective Services (APS) and multidisciplinary teams (MDTs).

Adult Protective Services Centralized state or county-administered APS represent the primary authority for receiving and responding to reports of suspected EM cases in the United States. APS is tasked with receiving reports of suspected abuse, conducting a formal investigation (including an assessment as outlined above), deciding whether abuse is substantiated, and initiating an intervention plan for substantiated cases. APS was recognized by U.S. federal law in 1975 under Title XX of the Social Security Act. All states have an APS system that responds to EM, and all but one state (New York) has enacted mandatory reporting laws requiring designated reporters to refer suspected cases of EM in the community to APS. APS programs across the country respond to over 760,000 reports of elder abuse or selfneglect each year, and trends suggest that APS caseloads are rising (National APS Association, 2012). Although APS exists in all states, programs are administered differently across jurisdictions. For example, some state APS systems serve all older adults above a certain age (e.g., 65), while other systems only serve older adults presenting with specific psychosocial, physical, and/or cognitive vulnerabilities. State APS systems also vary in regard to the types of services provided and the legislated investigation and case closure response timelines (ACL, 2016). Mandatory reporting laws also vary across states in regard to who is mandated to report (e.g., everyone, certain professions, etc.), under what circumstances (e.g., always, discretionary), and about whom information is reported (e.g., suspected victim, perpetrator, and/or other family members).

The mandated APS elder abuse intervention model is controversial in that some people view it as an intrusion on the civil liberties of older people. Critics suggest that the APS system threatens the autonomy of older adults because it removes choice in regard to when or from whom to seek help and it involves potentially intrusive, uninvited state involvement in personal affairs. However, proponents recognize that a mandated response system uncovers and initiates the opportunity for intervention with a population of older victims who are largely hidden, vulnerable, and reluctant to seek help (Burnes, Connolly, Hamilton, & Lachs, 2018). Regardless of viewpoint, experts would agree that further research is required to develop evidenced-based APS practice in responding to elder abuse (Ernst et al., 2014).

Multidisciplinary Teams (MDTs) The elder abuse literature strongly advocates for a multidisciplinary model of elder abuse intervention (Pillemer et al., 2016). Proponents suggest that a multidisciplinary approach provides the necessary diversity of professional resources and skills, used at various points along the assessment and intervention process, to problem-solve complex, multifaceted elder abuse cases. A coordinated multidisciplinary approach facilitates greater service delivery efficiency, as opposed to navigating through a silo system of disconnected disciplines and services. MDTs represent a relatively recent and promising form of elder abuse response intervention that has proliferated across the country. MDTs

typically work as a supplement to APS in either a third-party consultative or direct-service role to problem-solve particularly complex cases. An MDT typically meets bi-weekly or monthly and comprises professionals representing an array of disciplines/systems, including social work, geriatric health, law enforcement, legal justice, victim services, and financial services (Connolly et al., 2014). Evidence supports the use of multidisciplinary teams in improving elder abuse case outcomes (Gassoumis et al., 2014).

Despite the lack of rigorous evidence available to support specific elder abuse interventions, several promising interventions have emerged in recent years. Although a full description of emerging elder abuse interventions is beyond the scope of this chapter, the following represent promising strategies targeting various ecosystemic levels that could be integrated with APS: individual-victim-level problem-solving therapy (Sirey et al., 2015), empowerment education (Estebsari et al., 2018), goal attainment scaling (Burnes, Connolly, Hamilton, & Lachs, 2018), and motivational interviewing (Mariam, McClure, Robinson, & Yang, 2015); victim-perpetrator relationship-level emotion-focused couples therapy (Hazrati et al., 2017) and restorative justice (Beck, Lewinson, & Kropf, 2015); family-based cognitive behavioral therapy (Khanlary, Maarefvand, Biglarian, & Heravi-Karimooi, 2016); and systems-level combined legal/social work services (Rizzo, Burnes, & Chalfy, 2015) and trauma-informed care (Ernst & Maschi, 2018).

## Future Steps: Research, Policy, and Practice

The elder abuse field has developed significantly since its inception in social work practice in the 1970s. Much of this work has been interdisciplinary, with medicine, law, nursing, and other disciplines in collaboration with social work. As a result, important research initiatives have significantly broadened our understanding of prevalence, risk factors, and other dimensions of elder abuse within aging and vulnerable adult frameworks. However, some aspects of elder abuse remain underdeveloped and open for further exploration. The following section uses three distinct frameworks in which to consider the research, policy, and practice implications for elder abuse.

Feminist Perspective Social work scholars in the 1980s and 1990s began to consider elder abuse within a feminist perspective (Nerenberg, 2002), and some limited elder abuse intervention research in this frame was initiated (Brownell & Heiser, 2006; Vinton, 2003). Feminist gerontology has also been developing as a perspective within social work more broadly. Coming out of social gerontology and critical theory, this perspective focuses on unequal gender relations that accumulate over the life course into older age and builds on the pioneering work of feminist social work practice (Bricker-Jenkins & Hooyman, 1986). Bringing elder abuse within the feminist framework has resulted in increased understanding of gender-based vulnerabilities faced by older women and why they been invisible as victims

and survivors of intimate partner abuse. Informed by a feminist perspective, novel research methodologies have also emerged from the European Union (Luoma et al., 2011) and World Health Organization (Garcia-Moreno, Pallitto, Devries, Stöckl, & Watts, 2013) to examine the prevalence of abuse experienced by older women. Successful advocacy has resulted in the inclusion of older women as a category within the Violence Against Women's Act (VAWA) of 2000, and certain VAWA grants are now directed to programs serving older women.

On a local level, advocacy and education is needed so that their family violence programs recognize how to meet the needs of abused older women and to broaden the range of resources available. An additional form of advocacy moving forward might strive to link local/state/national-level policy initiatives targeting abuse of girls and women of all ages. One challenge is the siloed nature of current funding mechanisms that can pit child abuse, domestic violence, and elder abuse advocates against one another. An integrated approach to addressing domestic violence across the life span could ease some of the tensions inherent in the current competition for funding across siloed service systems.

Life Course Perspective To place elder abuse within the field of family violence, we need to move beyond a siloed approach to understanding abuse only as child maltreatment (vulnerable dependent) and spouse/partner abuse (reproductive age women as victims/survivors). These siloes when applied to elder abuse have resulted in a misunderstanding of older adults as frail care dependent victims or as invulnerable to abuse by family members in later life. It has also obscured an identified risk factor in elder abuse: abuse experienced earlier in the life span predicts a higher likelihood of abuse in older adulthood (Acierno, Hernandez-Tejada, Anetzberger, Loew, & Muzzy, 2017). While theory has lagged behind observation, a growing body of social work research has demonstrated that interpersonal violence is a life course issue, rather than one that occurs at independent, discreet stages. A model of intervention in which interpersonal violence is approached as a life course issue, rather than a life stage issue focused on children, younger adults, and older adults separately, might more effectively address the developmental impact of abuse and trauma across the life span. For example, clinical models are evolving to identify and treat cumulative exposure to traumatic events in older adults based on the developmental timing of trauma exposure and its impact on complex PTSD symptoms and psychosocial functioning among older adults (Ogle, Rubin, & Siegler, 2014).

Trauma-Informed Care Only recently has trauma been considered a factor in elder abuse (Ernst & Maschi, 2018). Social work is a leading profession that has placed trauma-focused care in the fields of child maltreatment and spouse/partner abuse. However, the medical model dominating elder abuse has resulted in a lack of understanding of the role of trauma in elder abuse. Social work practitioners and researchers are beginning to develop and assess trauma-focused interventions and care. Among promising models include psycho-educational support groups, groups promoting spirituality among older women who have experienced familial abuse, and interventions intended to target depression and abuse (Bowland, Biswas, Kyriakakis, & Edmond, 2011; Brownell & Heiser, 2006; Sirey et al., 2015).

## Conclusion

Elder abuse is a pervasive social and public health concern associated with devastating consequences to older adults. Historically, and currently, social workers have been at the forefront of addressing elder abuse in the research, policy, and practice arenas. As a profession, social work is well-positioned to continue to advance the elder abuse agenda in all three arenas in collaboration with other disciplines as part of the "Stop Family Violence" Grand Challenge.

## **Discussion Questions**

- 1. How would you explain why elder abuse has received relatively little attention compared to other domains of interpersonal violence, such as child maltreatment and intimate/domestic violence?
- 2. What theories can be used to help understand why elder abuse occurs and how would they be applied?
- 3. How does the older person's right to self-determination affect a social worker's recommendations for service in families where elder abuse has occurred?
- 4. Why is the multidisciplinary intervention response seen as a promising approach to address cases of elder abuse?

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## **Chapter 4 Advance Long and Productive Lives**



Andrea L. Jones and Stacey R. Kolomer

## **Grand Challenge: Advance Long and Productive Lives**

The "Advance Long and Productive Lives" Grand Challenge aims to keep people connected to one another and change the meaning of productivity across the life span. In addition to employment, expanding the meaning of productivity and engagement to include caregiving and volunteering are important aspects of being active. Expansion and flexibility when considering activities, such as employment, caregiving responsibilities, and volunteering, are critical to staying engaged and productive members of society.

## Overview

What constitutes productive aging? Individuals must define this term based on personal interests, desires, and resources. The formal term *productive aging* was first coined by Robert N. Butler, a celebrated gerontologist, in his 1975 book, *Why Survive? Being Old in America*. As the first director of the National Institute on Aging, Butler noted a trend of characterizing older adults in America as less capable than younger Americans and as a drain on societal resources. Butler was among the first to note the institutionalized discrimination, exclusion, and stereotyping of older adults, which he termed *ageism*. Throughout his career, he sought to reframe society's perceptions of older adults, including conducting research on leading healthy,

productive lives. Over the decades, the definition has been refined to include a professional conceptualization of productive aging as endeavors that are measured in terms of time spent and have direct or indirect economic value (Caro, Bass, & Chen, 1993).

The "Advance Long and Productive Lives" Grand Challenge for older adults focuses on three activities: work, caregiving, and volunteerism (Morrow-Howell, Gonzales, & Matz-Costa, 2016). Moving forward these areas must adapt to better serve the needs of an aging population. Flexibility in hours, salary increases, financial opportunities, and expansion of existing policies would benefit advancing lives and productive aging. The following section will outline employment, caregiving, and volunteerism in older adults.

*Employment* The National Council on Aging (2019, n.d.) reports that as of 2019, Americans aged 55 and older represent more than 40% of the U.S. workforce. The US Bureau of Labor Statistics (2016) notes the increase in older adult employees is attributable to increased longevity, better education in the cohort presently retiring, modifications related to the age qualifier in Social Security benefits, as well as changes in traditional employer-sponsored retirement benefits over the past 30 years.

Research related to demography of the older workforce tends to be available based upon age groups, as opposed to data available by race and ethnicity. However, recent data notes the percentage of Black Americans over 65 who remain in the workforce has risen 2.0% in 2010 to 2.6% in 2016 (Toossi & Joyner, 2018). Living longer with fewer financial resources causes many older adults to continue to work to ensure financial stability. Lower income older adults, many of who have job histories of lower wage jobs, are particularly vulnerable. Moreover, disrupted job histories, for instance, women who took time off from work to raise or care for families, also predict lower Social Security benefits, which creates financial insecurity later in life.

Benefits related to working past retirement age are difficult to ascertain. Johnson, Pitt-Catsouphes, Besen, Smyer, and Matz-Costa (2008) note a job that matches employee preferences is associated with reported higher quality of life and life satisfaction. Challenges that complicate the ability to work may be related to personal health changes associated with aging, such as chronic health conditions, changes in vision, or other medical complications. Also, older adults who work in physically demanding positions may have limited ability to continue to work as physical health changes occur. Many older adults cannot work due to caregiving demands, with the cost of caregiving creating greater financial insecurity. Moreover, for older adults who seek work, ageism may be a factor in their ability to find employment, as employers make assumptions about ability, cognitive status, and physical capabilities. Transportation to and from work may also be a barrier, particularly in rural areas that may not provide public transportation services.

Staying employed is a necessity for many. Williams and Brown (2017) reported 29% of retirees have less than \$25,000 saved for retirement, and 21% of retirees have no confidence in their financial security. Moreover, the authors noted about

38% of the retirees they surveyed indicated they worked for pay in retirement to make ends meet; thus demonstrating work for many is a necessity, not a choice.

In research conducted by the Urban Institute Retirement Policy Program, results indicate that many older adults are prematurely and involuntarily separated from employment because of layoffs, business closures, job dissatisfaction, and personal or health reasons (Johnson & Gosselin, 2018). Moreover, employers may demonstrate strong preferences for younger workers in hiring and retention practices. Employers have lobbied successfully for changes in the Age Discrimination in Employment Act, which is a federal legislation that requires employers to treat people equally irrespective of age (Gosselin, 2018). For example, the US Supreme Court decision in Ledbetter v. Goodyear Tire & Rubber Co. impairs statutory protections against discrimination in compensation, including compensation discrimination due to ageism, by limiting the time period in which victims can challenge and recover for discriminatory compensation decisions (US Equal Employment Opportunity Commission, 2009). These subtle changes to employment tactics may be damaging to older adult workers, and as such, require strong advocacy toward equitable policy.

For Americans 65 and older, there is a growing trend in self-employment and entrepreneurship, which may meet the need for schedule flexibility (Giandrea, Cahill, & Quinn, 2008; Toossi & Torpey, 2017). In addition, employers may provide employees with an option for remote work (i.e., work from home). Older adults may also seek bridge jobs that offer a transition from full-time to part-time work or full retirement, and generally provide schedule flexibility, but may not offer benefits (Ameriks et al., 2018; Cahill, Giandrea, & Quinn, 2007).

Work accommodations for older adults are important areas of advocacy and policy. For all older adult workers, but specifically for those who must continue to work for financial reasons, the American Academy of Social Work and Social Welfare's policy recommendations address the importance of advocating for flexible employment relative to schedule, location, and consideration given to transitioning from full-time employment to retirement (Morrow-Howell et al., 2016).

There are many resources for social workers seeking to help older adults be gainfully employed. The AARP Foundation Back to Work 50+ website offers possibilities for older adult workers to connect with prospective employers. Encore (at www.encore.org) is a national organization that supports collective action and networking for older adults. The Center on Aging and Work at Boston College (https://www.bc.edu/research/agingandwork/) provides current and useful data and research on older adult employment issues.

Caregiving/Informal Volunteering Caregiving is characterized by all the opportunities many older adults have to support ill or dependent partners or spouses, assist with childcare or child rearing, or check on neighbors in need. Often these are not voluntary, but obligatory. In the 2015 report Caregiving in the US, 49% of caregivers report not having any choice about being a caregiver (National Alliance for Caregiving, 2015). In Valuing the Invaluable 2015 Update, AARP's research indicates in 2013, informal caregivers of all ages provided volunteer services with an

economic value of \$470 billion in the United States (Reinhard, Feinberg, Choula, & Houser, 2015).

The 2015 Caregiving in the US report provided a wealth of information on caregiving in the United States (National Alliance for Caregiving, 2015). Over 34 million people provided care for an adult over age 50 in 2015. Approximately one in five caregivers is a spouse, and spouses provide the highest number of hours of care than any other caregiver group. Typically, these caregivers are older and at risk for health problems themselves. One in 10 caregiver is over age 75. Women are more likely the caregivers but also more likely to be care recipients. Approximately 60% of caregivers are White and 16% are Latino (National Alliance for Caregiving, 2015).

While caregiving for family members or friends can be rewarding, often it is accompanied by stress (Walker, Powers, & Bisconti, 2016). Half of caregivers providing the most hours of caregiving report high levels of emotional stress (National Alliance for Caregiving, 2015). Caregivers often struggle with challenges to their physical and mental health and economic strain. Depression, anxiety, and somatic illnesses are common (Feinberg & Levine, 2016; Kropf, 2018). Caregivers also find themselves struggling in relationships with other family members and are lacking social support. Managing medication and performing nursing activities for a family member or friend may be overwhelming (Look & Stone, 2018). As a result, older caregivers are at greater risk for compromised health (Talley & Crews, 2007).

In the American Academy of Social Work and Social Welfare policy recommendations, financial support for caregivers is highlighted, specifically with regard to expanding family leave and increasing cash benefits for low-income caregivers (Morrow-Howell et al., 2016). Supporting policy to monetize family caregiving may assist in a greater understanding of how much family caregiving is provided in the United States. The cost of this uncompensated time is comparable to care supplied by home health and long-term care personnel. In addition, considering expansion of respite care would benefit the long-term health of caregivers.

Numerous resources for older adults who need programs, services, or information about informal caregiving are available. Eldercare locator is a public service of the U.S. Administration on Aging to help older adults and their loved ones find services anywhere in the United States. The National Alliance for Caregiving is a national coalition to advance caregiving through advocacy and research (https://www.caregiving.org). AARP provides guides, care options, and online support for caregivers. The ARCH National Respite Network and Resource Center helps families locate respite options for loved ones. Resources online are easily accessible to professionals and loved ones.

Formal Volunteering Unlike employment or caregiving, volunteering is intentional and a chosen activity by the older adult. In this way, formal volunteering is uniquely different when considering productive activities. Unlike employment that may be necessary because of financial stress or obligatory caregiving, formal volunteering is a choice. These tasks are performed through, or for, organizations or agencies, including schools and faith-based organizations (FBOs) and tracked through the U.S. Bureau of Labor Statistics (BLS) capturing the amount of volunteerism

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occurring in older adults. The BLS (2016) noted 62.6 million Americans volunteered from September 2014 to September 2015, primarily with faith-based organizations (31.1%), education/youth service organizations (25.2%), and social/community service organizations (14.6%). Moreover, the government-sponsored Corporation for National and Community Service (CNCS) (n.d.) reported those 62.6 million volunteers contributed 7.8 billion volunteer hours with an estimated value of \$184 billion dollars (approximately \$23.58/hour). These data describe volunteerism across all age groups; Americans 65 and older represent only 14.8% of the 62.6 million Americans who volunteer. Characteristically, older adults engaged in formal volunteer activities tend to be college educated, religious, have higher incomes, and perceive themselves to be healthy (Zedlewski & Schaner, 2006).

Research has strongly associated volunteering with positive life and health outcomes for older adults (Morrow-Howell, Hinterlong, Rozario, & Tang, 2003; Musick, Herzog, & House, 1999). In research comparing foster grandparents (FG) and senior companion (SC) volunteers to respondents of the Health and Retirement Survey (HRS), Tan et al. (2016) found FG and SC volunteers reported better health and greater life satisfaction than other HRS respondents. Both FG and SC were also found to attract a more diverse group of volunteers. In a seminal review of the state of volunteerism, Wilson (2012) notes undertaking a new role as a volunteer in later life is uncommon with the best predictor of volunteerism actually being a personal history of volunteerism. This has been supported by other research (Morrow-Howell, 2010).

There are many challenges associated with volunteering including:

- People simply do not know where to look for volunteer opportunities. Volunteers are most often recruited by other volunteers or commonly called the *concentric circle of volunteer recruitment* (Flynn & Feldheim, 2003). People volunteer due to individuals in their social communities encouraging and supporting that behavior.
- Time spent helping friends and loved ones—*informal* volunteerism—may account for a great deal of leisure time. Without respite from informal volunteer activities, many older adults simply may not have time for formal volunteer tasks.
- Potential time challenges are mirrored in other volunteers of all ages. Traditional volunteerism was often viewed as a commitment to a certain number of hours on specific days of the week. Older adults may have other time commitments, face health challenges, or, as a benefit of retirement, may wish to be less beholden to a schedule. This trend is called *episodic volunteerism* (Hustinx, 2010). Some volunteers prefer to volunteer their time to organizing events, such as walks and fundraisers, where time spent is concentrated on a single activity (e.g., Alzheimer's and American Heart Association walks).
- Many older adults must work due to financial insecurity and have less time to
  volunteer. The need for senior employment opportunities will increase as current
  retirees enter retirement with less-than-adequate retirement savings. Volunteer
  opportunities with small stipends will help fill this gap. The Grand Challenge

- policy brief supports increasing the income limits on national programs such as Foster Grandparents and Senior Caregivers (Morrow-Howell et al., 2016).
- Limited transportation is another barrier to volunteering. CNCS programs cover
  the cost of transportation via a volunteer stipend. However, some older adults do
  not drive or own a car. We may need to encourage a trend toward tele-volunteer
  opportunities or center-based volunteer opportunities where van transportation
  options may be available. Accessible van/public transportation may also encourage individuals with physical and cognitive disabilities to volunteer.
- Some people start a volunteer experience, but do not continue in the role long-term. Attrition in volunteerism is common for a variety of reasons led primarily by dissatisfaction with the volunteer role. Unfortunately, few social service or faith-based organizations can afford trained staff to administer a volunteer program, which could make a significant difference in recruitment and retention of volunteers. Best practices on *professional volunteer administration* are available, and organizations do offer training and credentialing. Viable volunteer programs operate best when administered in light of key realities: volunteers will not simply appear and stay; recruiting and retaining volunteers may be prohibitively expensive; volunteers should be managed, disciplined, and even fired if necessary; volunteers raise risk management concerns; and volunteers and staff may or may not bond (Brudney, 2002).

## Reasons for Volunteering

The reasons for volunteering have a research history dating back more than 30 years. Over time, a model and a volunteer functions inventory (VFI) of why people volunteer has been constructed. A functional framework of motivation to volunteer (Clary et al., 1998; Clary, Snyder, & Stukas, 1996) emerged from this research, identifying six factors that motivate volunteer behavior: a values factor, such as humanitarian/ altruistic reasons; a social factor, volunteering to spend time with friends; an understanding factor, related to learning/practicing skills; a career factor that motivates many younger volunteers who wish to explore a specific field; a protective factor that mitigates against negative affect (depression, loneliness); and an enhancement factor, described as facilitating enhancement of self-esteem and ameliorating a sense of guilt by serving individuals perceived as less fortunate. This six-factor model is depicted in Fig. 4.1. The VFI has been validated across a wide variety of volunteer populations. An individual's predominant motivational factor varies based upon multiple variables, such as type of volunteer task and demographic groups. Clary et al. (1996) note older adults tended to place more weight on the values, social, and enhancement factors. Understanding what motivates people to volunteer has become increasingly important to addressing an age-old problem in volunteer administration: recruiting and retaining volunteers.

Nationally there are several aging-specific volunteer opportunities for older adult seeking to be active. Tapping the volunteer initiative of Americans age 55 and older, Senior Corps is comprised of the Foster Grandparents program, Senior Companions, and the Retired Senior Volunteer Program. Social Work Grand Challenges reflect a need to expand and promote these specific national volunteer opportunities (Morrow-Howell et al., 2016).

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Fig. 4.1 Motivation to volunteer six factor model (Clary, Snyder, Ridge, Copeland, Stukas, Haugen, & Miene, 1998)

Started in 1965, Foster Grandparents provides children with mentoring and tutoring by older adult volunteers. Since 1974, Senior Companions (SC) has matched older adult volunteers to individuals in their communities to assist with in-home and transportation tasks. Both FG and SC are nontraditional as they are volunteer positions that provide a small stipend. Volunteers are asked to serve 15–40 hours per week and receive a small tax-free stipend (approximately \$2.65 per hour in 2016). This recognizes many older adults living on small, fixed incomes, who may wish to volunteer but are precluded from doing so by challenges such as the cost of transportation. There is an income qualifier associated with SC volunteers (125% above poverty line or less income).

The Retired Senior Volunteer Program (RSVP) is also sponsored by CNCS but does not have an hourly requirement or offer a stipend. RSVP matches Americans 55 and older to service opportunities in their communities, such as disaster relief services, classroom mentoring, service in community environmental activities, and assistance to help Americans develop economic opportunities. Today, RSVP offers

more general volunteer opportunities and intersects with several other government programs, such as the Veterans Administration and Meals-on-Wheels, to offer professional expertise. Because it has no time requirements, RSVP may more easily meet the needs of today's generation of older adult volunteers.

Many FBOs are associated with community organizations that engage cohorts of volunteers to address community challenges, such as food supply, housing, and services for the homeless (Garland, Myers, & Wolfer, 2008; Yamada & Gutierrez, 2014). Many FBOs have well-developed community outreach networks and an online presence in the form of a website that may be instrumental for people searching for a volunteer experience to match their spiritual beliefs.

## **Case Presentation**

Florence G. is a 72-year-old widowed female who lived in a small town in a north-eastern state in the United States. Equidistant from two very large cities, the town has a well-developed sense of community, and citizens in this town tend to live there their entire lives. Neighbors know each other. Citizens express and demonstrate strong civic engagement. Florence was raised in this town. Her parents emigrated from Poland during World War II. She married and raised a son with her husband of 45 years, who died after a long illness. Their son moved away many years ago to pursue a career. Florence reports he was marginally involved in caring for his ill father, and that their relationship has been strained since that time.

Florence worked as a bookkeeper for the local school district. Her husband operated the community florist shop, and Florence also helped him run this business. When her husband became ill, he required more and more care from her over the course of an 8-year disease progression. Over time, Florence needed to resign from her job and eventually had to sell the florist shop. Ultimately, her husband required placement in a long-term care facility and died shortly thereafter.

Although she thought she had adequate financial resources to meet her current needs, after her husband died, Florence was lonely and socially isolated. She briefly considered returning to work, but because of her lifelong community ties, she believed she could benefit more from volunteer activities.

### **Assessment and Intervention**

Volunteer opportunities can be difficult to find in many communities. Florence began her search using a national internet volunteer match service. She chose to volunteer for Meals-on-Wheels, an organization well known in her community. Initially, Florence responded positively to the challenge of delivering meals to many people in town who were her neighbors and her peers in age. However, over time, Florence thought she was not able to spend any time with these clients because

delivery needs in the community were too high. This may reflect the *social* factor in the six-factor model of motivation to volunteer (Clary et al., 1996). She wished to spend time with many of these clients because she understood the sense of social isolation many of them faced on a daily basis.

Visiting a neighborhood coffee shop, Florence saw a bulletin board notice for a local agency that recruits, trains, and mentors volunteer legal guardians (VLG). Florence thought about this opportunity, and although it seemed interesting, it also seemed extremely challenging, especially with regard to the legalities of assuming this type of volunteer role. She contacted the agency and spoke with the volunteer coordinator.

During a lengthy in-person interview, Florence provided information regarding her many skill sets, including her bookkeeping background, and talked at length about the care she provided to her husband during his illness. It had not occurred to Florence that she had acquired essential case management skills during her husband's illness. In fact, she had learned to use county aging services, traversed Medicare guidelines and policies through her husband's frequent hospitalizations, and ultimately learned quite a bit about long-term care when she placed her husband in a local facility. The agency saw great utility in Florence's competencies and in her desire to give back to her community.

Florence met several of the agency's administrative personnel during the interview, including another VLG who happened to be the town's rabbi and was also a master's-prepared social worker. He assured Florence she would receive all the support and mentoring she may need and he would personally serve as Florence's mentor for her initial cases. Florence learned the agency board of directors was comprised of people from all professional walks, including an administrator for the local hospital, a financial services advisor, an accountant, a funeral director, an elder law attorney, a long-term care administrator, and a member of the clergy. This was important to Florence because she lacked the confidence initially to take on the responsibilities of a VLG. Florence completed the onboarding process and was accepted to become a VLG.

The agency initially assigned Florence to become a VLG for Mrs. B, an 82-yearold member of the community who had also helped her husband with care in their home until he died. Mrs. B faced a number of challenges, including affecting a safe discharge from a brief hospital admission. Unfortunately, Mrs. B had no one to help her. The agency saw these challenges as similar to Florence's experiences with her husband's illness, and thus, a good match.

Florence, who lived a few blocks from Mrs. B, was able to assist with a safe discharge, used her bookkeeping skills to review Mrs. B's unpaid bills, and made a successful referral on Mrs. B's behalf to county services for some home health assistance. Over time, Florence encouraged Mrs. B to volunteer at the local synagogue.

The minister on the agency board of directors was able to provide Mrs. B some information regarding end-of-life planning, a subject Florence believed was too challenging for her, although she had faced many of the same decisions with her husband. By relying on the minister, Florence believed she gained confidence to

approach this subject with other guardian clients over the course of her volunteer role. Florence was able to devote the time to assisting Mrs. B that she had not been able to give to clients in previous volunteer activities, and to Florence, this was immensely gratifying. This experience helped Florence see just how much she *mattered* in her community.

Florence assumed other VLG assignments over time after Mrs. B was successfully placed in a long-term care facility. Some cases were more difficult than others; one case in particular challenged Florence's emotions about conflicts with her son. However, she persevered, and the client's family situation became more tenable. Ultimately, through the eyes of this client's family, Florence was able to see her son's point of view with regard to caring for his father.

This case demonstrates the value of older adult volunteerism to define productive aging for the volunteer. Experience and a personal understanding of the challenges of growing old in America are powerful informers. Many VLGs gain a sense of confidence and mastery of complicated aging concerns. For some, becoming a volunteer legal guardian validates the importance of their life experience. Moreover, Florence's story depicts clear motivations to volunteer for humanitarian (values) and social reasons—common motivators for older adult volunteers (Clary et al., 1996). Florence also reflected that she thought her contribution and her time mattered.

A VLG model requires strong supervision and support to ensure the ethical delivery of services and satisfaction of a volunteer. Volunteer legal guardians provide a unique opportunity that would be challenging for many people. However, there are many other types of volunteer opportunities, as discussed earlier in the chapter.

## **Future Steps**

**Research** Research indicates innovative models of volunteerism are required to capture the interests of new retirees, who, in the main, may be healthier and longer-lived than earlier generations of retirees. Because of possible shortfalls in individual retirement savings, blended or stipend models of volunteerism should be explored nationally and at community levels. Moreover, we must explore creative forms of paid work for economically challenged retirees. This will require exploratory research on barriers to employment faced by older adults. Research on this is being conducted at the Boston College Center on Aging and Work and at AARP.

Research should also drive new models of volunteering related to other challenges, such as physical, transportation, and cognitive limitations of volunteers. Home-based volunteering—perhaps delivered via home visit services, such as Meals-on-Wheels or Senior Companions—may provide volunteer opportunities to

individuals who cannot leave their homes and therefore might be overlooked as potential volunteers. For instance, the possibility of engaging in individual crafts projects, such as knitting caps for newborn hospitalized babies, could be offered via home visit services.

**Policy** American Association of Retired Persons (AARP) (n.d.) supports policy to create flexible workplace options related to health and endurance and notes a need to advocate strongly for strict enforcement of age-discrimination laws. Making workplaces flexible and age-friendly is critical to ensuring people have access to non-volunteer productive aging possibilities, which may be increasingly important in a time of diminished retirement funding. Moreover, AARP supports public policy to offer appropriate, affordable transportation for older adults. Policy around workplace environmental support of older workers should also incorporate more volunteer programs with stipends for individuals who wish to contribute but cannot afford the cost of volunteering.

In addressing the profession's "Advance Long and Productive Lives" Grand Challenge, Morrow-Howell et al. (2016) outline three policy recommendations. First, like AARP, Morrow-Howell et al. (2016), suggest creating age-friendly work opportunities and providing monetary support to caregivers, who as informal volunteers supply a service to their loved ones and to society. Second, in the absence of the work provided by informal caregivers, more public funding of supportive programs would be required to cover the labor shortfall. Third, Morrow-Howell et al. (2016) recommend supporting and expanding the Corporation for National and Community Service programs, such as Senior Corps, RSVP, and Foster Grandparents. Several of these programs offer small stipends to volunteers to address income shortfalls faced by many older adults.

**Practice** Asking clients if they have an interest in being active or engaged, and if so, to be prepared to help them search for an appropriate opportunity is important. Often, people do not volunteer because they are unaware of opportunities. Social workers need to be aware of local volunteer opportunities to advise clients about ways to be engaged. An assessment should include questions about volunteer history and volunteer interests, including what may motivate an older adult to volunteer.

For clients facing other challenges, such as physical or cognitive limitations, considering special volunteer opportunities is important. Approaching local faith-based organizations for assistance or partnership in developing a potential new volunteer program is one possibility. Remember to invite social media and press coverage of efforts in order to encourage others to adopt your innovative volunteer ideas. Individual and small group volunteering at the practice level requires out-of-the-box thinking. Appreciating the personal and the economic value of volunteering may help us keep focus.

#### Conclusion

A majority of aging adults aspire to be productive citizens. As employment, caregiving, and volunteering are activities that contribute to helping individuals stay engaged, society must strive to create policies to enable people to be active throughout their lifetimes. Social workers can help by dismantling preconceived notions about aging while empowering individuals and their families to stay engaged and productive.

#### **Discussion Questions**

- 1. In this chapter, volunteer legal guardianship was described. What are ethical challenges that may face these volunteers? Why might it be difficult to launch a volunteer guardianship program?
- 2. How might you be challenged when launching a volunteer program that spans people of different ethnic and racial backgrounds?
- 3. Ageism (or age discrimination) is discussed throughout the chapter. How are you prepared to learn more about and discuss ageism in your community?
- 4. Compare and contrast faith-based volunteerism and secular volunteer opportunities, such as FGs, SCs, and RSVP. Using challenges to volunteerism noted in this chapter, which volunteer opportunity may have better recruiting and retention possibilities?
- 5. How prepared is your present agency of employment to incorporate volunteers into its service delivery?

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## Chapter 5 Eradicate Social Isolation



Alicia M. Sellon

#### **Grand Challenge: Eradicate Social Isolation**

The American Academy of Social Work and Social Welfare has identified the eradication of social isolation as one of 12 Grand Challenges for Social Work over the next decade. This Grand Challenge recognizes the devastating influence that social isolation can have across the life course and highlights the important contributions that social workers can make. In particular, social workers can play a key role in integrating knowledge from diverse fields of study, increasing our understanding of the intersections of various physical, psychological, social, and environmental factors that contribute to a person becoming socially isolated. This approach can help to develop both a more holistic understanding of and more appropriate interventions for addressing social isolation. In addition, social workers can also help to make important strides in educating the public, as well as health and human service professionals, about ways to identify and intervene (Lubben, Gironda, Sabbath, Kong, & Johnson, 2015).

#### Overview

A lack of meaningful relationships, or social isolation, poses a major risk to the health and well-being of individuals, families, and communities. Social isolation is related to a number of health problems and can increase the risk of mortality (Gerst-Emerson & Jayawardhana, 2015; Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Nicholson, 2012). Social isolation also reduces opportunities for people to engage with others and participate in the life of their communities (Nicholson,

2012). Given that people are more isolated than ever before (McPherson, Smith-Lovin, & Brashears, 2006) and with the increasing recognition of the detrimental consequences associated with being socially isolated, there is a need to take a more holistic approach to understanding health and wellness by including a focus on social health. Social work, with its focus on person-in-environment, is well suited to play a leading role in efforts to reduce the incidence of social isolation.

While social isolation can occur at any point during the life course, it is particularly virulent among older adults. Consequently, with high rates of social isolation and loneliness among older adults (17–30%) and an increasing number of older adults in the United States and around the world, improving knowledge of the dynamic factors associated with isolation and identifying opportunities to reduce isolation are an important focus of gerontological social work (Elder & Retrum, 2012; Hawkley & Kocherginsky, 2018).

What Is Social Isolation? Social isolation can be classified in two ways (Elder & Retrum, 2012; Nicholson, 2012): objective social isolation and subjective social isolation. Objective social isolation relates to persons' social networks, or their total number of social contacts. Social networks include primary contacts (family, friends, neighbors) and secondary contacts (religious, community, or other social organizations) (Lubben et al., 2015). Subjective social isolation focuses on perceptions of social isolation and feelings of belongingness. Loneliness can occur when there is a mismatch between an individual's desired and actual levels of involvement and connection with others (Cacioppo & Cacioppo, 2014). It is possible for people to be objectively socially isolated and not lonely and vice versa. Recent research highlights the importance of considering both social isolation and loneliness, as both have been associated with significant health and mortality risks for older adults (Cacioppo & Cacioppo, 2014; Gerst-Emerson & Jayawardhana, 2015; Holt-Lunstad et al., 2015).

Social Isolation and Loneliness Among Older Adults Recent research suggests that as many as 17% of older adults (50+) in the United States may experience social isolation (Elder & Retrum, 2012) and that as many as one in three older adults experience loneliness (Gerst-Emerson & Jayawardhana, 2015). Among older adults, there are a number of demographic features that are associated with social isolation. For example, lower socioeconomic status, lower education levels, and living in lower-income areas have been recognized as risk factors for both objective and subjective social isolation (Cacioppo & Cacioppo, 2014; Evans, Wethington, Coleman, Worms, & Frongillo, 2008; Nicholson, 2012; Portacolone, Perissinotto, Yeh, & Greysen, 2017; Yang et al., 2016). Women tend to be less objectively socially isolated than men but are more likely to experience loneliness than men (Beal, 2006; Nicholson, 2012; Pinquart & Sorensen, 2001; Taylor, Chatters, & Taylor, 2018). Research also suggests that racial and ethnic minority groups may be disproportionally affected by certain risk factors for social isolation, such as lower incomes, poorer health, and less access to services and social supports (Nicholson, 2012; Taylor et al., 2018). However, research also suggests that people of color may have

access to important protective factors, such as greater connection to their church (Taylor et al., 2018). Finally, people aging with disabilities may be at increased risk of social isolation, due to the fact that they often have fewer opportunities to develop wealth and income, lower marriage rates, smaller social networks, and fewer interactions with the community as compared to those without disabilities (Kessler/NOD/Harris, 2010; Schur, Kruse, & Blanck, 2013).

The Life Course and Related Risk Factors In order to better understand risk factors and identify possible interventions for social isolation and loneliness, it is important to consider life course profiles. There are two temporal dimensions to consider: enduring and situational social isolation (Machielse, 2015). The first dimension refers to older adults who have very small social networks and have been objectively socially isolated for much of their lives. These smaller networks may be by choice, with some people preferring to be alone or have a limited number of social contacts. They may also be due to structural or other factors that have limited opportunities to develop relationships (e.g., people aging with disabilities). Individuals with smaller social networks, regardless of choice, are particularly at risk for adverse outcomes if they have declines in health and functioning and do not have access to, or lose, people in their networks who could provide instrumental (e.g., transportation) support. The second dimension refers to experiencing recent, negative life changes that contribute to a person becoming isolated. Individuals in this group have a supportive social network but are at risk due to life changes, such as loss or change of role (e.g., retirement, becoming a caregiver, etc.); the death of a spouse/partner, family member, or friend; loss or change in access to resources (e.g., transportation/driving cessation); and declines in health and functioning (Elder & Retrum, 2012).

In addition to major life changes, there are a number of risk factors for social isolation and loneliness at the micro, mezzo, and macro level. Many of these factors can have a bi-directional relationship, being both a risk factor for and an outcome of social isolation and loneliness.

*Micro* This level refers to the individual and focuses on risk factors related to physical and psychological functioning. Older adults who experience declines in health and functioning later in life are also at increased risk for social isolation and loneliness, particularly when social and instrumental supports, such as assistive devices and transportation, are not available. Research suggests that older adults who rate their health as poor or who have one or more chronic health conditions are more likely to be social isolated (Hawkley & Kocherginsky, 2018; Kobayashi, Cloutier-Fisher, & Roth, 2009; Nicholson, 2012). In addition, experiencing declines in physical or sensory (hearing) functioning increases the risk for both loneliness and social isolation (Hawkley & Kocherginsky, 2018; Mick, Kawachi, & Lin, 2014; Nicholson, 2012). Research also suggests that having a larger social network and being socially engaged can help reduce the risk of functional disability (de Leon, Gold, Glass, Kaplan, & George, 2001; Nicholson, 2012).

A number of psychological and cognitive predictors of social isolation and loneliness exist. Older adults with mental health concerns, particularly those who experience symptoms of, or have a diagnosis of, depression, are at high risk for social isolation and loneliness (Elder & Retrum, 2012; Nicholson, Dixon, & McCorkle, 2013). Depression can be a risk factor or consequence of social isolation, and experiencing depressive symptoms nearly doubles the risk of becoming socially isolated (Nicholson et al., 2013). Both passive coping skills, such as avoidance, (Machielse, 2015) and declines in cognitive functioning (Elder & Retrum, 2012) also increase the risk for social isolation.

*Mezzo* This level focuses on risk factors related to a person's home environment and social relationships. Although given relatively less attention compared to other risk factors, the home environment can play an important role in terms of older adults' ability to socialize with others. For older adults who have aged with a disability or experienced functional declines later in life, an accessible and usable home environment is critical to their ability to remain socially engaged (Greiman, Fleming, Ward, Myers, & Ravesloot, 2018; Hammel et al., 2015).

The size and quality of individuals' social networks can strongly influence their risk of social isolation. In particular, living alone, having a small social network, and having infrequent or negative interactions with network members increase the risk for social isolation (Hawkley & Kocherginsky, 2018; Holt-Lunstad et al., 2015; Nicholson, 2012). The death of network members also increases the risk for social isolation (Nicholson, 2012). Conversely, being in a supportive marriage reduces the risk for isolation (Hawkley & Kocherginsky, 2018; Nicholson, 2012). Similarly, positive and supportive relationships with family members are an important protective factor (Hawkley & Kocherginsky, 2018).

*Macro* Focusing on the community and societal factors, research has identified a number of factors associated with social isolation. First, living in economically disadvantaged areas, areas with high crime, or communities that lack health services and supports increases the risk of social isolation (Elder & Retrum, 2012; Portacolone et al., 2017). Second, communities that lack transportation, accessible and usable sidewalks, and buildings increase the risk for social isolation (Elder & Retrum, 2012; Hammel et al., 2015). In addition to the physical accessibility of the community, negative social attitudes, including, but not limited to, ageism, racism, and ableism, make it much more difficult for many older adults to stay socially engaged in the community (Elder & Retrum, 2012; Hammel et al., 2015; Schur et al., 2013).

Consequences of Social Isolation There are a number of negative health-related outcomes linked with social isolation. Social isolation is associated with poorer health behaviors, such as smoking and sleeplessness (Cacioppo & Cacioppo, 2014; Hawkley, Thisted, & Cacioppo, 2009; Nicholson, 2012). In addition, social isolation has been linked with increases in hypertension, coronary heart disease, and declines in physical functioning (Nicholson, 2012; Shankar, McMunn, Demakakos,

Hamer, & Steptoe, 2017). Social isolation can also negatively affect mental health, increasing the risk of experiencing depression or depressive symptoms (Weldrick & Grenier, 2018). Older adults with limited social contact are at increased risk for cognitive decline (Weldrick & Grenier, 2018). Importantly, social isolation and loneliness also increase the risk for falls, rehospitalizations, and premature mortality (Gerst-Emerson & Jayawardhana, 2015; Holt-Lunstad et al., 2015; Nicholson, 2012).

In addition, social isolation may have negative social outcomes for families and communities. Older adults have a wide array of strengths, such as wisdom and skills, that can be lost when they become cutoff from others (Weldrick & Grenier, 2018). Research has highlighted the important contributions that socially connected and engaged older adults can make to their communities (for an overview, see Gonzales, Matz-Costa, & Morrow-Howell, 2015).

#### **Case Study**

Mr. J is a 73-year-old African American man who lives alone in his own home. He and his wife divorced 30 years ago, and his relationship with his daughter is strained: they have not spoken in at least a decade. He is a former firefighter, who was forced to retire early due to a back injury. Two years ago, he had a stroke. He received some support from visiting nurses after moving back home from the skilled nursing facility where he completed his rehabilitation. However, he has not sought out more assistance, as he considers himself to be a very independent person. With the loss of functioning in his left side and his former back injury, Mr. J now uses a wheelchair and is having trouble maintaining his home and his health. With the amount of effort it takes to shower, get dressed, and otherwise take care of himself and his home, he does not have much time or energy left for socializing. He has also been in and out of the hospital many times with worsening pressure ulcers.

Mr. J considers himself to be somewhat social but has only talked to his doctor in the last 2 weeks and feels very lonely. He wishes that he could still meet with his friends from the old fire station. They would get together regularly to drink and play cards. However, they lost touch when he had to retire early due to his back injury. He has not spoken to any of them since his stroke. In the few times that he has gone out into the community, Mr. J feels that people have stared and assumed that he was "stupid" and incapable of doing anything. He also used to attend bible study and church weekly. However, he has stopped going, as it costs too much money to take the bus to church and bible study is on the second floor and his church does not have an elevator, so he cannot join in. In addition, in the few times he went to church, the only accessible places were in the back row of pews, so he had to "stare at people's backsides" for most of the service.

#### **Assessment and Intervention**

As seen in the case of Mr. J, there is often a complex interaction between biological, psychological, social, and environmental factors that can both create risk for, and perpetuate, social isolation. This intricacy requires viewing the issue from many vantage points in order to develop both a holistic understanding of a person's experiences with social isolation and possible opportunities for intervention. In addition to assessing for social isolation and related risk factors, it may also be useful to consider the strengths of the older adult. The strengths perspective encourages a collaborative relationship and has been used extensively with older adults, highlighting the resourcefulness and resiliency that they can develop throughout their lives (Chapin, Nelson-Becker, Macmillan, & Sellon, 2015). Drawing on the example of Mr. J, this section discusses opportunities for assessment and intervention with older adults at risk of, and experiencing, social isolation.

**Assessment** To develop a more complete understanding of an older adult's experiences with social isolation, several steps can be taken. These include assessing for social isolation (objective and loneliness), identifying and developing goals, identifying strengths and needs, and examining the accessibility of home and community environments.

In addition to commonly used screens for depression, health status, and functional ability, it is important to pay more attention to social health in healthcare settings. Health and human service professionals are in an excellent position to screen for social isolation. In the case of Mr. J, his repeated trips to the hospital suggest that there is a need to explore how other factors in his life, such as his social health, are affecting his physical health and ability to take care of himself.

While there are many instruments available to screen for social isolation and loneliness (see Elder & Retrum, 2012), three may be particularly useful. The Lubben Social Network Scales (LSNS-18 and LSNS-6) look at network size, frequency of contacts, and potential support from network members. Reliability has been demonstrated for both scales and they have been validated for use with a variety of populations (Lubben et al., 2006). Another commonly used assessment tool is the Berkman-Syme Social Network Index (SNI). This is a reliable and valid tool that focuses on the size of social networks and degree of social integration (Berkman & Syme, 1979). The UCLA Loneliness Scale is a valid and widely used tool to measure subjective social isolation (Russell, 1996).

After identifying an older adult, such as Mr. J, who is at risk for, or experiencing, social isolation, developing an understanding of their potential goals related to social participation is important (Machielse, 2015). For example, some older adults may wish to focus only on increasing or improving relationships with family, friends, or neighbors. Others may be interested in joining a club, volunteering, or finding paid work. Some older adults may not wish to increase their social contacts. In this case, the focus can be on identifying opportunities to increase their self-sufficiency or connect them with services and programs that can help them cope

with issues related to health and wellness (Machielse, 2015). Collaborating with the older adult to identify goals and develop an action plan can help to better develop appropriate interventions. In the case of Mr. J, these goals may be related to helping him better manage his health and re-establish connections with his church and family.

Before developing an intervention plan, it is also important to consider the strengths and needs of the older adult. Assessing for strengths could include identifying any skills, knowledge, or experience that a person has and exploring how the individual overcame past challenges and things that bring them hope (Saleebey, 2013). For example, Mr. J has a wealth of knowledge and skills from his time as a firefighter that could be useful in various volunteer opportunities (e.g., school, health centers, etc.). He also has connections, if somewhat limited, with his church that could provide support and be a source of motivation for him. As he was able to stay active with his church after his back injury, exploring how he was able to do this could provide further insight into potential resources or coping mechanisms that could be leveraged. In addition exploring family relationships and interest in reconnecting with his daughter should not be overlooked.

In addition to looking at what older adults have going for them, it is also important to consider areas where they may need more assistance. Of particular importance is the accessibility of the person's home, access to assistive devices or equipment, and access to public or private transportation. As noted earlier, inadequate or inappropriate supports in a persons' homes can result in individuals not having as much time or energy to engage in social activities (Greiman et al., 2018). In the case of Mr. J, additional supports in his home environment, such as a personal attendant or help with meals and cleaning the house, could help him take better care of himself and leave more energy for other activities. Beyond exploring the home environment, it is also important to consider other assistive devices or equipment, such as hearing aids, that increase older adults' abilities to connect with others (Elder & Retrum, 2012).

Besides assessing the person and the home environment, the accessibility of the community and access to transportation should be taken into consideration. Researchers suggest that communities that are less physically accessible or seen as unsafe increase the risk for isolation (Eisenberg, Vanderbom, & Vasudevan, 2017; Hammel et al., 2015; Portacolone et al., 2017). There are many aspects of the physical environment that can make it difficult for individuals with physical disabilities to access services or participate in community events, such as uneven sidewalks or a lack of curb ramps, absence of access ramps (internal or external), the lack of an elevator, narrow doorways, or heavy doors (Hammel et al., 2015; Rosenberg, Huang, Simonovich, & Belza, 2012). As seen in the case of Mr. J, while he is able to get into his church, he cannot attend classes on the second floor.

Finally, access to transportation, either personal or public, can be an important facilitator of social participation (Elder & Retrum, 2012; Hammel et al., 2015). Older adults who do not have their own personal transportation may have more difficulty engaging with others due to the schedule or location of public transportation (Hammel et al., 2015). In addition, costs associated with using public transportation can make it difficult for lower-income older adults to participate in their communities (Portacolone et al., 2017).

Interventions As in the case of Mr. J, there are often a number of areas to target when it comes to implementing interventions to reduce social isolation. Before connecting an older adult with an established intervention program, it is necessary to address issues identified during the needs assessments. It is also important to consider the older adult's goals when identifying potential intervention programs. A wide range of interventions has been developed, and many interventions are complex and use more than one approach to reduce social isolation (Cotterell, Buffel, & Phillipson, 2018; Gardiner, Geldenhuys, & Gott, 2018). Interventions can be broadly grouped into three categories: one-on-one, group, or community-focused. The use of technology interventions has increased in the last decade, and interventions designed to leverage social media and the internet to help older adults connect or to educate older adults about health and risk signs of social isolation exist across all three levels (Elder & Retrum, 2012; Gardiner et al., 2018). This section provides an overview of the different types of interventions and highlights approaches that may be particularly useful for an older adult like Mr. J.

Before connecting older adults with one or more intervention programs, it may be necessary to help them access services and supports to address needs identified during the assessment process. As Mr. J expends considerable energy taking care of his hygiene and home and has been in and out of the hospital with pressure ulcers, helping him access a variety of services and supports could increase the chances that he will be able to successfully participate in an intervention program. For example, helping him to access assistive equipment, such as an inflatable cushion, could help to reduce the risk of further development of pressure ulcers. It may also be useful to connect him with community-based resources, such as a local Center for Independent Living (CIL), that could provide support and advice on how to maintain his health while using a wheelchair.

After addressing issues identified during the needs assessment, interventions may be employed to maintain or improve an individual's health. One-on-one interventions pair an older adult with another individual. These individuals are generally aimed at developing new friendships or health promotion. Befriending programs, such as the Senior Companion Program, connect frail older adults with a peer who provides friendship and support (Butler, 2006). Interventions aimed at health and wellness connect the older adult with health professionals or trained volunteers who provide regular contact and support (Chapin et al., 2012; Elder & Retrum, 2012; Gardiner et al., 2018; Nicholson & Shellman, 2013). For example, CARELINK is an intergenerational program that pairs nursing students with older adults. The dyads focus on reflecting on the experience of being isolated, developing goals, and identifying opportunities to increase physical activity and social engagement (Nicholson & Shellman, 2013). The Reclaiming Joy program is a peer support program that matches a trained older adult volunteer with an older adult who experiences symptoms of depression or anxiety and receives Medicaid. The pairs develop goals together to improve health and social connections (Chapin et al., 2012). Connecting an older adult, like Mr. J, with similar interventions could help improve his health and provide him with opportunities to socialize and increase his social network. One-on-one interventions may be particularly useful for older adults who are not interested in group activities (e.g., volunteering) or who need help maintaining their health.

In addition to more individually focused interventions, a wide variety of groupfocused interventions have been developed. These often focus on multiple risk factors for social isolation and have been shown to improve mental and physical health and increase opportunities for socialization (Elder & Retrum, 2012; Gardiner et al., 2018). Common types of group-based interventions include hobby groups or interest clubs, physical activity groups (e.g., swimming), group therapy, and volunteer programs. The latter two types of interventions appear to be particularly beneficial (Gardiner et al., 2018). For example, there is robust support to suggest psychological interventions, such as reminiscence and mindfulness groups (Creswell, 2017; Liu et al., 2007), conducted in group settings by licensed therapists or health professionals are effective at reducing loneliness and improving life satisfaction (Gardiner et al., 2018). In addition, volunteer programs, such as Experience Corps<sup>©</sup>, may help reduce social isolation and loneliness, increase self-esteem and life satisfaction, and improve health and wellness (Elder & Retrum, 2012; Fried et al., 2013; Gardiner et al., 2018; Parisi et al., 2015). Depending on the older adult's goals, group-based interventions may provide an important opportunity to be involved in meaningful and rewarding activities with others.

While group-based interventions are conducted in community settings, there is also a category of community-focused interventions that focus more specifically on addressing structural issues that contribute to social isolation and loneliness (Elder & Retrum, 2012; Gardiner et al., 2018). Many of these interventions are unique in that they include preventive measures. For example, the "Village Model" is a community-developed and membership-driven approach that provides both services and referrals to older adults to help them remain in their own homes and opportunities for social engagement. Villages are run by volunteers (many of whom are members) and paid staff who help with housekeeping, transportation, and referral to health services (Graham, Scharlach, & Price Wolf, 2014). Similarly, the World Health Organization (WHO) has developed a framework to help communities become more accessible and supportive for older adults. This approach, referred to as "aging-friendly" cities, directs attention toward addressing issues such as access to transportation, the accessibility and walkability of communities, access to appropriate health services, and increasing opportunities for civic engagement and employment (World Health Organization (WHO), 2007).

#### **Future Steps**

This section reviews opportunities and future directions in terms of research, policy, and practice.

**Research** Understanding of social isolation and loneliness among older adults has increased dramatically in the last few decades. However, research on social isolation and loneliness among diverse and marginalized populations, such as racial and ethnic minorities, immigrants, and people aging with disabilities, has been limited (Coyle & Mutchler, 2017; Taylor et al., 2018). In order to develop more effective interventions, more knowledge about the experiences and resources of members of these groups is needed. In particular, research focusing on both the mechanisms that lead to social isolation and the potential protective factors available to members of these groups could greatly enhance our knowledge.

In addition to increasing the diversity of populations studied, there is also a need to diversify the research methods used. The majority of studies on social isolation and loneliness have employed quantitative approaches. Increasing the use of qualitative methods will provide an opportunity for a richer understanding of unique experiences with social isolation and loneliness (Cloutier-Fisher, Kobayashi, & Smith, 2011; Gardiner et al., 2018; Machielse, 2015). Increasing qualitative and mixed methods approaches in the evaluation of interventions could also provide additional insights into the mechanisms that are most critical for reducing social isolation and loneliness (Gardiner et al., 2018).

Providing more opportunities for older adults to be directly involved in the development, implementation, and evaluation of studies and interventions could also be beneficial. Gardiner and colleagues (2018) noted that successful interventions often provided some opportunities for older adults to be involved in the development of the program. A participatory approach would allow for the development of interventions that are more specific to the needs of different communities and could also help to empower older adults to take a more active role in preventing and reducing social isolation in their communities.

**Policy** In addition to advancing our research knowledge, social workers can be involved in policy and advocacy work at the local, state, and national level. Social workers can also work with and empower older adults to become personally involved in advocacy activities.

There are several possible routes for advocacy efforts at the national, state, and local levels to address these issues. First, at the national level, social workers and older adults can become involved in efforts to increase funding for the Older Americans Act (OAA). The OAA and its various reauthorizations provide funding for key services to help older adults remain independent and living in the community. However, increasing funding for this legislation to meet the needs of the current and future aging population is critical (Administration on Community Living, 2018). Second, at the state and community levels, social workers and older adults can educate officials about the benefits of making communities age-friendly. Together, advocates and officials can conduct a needs assessment of the community and identify areas for improvement, such as improving the quality and number of sidewalks or developing supportive and affordable housing options for lower-income older adults. They could also explore opportunities to apply for grants or

otherwise identify potential revenue streams for changes (WHO, 2007). Finally, accessible and affordable transportation is an important facilitator for health and wellness of people of all ages. Reductions in funding for public transportation increase the need to rely on private transportation and social networks (Schur et al., 2013). At the local and state levels, social workers and older adults can advocate for the development or improvement of an affordable public transportation system.

**Practice** Beyond involvement in research and policy efforts, social workers can also help to eradicate social isolation and loneliness in their day-to-day practice. Social workers, regardless of practice setting, can begin to include measures of social isolation and loneliness, such as those discussed in this chapter, when intakes or otherwise assessing the health and functioning of older adults. In addition, social workers can play a key role in helping to increase education and awareness of social isolation and loneliness both among other health and human services professionals and older adults. Finally, social workers have a wealth of knowledge and skills that can be leveraged, in collaboration with researchers, to design programs and develop interventions that help to prevent or reduce social isolation and loneliness.

#### Conclusion

Social isolation and loneliness can have devastating consequences for individuals, families, and communities. Too often, the social health of older adults is overlooked in the face of more noticeable and pressing health concerns. However, as reviewed in this chapter, social isolation and loneliness are intricately connected with physical and mental health. As public interest in reducing and preventing social isolation and loneliness among older adults continues to grow, social workers can play a key role in integrating this knowledge to develop new and innovative approaches. Eradicating social isolation and loneliness will require a multifocal approach, with social workers addressing this issue at all levels of practice.

#### **Discussion Questions**

- 1. Why is it important to consider race and ethnicity or ability status when studying social isolation?
- 2. What is meant by the phrase "social isolation and loneliness are related but distinct concepts?"
- 3. Why is it important to consider an older adult's goals when conducting an assessment for social isolation and/or loneliness?
- 4. "What are the differences between micro, mezzo, and macro level risk factors for social isolation and loneliness?"
- 5. When working with Mr. J, what areas in his home life would you focus on first and why? What are ways you could help Mr. J increase his level of socialization?

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## Chapter 6 End Homelessness



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#### **Grand Challenge: End Homelessness**

The Grand Challenge to End Homelessness seeks to address the persistent problem of homelessness and build on the evidence supporting housing-based interventions by expanding available housing resources, ensuring evidence-based psychosocial support to accompany housing, and developing and evaluating new housing-based interventions for specific populations, including older adults and elders.

Each year, nearly 1.5 million people in the United States experience homelessness, at least a third of whom are over the age of 50 (Henry, Bishop, de Sousa, Shivji, & Watt, 2017). The overall estimate of homelessness is recognized as consistent but also an undercount of those who meet the federal definition of homelessness—individuals and families living in a shelter or a place not intended for human habitation—and an undercount of those whose housing instability does not meet this definition, such as households living with friends or family or in a hotel (Gultekin & Brush, 2017). In the last decade, homelessness has decreased by about 10% in the United States due in large part to the increased emphasis on permanent housing interventions. However, the last two Annual Homeless Assessment Reports

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to Congress (Henry et al., 2017, 2018) suggest slight increases in unsheltered homelessness, and the latest report voices concerns that the reduction of homelessness has slowed as the overall availability of housing affordable to the lowest incomes continues to decline.

Overall, the homeless population is aging at a faster rate than the general population (Culhane, Metraux, Byrne, Stino, & Bainbridge, 2013). In 1990, the average peak age of unaccompanied adults experiencing homelessness was 30, but by 2013, the average peak age had increased to 55, with the most growth among those ages 50–64 (Culhane et al., 2013). While only 2–8% of those experiencing homelessness each year are over the age of 65, the proportion is growing and is expected to triple by 2030, with the costs of shelter, health care, and nursing home care expected to rise precipitously (Culhane et al., 2019). Among a number of psychosocial predictors of older homelessness, such as social isolation, childhood maltreatment, mental illness, substance abuse, and serious health conditions, lack of housing and poverty are "ultimate determinants" of homelessness in older adulthood (Burt, Aron, & Lee, 2001; Cohen, 1999; Shinn, 2007). The escalating affordable housing crisis, the lack of housing options for older adults before age 62, and the disappearance of affordable, aging-friendly, senior housing for low-income older adults further reduce residential options for those over age 65. Limited affordable housing combines with other aging vulnerabilities to cause and prolong homelessness (JCHS, 2017). The growing national affordable housing crisis and growth of older adult homelessness suggest a pressing need to address homelessness at every stage of the life course and to specifically apply evidence and develop innovative solutions to meet the needs of an aging homeless population.

#### **Overview**

Definition The definition of older adult and/or elder homelessness varies. The annual national Point-In-Time (PIT) census that counts all unsheltered and sheltered homeless individuals on one night in January captures only adults who are over age 24 (Henry et al., 2018). However, annual assessments of sheltered homelessness capture additional adult age categories including ages 51-61, which were approximately 25% of the homeless population in 2017, and ages 62+, which were 8% of the population (Henry et al., 2018). Adults ages 50 and over comprise over 50% of individuals experiencing chronic homelessness, which is defined as homelessness with a disabling condition and consistent or intermittent periods of homelessness that total at least 12 months. Because early onset of chronic health and mental health conditions and the deterioration of general health can begin as early as age 40 among those literally homeless and living in emergency shelters, older adulthood among the homeless can conservatively be estimated to begin at age 50 (Cohen, 1999; Gelberg, Linn, & Mayer-Oakes, 1990; O'Connell, 2005). There is some distinction in literature between older homeless adults (50 to 64) and elder homeless adults (65+) (Biegel & Roberts, 2015).

Pathways to Older Adult Homelessness There are multiple pathways that lead to older adult homelessness. In a population-based sample of 350 homeless adults over age 50 in Los Angeles, approximately half became homeless for the first time after they turned 50, and their experiences were different than those who had experienced homelessness earlier than 50 (Brown et al., 2016). Of these individuals, they were likely to have fewer adverse experiences (mental health, substance use, criminal justice involvement) and tended to meet more life course milestones (marriage, job attainment) than were older homeless adults who became homeless before 50. Those homeless before 50 were also more vulnerable, reporting more problems associated with mental health, substance abuse, and functional impairment (Brown, Goodman, et al., 2016).

These and other studies (Lee et al., 2016, 2017) contribute to an emerging understanding of three distinct pathways for this population. First, some older adults age while homeless, typically as a single adult and often related to adverse life experiences and a disabling condition including a mental health or a substance use disorder. Second, some older homeless adults become homeless later in life after they have been marginally housed and employed through their working years but have no economic safety net to rely on as older adults. Finally, some older adults, particularly women, become homeless due to sudden loss in older adulthood such as the death of a spouse, parent, or caregiver.

Race and Gender Older adult homelessness and paths to this status vary by race and gender. African Americans are disproportionately represented in every category of homelessness, although less so in older adult homelessness (Henry et al., 2017). Lee et al. (2016) found that African Americans were particularly overrepresented among those that become homeless after years of marginal housing and employment, while White men predominantly aged while homeless related to a disabling condition and adversity. Chekuri, Turturro, Nekkalapudi, and Mittal' (2016) findings are similar noting that mental health, chronic health conditions, and domestic violence are more predictive of homelessness for White older adults, while the homelessness of older African American adults may be more likely attributed to safety net issues such as unaffordable and inaccessible housing.

Latinos and Asians have been relatively underrepresented among people who are homeless and little research is available specifically regarding older adults (Conroy & Heer, 2003; Lim et al., 2006). Across the lifespan, Latinos have similar risk factors, such as poverty, but report lower rates of homelessness (Burt et al., 2001). Conroy and Heer shared that "the underrepresentation of Latinos amongst the homeless can be interpreted in a couple of ways: (1) Latinos may have found methods of avoiding the streets or the shelter system... or (2) Latinos are systematically undercounted in homeless samples" (pg. 953). Among Latinos, alcohol abuse or dependence, conduct disorder, and intermittent explosive disorder were identified as risk factors for homelessness, while attending a religious service more than once a week was a protective factor (Oh & Devylder, 2014). Homelessness among Asians is even more rare. Having a mood disorder, receiving welfare services, and having

at least one physical health condition were all risk factors for Asians. The risk factors for Latinos and Asians appear to fit a pathway attributed to life experiences. However, other pathways may be uncovered when additional research is conducted.

Women are particularly vulnerable to the sudden loss of a spouse or caregiver who was a primary earner, often hastening economic insecurity that leads to losing stable, affordable housing (Cheung & Hwang, 2004). Once homeless as an older adult, men are more likely to be unsheltered than women, and women are more likely to be institutionalized or cohabitating but in unstable and sometimes dangerous situations (Lee et al., 2016).

Physical and Mental Health Evidence suggests that older adults experiencing homelessness have the physical and mental indicators of aging 10–20 years earlier than the general population (Cohen, 1999) and experience premature mortality due to age-related chronic conditions (Baggett et al., 2013). This accelerated aging includes geriatric conditions (cognitive functional impairment, urinary incontinence, falls, etc.) that typically begin in the general population around age 75 but begin in homeless adults at age 50 (Brown, Kiely, Bharel, & Mitchell, 2012; Hurstak et al., 2017). The conditions persist across varying residential environments (Brown et al., 2016) and may impact the typical course of treatment for other conditions associated with homelessness, such as mental health and substance use disorders. For example, Hurstak et al. (2017) found that alcohol use was a risk factor strongly associated with cognitive impairment in older homeless adults and that impairment impacted treatment for substance abuse. Because of these vulnerabilities, high rates of emergency room utilization are common among older adults (50+) (Brown et al., 2013).

Homelessness itself is a "psychological trauma" that predicts poor health and mental health outcomes (Goodman, Saxe, & Harvey, 1991). Homelessness in later life is characterized by the impact of trauma over the life course. Studies suggest that 25% to 72% of homeless adults have experienced childhood victimization (Burt et al., 2001; Christensen et al., 2005; Padgett & Struening, 1992). Homeless adults also report high rates of childhood involvement with protective services and childhood adversity, such as inadequate food, housing instability, and education barriers (Burt et al., 2001; Koegel, Melamid, & Burnam, 1995). Lee et al. (2017) found that just one incidence of childhood adversity increased the odds of moderate to severe depressive symptoms in older homeless adults and four or more adversities increased the odds of a lifetime history of psychiatric hospitalization.

Some studies report high rates of drug and alcohol use among older adults and elders experiencing homelessness when compared to the general population (e.g., Spinelli et al., 2017). Other studies note that alcohol use is lower among older adults than younger adults experiencing homelessness and describe declining use of substances in older adulthood (e.g., Dietz, 2009). Research to date paints an inconclusive picture of substance use in older homelessness.

Economic Impact of Older Adult Homelessness Homeless adults are high users of medical care, often cycling in and out of emergency departments (ED) and

psychiatric hospitals (Poulin, Maguire, Metraux, & Culhane, 2010) and, when hospitalized, staying longer than those who are housed (Kuno, Rothbard, Avery, & Culhane, 2000). The prevalence of chronic medical and geriatric conditions results in high hospitalization rates for older homeless adults (Brown & Steinman, 2013). Older homeless adults that are unsheltered and those with multiple institutional placements have higher ED utilization rates than those older homeless adults who were housed in last 6 months in rental housing or those that lived with friends and families (Raven et al., 2017). The utilization of health care, housing, and eventually nursing home care translates into significant community costs. Despite actual and expected increases in the older adult homeless population and related health and mental health conditions, services in homeless shelters or housing programs are rarely tailored for aging individuals (Brown, Thomas, Cutler, & Hinderlie, 2013; Cohen, 1999).

#### **Case Presentation**

Jessica is a social worker at a local men's emergency shelter with the new responsibility of locating housing for the individuals on her caseload. Some of Jessica's caseload are young adults, but in recent years, she has an increasing number of clients who are 50 years old and older. Recently Jackson, a 60-year-old cisgender Black man was assigned to her caseload. Jackson was not new to the shelter, but with the community's recent effort to end chronic homelessness, the effort to house him and the others on Jessica's caseload is a new challenge.

About 15 years ago, when Jackson was in his mid-40s, his company notified him that he was being laid off along with more than a hundred other employees. He searched aggressively for jobs, but he was unsuccessful for more than a year, and many of the jobs he was hired for did not include health insurance or sufficient hours to pay for housing. Demoralized by the loss of his job and his lack of access to a new job and one that provided health care, Jackson's diabetes worsened, and he began to drink more heavily to cope with his stress. After several years of this stress, his wife filed for divorce. No longer able to pay the rent, Jackson was evicted from his apartment, leaving a mark on his rental history that often prevented him from finding any other affordable apartments. While he looked for a job and affordable apartments or rooms to rent, Jackson "couch surfed" with various family members and friends but left before overstaying his welcome and straining the resources of others. Finally, when he ran out of people to call, he started sleeping in the local park and then began a cycle of sleeping outside and in shelters when it got too cold. This made his already volatile health status with his diabetes worsen.

During the winter, Jackson often stays at this crowded shelter, located in a busy metropolitan area. After standing in line to secure his shelter bed, he is required to do the same chores as the younger residents, which are difficult due to his health. Each morning, he has to leave the shelter by 6 a.m. and is not allowed to return during the day despite his health status on any given morning. He walks the streets all

day and often "flies a sign" for spending money when he cannot find day labor that he can physically do or that ends in time for him to get in line for shelter. There are few accommodations for older adults available at the shelter. With his chronic health conditions and accelerated aging, Jackson faces a unique set of difficulties. The stairs present mobility challenges, and the bunk beds and shared bathing facilities have become harder to manage.

After a few months of trying, Jessica finally secures Jackson a housing choice voucher. This is a federal government program that assists very low-income families, older adults, and the disabled to afford decent, safe, and sanitary housing in the private market. Housing assistance is provided on behalf of the family or individual, and participants are able to find their own housing, including single-family homes, townhouses, and apartments. Jackson has had a difficult time locating an affordable unit that addresses his physical needs on a public transportation route. She has also discovered, while working with him and three other older men on her caseload, that they qualify for few aging services, but even if they did, there is little coordination between the aging services network and the homeless services network. In order for Jackson to live independently, he will need essential services such as case management, care coordination for chronic health conditions, social opportunities, transportation, meal programs, health screenings, and continued assistance with public benefits. Jessica knows the importance of adjusting the environment to mitigate the typical outcomes of the geriatric conditions associated with aging, but she feels her hands are tied by the constraints of available housing and services. She has become particularly aware of the challenges of securing stable housing and essential services for older homeless adults.

#### Assessment and Intervention

Understanding how to best serve clients like Jackson and other older homeless adults begins by talking to them about their needs and the support they feel they need to stabilize their housing. While building relationships and engaging individuals in their own intervention is effective practice across populations, it is particularly important in homeless shelter settings where, because of transience, shelter volume, and the crisis nature of the work, individuals access emergency shelter services with limited personal attention and often express feeling invisible (Chinman, Rosenheck, & Lam, 2000). Relationship development provides a foundation for shared decision-making about life choices for the future (Brown et al., 2013). Social workers and other human service professionals can then utilize existing assessments that are often mandated upon entry into the homeless services system, as well as more traditional biopsychosocial spiritual assessments, to identify pressing needs.

There are challenges to providing a comprehensive assessment for older adults experiencing homelessness, particularly in nonmedical settings, such as emergency and transitional shelters and permanent housing placements. Older adults share similar experiences of younger adults experiencing homelessness (Lee et al., 2017).

Yet age-related differences, such as difficulties in maintaining health status, cognitive impairment, and other geriatric conditions, and increased mortality make the case for adding attention to modification to current assessment tools and interventions to suit the different needs (CSH and Hearth, 2011). A service provider should first assess for cognitive decline or impairment before gathering other assessmentrelated information about a client's status. Tools like the Mini Mental Status Exam (MMSE, MMSE-2) assess cognitive function and memory in a time-efficient manner in the event that a service provider suspects cognitive impairment (Folstein, Folstein, & Fanjiang, 2001). In addition, service providers should pay close attention to what the loss of independence means to older adults who are experiencing homelessness. Using a modified activities of daily living (ADLs)/instrumental activities of daily living (IADLs) checklist to ask questions about any changes they have had to make because of their homeless status is another assessment tool that can be utilized to assess personal and health-related needs related to independence and independent living. Assessment should identify necessary organizational and environmental accommodations to meet the needs identified in assessment.

Assessments should also consider the accumulation of experiences, particularly traumatic and adverse experiences. These experiences over the life course are prevalent among homelessness adults (Padgett & Struening, 1992) and are consistently linked to a number of poor health and mental health outcomes (Felitti et al., 1998). In addition to measures like the PTSD Checklists for the DSM-V (Civilian and Veteran versions) to screen for PTSD (Ruggiero, Ben, Scotti, et al., 2003), assessments should document other adverse experiences such as the frequency and duration of homelessness and housing instability, accidents, physical and sexual assaults, and other stressful life events that can be captured through tools like the Life Event Checklist (Gray, Litz, Hsu, & Lombardo, 2004) and help service providers understand the chains of risk experienced by and still shaping older homeless adults (Ben-Shlomo & Kuh, 2002). Biopsychosocial assessments account for past to present circumstance, particularly in terms of medical information, but modifications should consider the prevalence and accumulation of adversity and trauma among older homeless adults.

In addition, modifications to the assessment should include a spiritual domain to account for cultural beliefs and practices that are important and may serve as resources for older adults experiencing homelessness (Washington, Moxley, Garriott, & Weinberger, 2009). Given the fluid nature of the spiritual dimension in a biopsychosocial assessment, clinicians should be cognizant that it has varied meanings and should consider how to capture them in assessment (Saad, de Medeiros, & Mosini, 2017).

Service providers can also use assessment tool(s) required by the community's Coordinated Entry into homelessness services as a source of information and an engagement tool with clients. Coordinated Entry is a mandated process for federally funded Continuums of Care to ensure that resources are allocated effectively and are easy to access for households experiencing homelessness (US Department of Housing and Urban Development, n.d.). Coordinated Entry is intended to prioritize resources for those with the greatest need, match people with the services that are

most likely to help them exit homelessness, reduce the time it takes for clients to access services, and ensure that limited resources are allocated efficiently. A number of measures are designed for this process, and communities use one or multiple measures to assess individuals who request homeless services.

The Vulnerability Index - Service Prioritization Decision Assistance Tool (VI-SPDAT) is a common measure used in 40 states and three countries (Brown, Cummings, Lyons, Carrión, & Watson, 2018). The VI-SPDAT is a combination of a street outreach tool to determine the chronicity and medical vulnerability of homeless individuals (VI, Community Solutions) and an intake and case management tool to allocate resources (SPDAT, OrgCode). Based on a wide body of social science research, the tool helps service providers allocate resources in a logical, targeted way. Developers contend that the VI-SPDAT allows communities to assess clients' health and social needs and then match them to the most appropriate housing interventions available including permanent supportive housing, rapid rehousing, or finding housing on their own (OrgCode, n.d.). Existing assessment tools like the VI-SPDAT do not yet have a strong evidence base that suggests their reliability and validity. While the VI-SPDAT developers cite the use of evidence and extensive stakeholder input to create the tool (OrgCode & Community Solutions, n.d.), questions remain about its effectiveness as a measure and predictor of success in housing placements (Brown et al., 2018). In addition, instruments like the VI-SPDAT have not yet been normed on an older adult population, and it is unclear if it accounts for the developmental stages of clients. Nevertheless, the VI-SPDAT is widely used in communities across the country and could provide a source of information for service providers and a starting place to gather additional information.

Regardless of needs identified in the assessment process, evidence continues to suggest that permanent, stable housing and other key service components of the Housing First permanent supportive housing model provide a crucial platform to effectively address a range of needs often associated with homelessness including chronic health conditions as well as mental health and substance use disorders (Rog et al., 2014,). Housing First permanent supportive housing is also an effective way of managing the geriatric conditions experienced by older homeless adults (Brown et al., 2015). It is an approach to quickly and successfully connect individuals and families experiencing homelessness to permanent housing without preconditions and barriers to entry, such as sobriety, treatment, or service participation requirements. Supportive services are offered to maximize housing. Currently, two models of Housing First are emphasized in federal policy—permanent supportive housing and rapid rehousing.

Permanent supportive housing (PSH) is targeted toward individuals experiencing chronic homelessness, provides a permanent housing subsidy (a Housing Choice Voucher, a Shelter Plus Care Voucher, a unit in subsidized senior and disabled housing, etc.), and wraps intensive but voluntary services around individuals to ensure ongoing housing stability. This type of housing is resource intensive and is appropriate for those with the most extensive needs, including older adults with geriatric and other disabling conditions (Brown et al., 2015; Henwood, Katz, & Gilmer, 2014). Housing First permanent supportive housing is an evidence-based practice

(SAMHSA, 2010) and has the most extensive research base of the Housing First models promoted by federal government policy.

Rapid rehousing (RRH) is targeted toward individuals and households with less extensive needs and more access to resources. RRH provides a time-limited subsidy and initial services to help a household gain stability. RRH may be appropriate for older adults without chronic conditions; however, no research has examined how effective this model is with older adults, and the implications of aging once housed through RRH, particularly as age-related disabilities, become more relevant.

The Housing First philosophy can be contrasted with *treatment first* models that assume that individuals must attain some semblance of service success in order to become "housing ready" and eligible for permanent housing (Padgett, Gulcur, & Tsemberis, 2006). In practice, housing readiness becomes a barrier to stable housing as individuals with chronic and complex needs were perceived as not ready for housing and thus not prioritized for limited housing opportunities. Housing First flips what was standard practice in homeless services until the mid-2000s and recognizes that stable housing is necessary in order to make progress on other health, mental health, and social goals.

The Pathways Housing First Fidelity Scale defines five key characteristics of Housing First permanent supportive housing programs (Stefancic, Tsemberis, Messeri, Drake, & Goering, 2013). First, to the extent possible, tenants have a choice of neighborhood, unit, and overall living environment. Second, housing is not dependent on serviced success or compliance, and tenants have the same rights and responsibilities as those with a standard lease. Third, services are voluntary and client-driven, utilizing a harm-reduction approach and active, person-centered, non-coercive engagement. Fourth, a range of necessary services are available, either provided directly or brokered, and crisis response is available 24/7. Finally, the program structure supports the above characteristics, prioritizing those with severe and complex needs and maintaining low staff to client ratios.

These fidelity criteria were developed specifically for permanent supportive housing programs; however, aspects of the underlying philosophy apply to other service settings for homeless adults such as emergency shelters, outreach, and case management. In addition, they are congruent with several best practices with older adults including person-centered care and maximizing choice and agency. Older adults are restricted by their age-related health and mental health conditions as well as environments.

While the Housing First intervention has provided an important corrective for homeless services, additional attention should be paid to the needs of aging adults in Housing First and other permanent housing settings. It is important to adjust the environment to mitigate the typical outcomes of the geriatric conditions associated with aging (Szanton et al., 2011). In addition, research suggests additional training is necessary for providers working with older adults (Henwood et al., 2014). As in other residential settings, without sufficient attention otherwise, older adults experiencing homelessness face barriers to aging well including no or limited choice in restrictive environments, social isolation and segregation, lack of neighborhood

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integration, and lack of integration with mainstream health, mental health, and aging services.

In addition to the evidence-driven models of intervention, the inclusion of key stakeholders—from service recipients to gatekeepers—into aging networks and coordinated care for those experiencing homelessness is necessary to create cultures that effectively work with older populations across different demographic and cultural groups as well as social issues. Education interventions for human service professionals, such as continuing education programs and course electives in social work programs, can offer training and education on delivering assessments and building effective programs and organizations for this population. By working with educational institutions, future human service providers can be positively influenced to consider the suggestions mentioned here to ensure that clients receive high-quality care that is inclusive of needs related to experiencing homelessness (Ross, Jennings, & Williams, 2018).

#### **Future Steps: Research, Policy, and Practice**

**Research** Despite recent accumulation of evidence on older homeless adulthood (e.g., Brown et al., 2015), further research is needed to guide effective practice including how we define and count older homeless adults, how current interventions impact older adults, how different pathways to older adult homelessness may require additional nuance in service delivery and interventions, and how ongoing aging impacts further transition once individuals are successfully housed. Relevant to both research and policy, more consistently operationalizing older adulthood in homelessness would advance the knowledge base and inform practice. Currently, the federally required Point-In-Time (PIT) count is the only representative enumeration of unsheltered homelessness. The PIT operationalizes older adults as 65 years old and older, combining all other adults in the ages 25–64 category. While the national sheltered homeless count can use a larger age range, the lack of consistency across counts prevents a more nuanced understanding of the population. Operationalizing older adult homelessness as at least age 50 and over across HUD reporting would acknowledge research to date that demonstrates accelerated aging among the population and provide some standardization for future research.

Further research is also needed to understand how key Housing First and other prominent interventions apply to individuals who are aging. Specifically, while research on Housing First permanent supportive housing continues to suggest the effectiveness with older adults experiencing homelessness (Henwood et al., 2014), research must also examine whether rapid rehousing models are effective with the population. Related, further research must be conducted to understand the specific intervention needs of those on different pathways into older adult homelessness. While the evidence-based Housing First permanent supportive housing model (SAMHSA, 2010) is appropriate for individuals with a serious and persistent mental

illness who have aged while homeless, the same level of services may not be required for an older adult who became homeless in later life because of the death of the primary breadwinner. Research is needed to identify the relative effectiveness of existing interventions with what we are learning about pathways into older adult homelessness.

In addition to research on housing interventions for older homeless adults, additional research is needed to understand what is necessary for continued well-being once older adults experiencing homelessness are housed, particularly as they age in place in settings not designed to provide higher levels of care. Possible transitions within or outside of supportive housing settings to address the ongoing challenges of aging and chronic health/mental health conditions should be a key research priority.

**Policy** The extent of homelessness in the United States is an outcome of public policy, and policy plays a key role in both creating the conditions related to homelessness and solving the problems associated with homelessness (Shinn et al., 2007). The intersection of different policy priorities and silos in mental health, health, labor, and housing is particularly evident in the phenomenon of older adult homelessness. Understanding the impact of various policies on older adult homelessness is important for effective social work at all levels.

Inadequate mental and behavioral health-care policies have led to absent or insufficient treatment and the criminalization of mental health and addiction disorders which, in turn, erect barriers to housing. Inadequate and inconsistent health-care policies have resulted in difficulty accessing and maintaining outpatient care. Attempting to access or qualify for care for a chronic health condition can bankrupt or drain lifetime savings and assets.

Labor policies have excluded domestic and farm laborers—historically people of color—from the benefits that secured income stability through older adulthood. Labor policies have also ignored household and caregiving labor traditionally provided by women and women of color impacting their lifetime earnings. Exclusionary housing policies have resulted in an insufficient housing stock to meet current demand and continue to result in lack of accumulated wealth for African American families and their descendants, creating the need for successive generations to rely on an ever-diminishing social safety net for basic survival needs (Rothstein, 2017).

The policies that have cleared the way for varied pathways into older adult homelessness suggest important policy foci in order to address and end older adult and elder homelessness. There are a few specific areas that could impact the population immediately. First, for those that age while homeless, often with a disabling health or mental health condition, policies that support access to health and mental health care, including mental health treatment and preventative care, are crucial, as are access to nursing homes and higher levels of care than those typically available in permanent supportive housing programs. Many states have been able to address the health and supportive services needs of older homeless adults through the expansion of Medicaid. Second, older adult homelessness could be better addressed by housing policies that extend the assumption of time-unlimited senior housing generally available at age 62 to earlier ages and further question the use of programs such as "move to work" for populations at risk of accelerated aging and the early onset of geriatric conditions. Policy efforts should be implemented that address and redress the damage done by prior and current exclusionary policies that lead to the accumulation of economic damages in older adulthood, particularly among women, Black, Latinx, and indigenous individuals. As Shinn (2007) notes, countries and localities whose policies support lower-income households have lower rates of homelessness.

**Practice** There are a number of opportunities to better address the needs of older homeless adults in social work practice. First, when delivering services for aging homeless individuals, social workers should be reminded of the various pathways into older adult homelessness and that one size and type of services does not fit all. Individuals who become homeless for the first time in later life may not need the same intensity of services as those who first experience homelessness earlier in life. For some older adults, addressing acute and chronic health and mental health issues is paramount: for others, simply stabilizing housing and helping address economic needs are the priority, so they can act as agents in their own aging process.

Second, social work practitioners should focus on creating intentional intersections among homeless and aging services networks, particularly for those who become homeless in later life. Aging networks are often the most developed social safety nets in US communities and can provide key nutrition, transportation, housing, and social integration services that stabilize older adults experiencing homelessness and possibly prevent older adults from becoming homeless in the first place (Brown, Goodman, et al., 2016). However, beyond case-by-case collaborations, these two networks of providers rarely formally work together to systemically meet the needs of older homeless adults. Frequently, each network assumes that the other network is meeting these needs.

Third, social workers should recognize the potential for a youthful bias in homeless services. Demanding frontline positions frequently turn over and often attract younger social workers, counselors, and other allied professions. Jobs interacting with the homeless are often entry-level positions for new graduates in social work and other helping professions. Effective supervision of direct service providers and education regarding the nuances of older adult homelessness and ageism can extend the capacity of workers to interact and intervene effectively. Incorporating older peer support specialists may help older individuals feel more at ease and connect more readily with programs staffed primarily by younger individuals with limited life experience.

Related, all interventions should be assessed to identify areas where they could more effectively address the needs of older adults. For example, Levin and Miya (2008) noted three adaptations made to the Assertive Community Treatment (ACT) model to better respond to an older adult population, specifically increasing knowledge about the interaction between physical and mental health, increasing knowledge about community resources available for older adults, and increasing knowledge about ageism.

Finally, paternalism and coercion have historically been common in the practices and assumptions of homeless services (Christensen et al., 2005). Homeless individuals are often caught between unrealistic expectations of self-sufficiency in an environment with few available resources and rigid expectations that they adhere to a service provider's particular path of achieving self-sufficiency. Between bootstraps and paternalism, service recipients perceive high levels of stigma and little control as they navigate—among many others—medication compliance, financial "payee" requirements, and success in mandated services in order to secure and maintain housing (Padgett et al., 2006). Both the recovery and successful aging literatures point to the importance of perceived control for a variety of health and well-being outcomes, including recovering from (Christensen et al., 2005). This evidence underscores the importance of examining program and practice elements and determining if they support perceived personal control.

#### Conclusion

Older adults or elders who are homeless comprise an increasing sector of the marginally or unhoused population. Several factors are driving this increase including insufficient affordable and aging-friendly housing, economic insecurity, accelerated aging over the lifespan, and inadequate and inaccessible health and mental health care. No matter what their pathway to homelessness is, older adults require different consideration regarding assessment and interventions than their younger counterparts. Policy and programs that address the needs of older adults, provide housing-based interventions, and secure adequate health care in aging-friendly environments are important factors to promote housing stability.

#### **Discussion Questions**

- 1. Compare and contrast homelessness for an older adult age 55 plus and an adult age 30.
- Explain the issue of accelerated aging as it relates to older adults homelessness and service provision.
- 3. What were the significant causes or life events that may have contributed Jackson's homeless? What are key elements of a good assessment?
- 4. How would you explain the pathways to older adults homeless discussed in this chapter?
- 5. Compare and contrast the Housing First philosophy to the treatment first philosophy.
- 6. What changes in policy, interventions, coordination, and training might enhance services for older adult homelessness?

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# Chapter 7 Create Social Responses to a Changing Environment



Allison Gibson, Nancy Kusmaul, Skye N. Leedahl, and Victoria M. Rizzo

### **Grand Challenge: Create Social Responses to a Changing Environment**

The Grand Challenge: Create Social Responses to a Changing Environment aims to strengthen individual and community capacities to anticipate, respond, and adapt to environmental changes (i.e., natural disasters, pollution, climate change, and an increasing global population). Challenges caused by our changing environment negatively affect individuals and communities, forcing them to breathe unhealthy air, drink tainted water, or ingest toxic chemicals. These harmful impacts are environmental and social justice issues, particularly for vulnerable populations, including older adults, the poor, children, and racial and ethnic minorities. This Grand Challenge calls on social workers to collaborate with multiple disciplines and societal sectors (i.e., business, government, policy, health care, and not-for-profit) to engage in activities focused on environmentally displaced populations, disaster risk reduction, and environmental justice.

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#### Overview

The occurrence of natural disasters, large events that threaten lives and/or possessions of those in affected areas, is on the rise (Mooney & Dennis, 2018). Each year, people all over the world experience various natural disasters, such as hurricanes, floods, earthquakes, and fires, which affect their ability to function with day-to-day activities. With climate change, the number of natural disasters is on the rise with record incidences recorded over the past few years (National Oceanic and Atmospheric Administration, 2018). In 2016, the United States broke previous records with 15 major weather and climate disaster events, followed by 16 major weather and climate disaster events in 2017 (National Oceanic and Atmospheric Administration, 2018). Internationally, natural and human-caused environmental disasters affected 1.7 billion individuals between 2005 and 2014. The estimated cost of these disasters was \$1.4 trillion (United Nations Office for Disaster Risk Reduction, 2015). In 2017, 962 million people aged 60+ comprised 13% of the global population (United Nations, 2018). This demographic shift toward an aging population necessitates profound economic and social changes, including disaster preparedness and response (Murdock, Cline, Zey, Perez, & Jeanty, 2015).

In disaster preparedness and disaster response, communities and caregivers, should address the distinct needs of older adults. For example, many older persons are diagnosed with chronic health conditions that are compounded by sensory deficits, (e.g., limited vision or hearing), reduced mobility, cognitive decline, or mental health conditions, such as depression or anxiety. Additionally, older adults who live in rural areas may be isolated, have limited social networks or family supports, and/ or fewer economic resources than those in more urban areas.

Because of these age-related risks, older persons are often exposed to more danger, encounter more life-threatening challenges when trying to evacuate or relocate, are less likely to receive disaster warnings, and often experience greater financial losses in natural disasters (Acierno, Ruggiero, Kilpatrick, Resnick, & Galea, 2006; Aldrich & Benson, 2008; Sakauye et al., 2009). Further, older adults experience significant anxiety about their ability to evacuate during a future disaster or terrorist attack, due to immobility or infirmity (Monahan & Lurie, 2007). Older adults also experience more difficulty recovering from disasters than younger persons, particularly if they have limited individual, social, and financial resources. Additionally, they are more likely to suffer significant financial losses after disasters than younger groups (Al-Rousan, Rubenstein, & Wallace, 2014) and frequently cannot absorb disaster-related expenses due to preexisting financial constraints and inability to recoup losses (Powell, Plouffe, & Gorr, 2009; Walsh, Gibson, & Brown, 2016).

Older adults, specifically the frail and/or homebound, are particularly vulnerable as a result of needs, including the accessibility of their homes versus that of a shelter, safe means to store vital medications, the availability of family members and/or paid caregivers, and transportation. In all types of natural disasters, including recent hurricanes and fires (Nedelman, 2017), older adults still disproportionality experience ill effects and mortality, making it evident that the needs of this population

have not been fully addressed. For example, in 2005, when Hurricane Katrina struck southeastern Louisiana and coastal Mississippi, "of the 1,836 residents who lost their lives, 71% were over 60-years-old and 47% were over 75-years-old" (Centers for Disease Control, 2006, p. 1). These statistics ignited conversations across the fields of public health, medicine, and mental health regarding the unique needs of older persons in preparing for, and recovering from, disaster events.

Since social workers work with vulnerable populations on a daily basis, they serve an important role in disaster preparedness, response, and recovery. While social workers in the United States often are not specifically trained in disaster preparedness and response, their experiences in assessing community strengths and needs and crisis intervention and their ability to organize disparate groups have prepared them to contribute to municipal disaster planning. Further, social workers account for 50% of responders post-disaster (Naturale, 2018) through both their existing roles and specific designation as disaster responders. As Torgusen and Kosberg (2008) said, "Social workers have always been seen as specially prepared for working with the victims of loss and trauma, including those resulting from disasters" (p. 31). Social workers interpret disaster context, advocate for effective services, and provide leadership in collaborations among organizations and larger institutions (National Association of Social Workers, 2015) using the disaster preparedness and response model described below in the assessment and intervention section.

#### **Case Presentation**

Diana Munoz was responsible for her 83-year-old father, Jose Munoz, who was diagnosed with Alzheimer's disease 3 years ago. Currently, Jose is exhibiting symptoms of the moderate stage of Alzheimer's disease. He is often withdrawn and moody and is confused about what day it is. He also wanders and gets lost. Two weeks ago, he wandered away from Diana while they were shopping at Walmart and could not be found for 2 hours. Hurricane Charley was expected to strike Florida in approximately 24 hours. The television was on and the weather broadcaster was urging people to evacuate the area. Mr. Munoz was agitated, disoriented, and continued repeating, "Where are you taking me? I don't want to leave home. I want to stay."

Ms. Munoz was unsure where the emergency shelter was located. She anticipated that the shelter would be loud, chaotic, and teeming with people who were in just as big of a crisis as she and her dad were facing. She was also concerned about access to medical care for her father and professionals available who understand dementia-related behaviors that often exacerbated during stress. Her mother, who passed away 2 months ago, had been her father's primary caregiver. As a new caregiver, Ms. Munoz realized when packing that she only had 3 days' worth of her father's incontinence products and a limited supply of his numerous medications. The main thought playing in her head was, "No one prepared me for this."

#### **Assessment and Intervention**

Disaster response, consistent with social work practice, is a holistic process that considers the biopsychosocial needs of individuals and their ecological systems, in preparing for, responding to, and recovering from disaster events (National Association of Social Workers, 2015). Disaster preparedness and response has three phases, all of which include assessment and intervention: (1) planning for the disaster (pre-disaster), (2) disaster occurrence and immediate response/recovery (during and post-disaster), and (3) disaster recovery (long-term disaster recovery). This section will highlight social workers' roles in these three phases using the case study to highlight each assessment and intervention phase.

## Stage 1: Pre-disaster

**Pre-disaster assessment** Social workers must consider the possibility that individuals are experiencing chronic conditions, limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), physical and cognitive disabilities, and/or sensory impairments (Aldrich & Benson, 2008; Dyer, Regev, Burnett, Festa, & Cloyd, 2008; Weisler, Barbee, & Townsend, 2006). Risk factors include, but are not limited to, frailty, medical conditions (i.e., cognitive impairment, hearing or visual impairments, and chronic illnesses), poverty, and the physical/built environment. Medication needs, special dietary needs, and medical supplies/equipment to manage health problems should also be identified because they lead to increased risk of illness, injury, or death during disasters for older adults (2013; Acierno et al., 2006; Centers for Disease Control and Prevention, 2012; The Hartford Geriatric Education Center, 2011a; The Hartford Geriatric Education Center, 2011b; World Health Organization [WHO], 2008). In the case of Jose Munoz, his cognitive status, incontinence, and recent death of his wife are all risk factors in the natural disaster. His medication and incontinence supply needs are also important.

Socially isolated older adults, even in large communities, are less apt to receive important warnings, ask for help, or evacuate, which can leave them "virtually invisible" to rescue and recovery efforts (Banks, 2013, p. 95). At the community level, social workers can help identify these vulnerable adults and develop and continually update a list of their names that first responders can use in the event of a natural disaster. Failure to assess these factors results in older adults experiencing greater mortality, morbidity, and functional decline than other populations in natural disasters (Banks, 2013). Given Diana's new role as a caregiver, and her father's agitation and disorientation due to Alzheimer's disease, including Mr. Munoz on a list of vulnerable adults would be advisable.

In addition to assessing for risk factors and needs in planning for disasters, social workers should also assess the strengths of older adults. Consistently, research

about older adults shows that social relationships and support are strengths at both motivating older adults to plan for disasters and enhancing their safety and well-being post-disaster (Ashida, Robinson, Gay, & Ramirez, 2016; Ashida, Zhu, Robinson, & Schroer, 2018; Eisenman et al., 2009; Eisenman, Cordasco, Asch, Golden, & Glik, 2007). Diana Munoz is a strong social support for her father despite the fact that she is new to her caregiving role following the death of her mother. As part of assessment, the social worker should identify ways to further educate and support Diana in her new role. Resiliency is also a protective factor for older adults post-disaster (Tuohy & Stephens, 2012). In assessing Jose Munoz, the social worker would want to ask how he has managed other crises in his life in order to determine his level of resiliency. For example, how has he coped with the death of his wife during the last 2 months? How has his cognitive status affected his ability to cope with the loss of his wife? How does this compare with the way he has dealt with crises prior to his diagnosis of Alzheimer's disease?

**Pre-disaster intervention** Social workers have roles in education about preparedness, establishment of support for disaster plans, organizational preparedness, and community planning. In a national sample of older adults focused on education about disaster preparedness, Al-Rousan and colleagues (2014) report that many older adults have not participated in any kind of educational program about disasters, most do not know where to find resources, and two-thirds of older adults do not have an emergency plan. Over one-third do not have basic supplies (e.g., food, water, medical supplies) available for emergencies, and about 14% would need electricity to keep medical devices working. Diana Munoz and her father do not have an emergency plan in place. In fact, Diana lacks knowledge of available resources, including emergency shelters, does not have adequate supplies to meet her father's medical needs, and does not feel prepared to respond adequately to natural disasters. Social workers can help caregivers like Diana Munoz to develop emergency plans for natural disasters using disaster preparedness materials provided by the American Red Cross (2009), the US Department of Homeland Security (n.d.), and the Administration for Community Living (Fordyce, Kenny, & Oettinger, 2006).

Families and other informal supports play an important role in establishing support for disaster plans. Older adults living with family members, or who have supportive neighbors, are more likely prepared for disasters (Loke, Lai, & Wai Man Fung, 2012). Kang (2014) found that older adults living with family members are better prepared with medications than those who live alone (e.g., Kang, 2014). With the assistance of family and friends, older adults can be empowered to take responsibility for disaster planning (Fernandez, Byard, Lin, Benson, & Barbera, 2002). However, Tuohy and colleagues (2014) found that older adults living in the community sometimes assume family members will be willing and able to provide physical or financial care when this actually is not the case. Given this, a social worker involved with the Munoz family would establish that Diana is agreeable to an emergency plan and include both her and her father in developing the plan. The social worker should also identify other family members or neighbors who

should be included in establishing support for the plan. Mobilizing neighbors is an area of untapped potential when planning for disasters because neighbors, in situations, such as floods or fires, may be the people to help since families may not be able to access affected areas. Older adults can be empowered to engage with community associations and regional groups about disaster planning and evacuation needs (Banks, 2013).

Involvement in *organizational preparedness* for natural disasters is another role for social workers. Community plans for disaster preparedness should include health and aging services organizations, such as hospitals, home health care, assisted living facilities, and nursing homes. In home health care, plans for staff identification and access to disaster zones can be critical for providing in-home services during a disaster. Furthermore, backup plans for staffing and locating clients and remote records should be clearly articulated ahead of time (Christopher & Goldstein, 2014). The National Association for Home Care and Hospice (2008) has a toolkit to help home health agencies prepare.

Situations, including when 35 residents drowned at St. Rita's Nursing Home in Hurricane Katrina and the photo of assisted living residents up to their waists in water during Hurricane Harvey, illustrate the importance of proactive planning in these settings. In nursing homes, a "one-size-fits all" approach is not likely to work due to the varied biopsychosocial needs of residents. Claver and colleagues (2013) suggest that disaster plans should be designed to meet the specific needs of residents whether evacuating or sheltering in place. The use of a biopsychosocial framework as a foundation for evacuation planning may allow communities to adapt or tailor plans to population-specific combinations of needs and risks. Nursing homes can harness the expertise of their social work staff in biopsychosocial assessment.

Successful organizational preparedness involves collaboration between long-term services and supports and community leaders to develop comprehensive plans. Health-care providers, including social workers, should advocate for elder preparedness in their communities, share their knowledge to guide community leaders, and register with their state's professional response registry [e.g., Emergency System for Advance Registration of Volunteer Health Professionals (US Department of Health & Human Services, n.d.)], so they can be available during an emergency (Banks, 2013). In addition, community-level disaster plans should take into account the impact of evacuation and relocation on the health and well-being of older adults (Elmore & Brown, 2007).

Community planning for most disaster preparedness occurs locally because in disasters the local community responds until outside help arrives. According to Elmore and Brown (2007), the planning process itself is important for fostering relationships across diverse stakeholder groups because these relationships can be helpful if disaster strikes. Planning should include experts from aging services, such as the US Administration on Aging, state aging units, area agencies on aging, Native American tribal organizations, and local providers, consumers, and caregivers (Administration for Community Living, 2018; Elmore & Brown, 2007). Planning should also include coordination among aging services; clarification about roles at the local, state, and federal levels; and drills to ensure responders can quickly meet

the needs of vulnerable groups (Pekovic, Seff, & Rothman, 2007–2008). Social workers should help develop realistic disaster plans and drills to ensure settings are as prepared as can be and to avoid the bureaucratic shuffle of disaster planning (Disaster Preparedness and Response, 2017), where plans are filed without reevaluating changing individual and family needs, staff availability, and resources. Just as older adults' emergency plans need to be individualized, organizations and communities should have customized plans tailored to their needs, risks, and existing resources

## Stage 2: During and Post-disasters

Post-disaster assessment includes (1) addressing immediate needs post-disaster and (2) assessing the impact of displacement and relocation. In addressing immediate needs and responding, social workers have unique responsibilities when caring for older adults and their families. Similar to planning for a disaster, what occurs during any disaster at the individual and family level looks different for older adults depending on family circumstances. Simultaneously, it is important for emotional well-being and recovery that social workers remind individuals and families that they need to maintain as much normalcy and routine as possible (Naturale, 2018). In an active rescue situation, the resources needed to rescue a family with an older adult may be different from those needed for an older person who is isolated or coping alone.

Social isolation is a significant problem for older adults, particularly during disasters, when the services and supports on which they rely are likely to be disrupted (Chandra et al., 2018). As previously discussed, older adults who are alone and isolated may have less ability to address their own needs. Seniors are more likely to respond to mandatory evacuation orders than voluntary evacuation requests (Gray-Graves, Turner, & Swan, 2011). Many reasons exist as to why an older person might choose not to evacuate. One reason is the desire to stay with one's pets. Many individuals will elect to stay at home with pets if they do not have the means to transport or shelter with their animals (Torgusen & Kosberg, 2008). Other reasons include health conditions, lack of accessible transportation, lack of finances, mobility issues due to chronic issues and/or disability, social supports, history of not evacuating in the past, or desire to avoid staying in shelters or other places where needs may not be met (e.g., Rosenkoetter, Covan, Bunting, Cobb, & Fugate-Whitlock, 2007; Taylor, Priest, Sisco, Banning, & Campbell, 2009).

Displacement and relocation are common outcomes of disasters. Age-related changes make older persons particularly vulnerable to the adverse effects of relocation (Pekovic et al., 2007–2008; Sanders, Bowie, & Bowie, 2003). Relocation can trigger long-term stressors, such as interruption of the older person's lifestyle, relationships, community connections, and sense of safety (Chao, 2017). In fact, relocation may be more dangerous to the older person's well-being than the disaster itself (Chao, 2017; Norris, Friedman, & Watson, 2002). While some older adults can go

home after post-disaster rebuilding, they often permanently relocate (Binder, Baker, & Barile, 2015). Social workers need to be aware of these effects when a senior arrives in their community due to a disaster event.

Post-disaster interventions include establishing shelters, acting as responders, and residential decision-making. When deciding to evacuate or shelter in place, older adults need to consider the perceived threat to their location, where they would go as an alternative (i.e., an established shelter) and how to get there. This information should be readily available by the community to help inform older adults who may be reliant on social supports or external resources. Social workers should advocate for community education regarding resources available in shelter and disaster recovery settings that accommodate older persons and should educate entities about the needs of older persons in such settings (e.g., chronic conditions, need for emergency access to medication, life-sustaining medical equipment that runs on power) (Gibson, 2016). Further, when a family's residence is interrupted, it is important for emotional well-being and recovery that social workers remind individuals and families that they need to maintain as much normalcy and routine as possible (Naturale, 2018).

Often social workers are disaster responders by default because they work in an affected area. After Hurricane Katrina, New Orleans senior center staff discussed their responses. They told a story about how, upon reopening the center, they had to drive around town trying to find their seniors to determine if the clients were safe, had left town, or had perished in the storm (Croom & Jenkins, 2007). During heat waves, case managers often contact their clients, even on weekends, to determine if they are able to access safe spaces and/or cooling equipment to prevent heat stroke.

Home health care is essential during a disaster: "During and immediately following natural disasters ... caregivers are the unsung heroes; usually responding before the first responders by choosing to stay with their clients to see them through to safety-even when it means not going home" (Poo, 2015, p. 83). Home health agencies also provide vital information about older adults in the community. Visiting Nurse Service of New York was prepared for Superstorm Sandy, a major hurricane, because of robust disaster planning and a designated incident response system. One of their essential pieces was a system in which each patient received a priority designation that considered a patient's medical conditions, whether they lived alone, and the level of risk without aide service. This allowed them to support patients during the storm and anticipate transit disruptions that limited staff abilities to reach patients (Christopher & Goldstein, 2014).

Residential decision-making by social workers is critically necessary during disasters. Older adults in nursing homes may be the most vulnerable during disasters since they are often the frailest. Nursing homes face the same critical decision as other systems, which is to evacuate or shelter in place (Dosa et al., 2008). They also have to assess the same conditions, such as safety, power, food, medicine, and transportation, made more difficult by complex resident needs, including end-of-life care needs (Frahm & Brown, 2011). Residents rely on staff to make decisions

for them in crises, yet staff often are not trained in disaster decision-making. Claver and colleagues (2013) examined lessons learned by Veterans Affairs' nursing homes during disaster evacuations and found staff were not told which patients to evacuate first. Each home made their own decision, with one evacuating the sickest first and another evacuating the healthiest, which made it harder to secure transportation for sicker patients later in the evacuation. Another found evacuation equipment they had been issued was useless when they needed it because no one had tried it out beforehand and discovered too late that it was not appropriate for the circumstances (Claver et al., 2013). Social work involvement in conducting well-crafted disaster drills could have helped anticipate this problem and resolve it in advance of the disaster.

## Step 3: Long-Term Disaster Recovery

Long-term disaster recovery assessment includes assessing and treating traumatic stress, assessing financial stress, and community assessment. In assessing and treating traumatic stress immediately post-disaster, social workers should offer a "compassionate presence" to older persons recovering from the grief and trauma of the disaster (Naturale, 2018). Social workers must be familiar with disaster mental health trends and cultural considerations that may accompany traumatic response in older adults, such as how exposure to a disaster increases risk for post-traumatic stress disorder (PTSD) (e.g., Galea, Tracy, Norris, & Coffey, 2008; Pietrzak, Goldstein, Southwick, & Grant, 2012). While many disaster survivors experience temporary distress, a small percentage (6–20%), without appropriate intervention, continue to experience debilitating trauma symptoms associated with PTSD (Breslau et al., 1998; Brewin, Rose, & Andrews, 2002; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Social workers need to be prepared to refer or provide older populations with evidence-based PTSD treatment, such as Cognitive Processing Therapy and Prolonged Exposure Therapy (Cox & D'Oyley, 2011; Jeffreys et al., 2014; Lopes, Macedo, Coutinho, Figueira, & Ventura, 2014) and Acceptance and Commitment Therapy (ACT) (Petkus & Wetherell, 2013). However, while there are numerous evidence-informed treatments available for conditions that can result from mass trauma, few studies have tested these interventions on older adults (Gibson, Walsh, & Brown, 2017).

Assessing financial stress is important because it can affect the emotional well-being of older adults and their families during long-term disaster recovery. Older adults are more likely to suffer significant financial losses after disaster than younger groups (Al-Rousan et al., 2014). They are less able to absorb disaster-related expenses and more likely than younger adults to incur such costs. Due to preexisting financial constraints, older adults are more likely to live in dilapidated older homes that are more vulnerable to the effects of natural disasters and less likely to be able to afford needed repairs (Powell et al., 2009). Unlike younger adults who have time

to rebuild, older adults have shorter time horizons and ability to recoup losses (Walsh et al., 2016). Social workers are well-suited to assist older adults in identifying resources to address financial need and to advocate for federal and state programs that can assist this unique need among the aging population.

Just as community assessments are conducted at the pre- and immediate-recovery stages of disaster, community assessments should be conducted post-disaster to analyze the needs of individuals and the larger community. With particular consideration to community assessment, social workers should work on interprofessional teams to evaluate the needs of older persons in their community and determine if the disaster has resulted in service limitations or other restrictions negatively impacting community residents (e.g., Gibson & Hayunga, 2006).

Long-term disaster recovery interventions include coping with community loss, physical rebuilding of the community, and building community resilience. Community loss is measured in physical damage and financial loss. However, a community often experiences shared grief. Immediately post-disaster, communities tend to unite. After the September 11, 2001, terrorist attacks, the United States rallied around the phrase, "United We Stand." But even with the outpouring of unity, when communities begin having conversations about using funds for recovery, building, and planning memorials, these political, bureaucratic discussions can become conflictual (Shughart, 2006) and communities that were once bonded through the disaster can splinter into factions each considering their own best interest. Social workers may need to provide conflict resolution for these community conversations.

In severe damage, the physical rebuilding of communities is necessary. Structures that house or support older adults need to be renovated or rebuilt. In October 2015, South Carolina had a historic 1000-year flood. Much of the southeastern part of the state experienced 20–24 inches of rain in 120 hours. In February 2016, a regional, rural hospital in Kingstree, South Carolina closed due to mold that developed from extensive water damage. Until replacement services were established, many residents had to travel 25–30 or more miles for emergency services (Brown, 2016; Carr et al., 2017). This distance could be life or death for an older person with a chronic illness or experiencing an acute medical emergency. Further, older adults with limited transportation and financial burdens experience additional barriers to access these services. Social workers should consider these issues and help identify solutions when working with older adults post-disaster.

Building community resilience and enhancing communities to reduce the negative impacts of disasters supports the well-being of older adults. Community resilience expands the traditional preparedness approach by encouraging actions that build preparedness while promoting strong community systems and addressing the many factors that contribute to health. While communities tend to consider community resilience following a disaster, social workers should facilitate conversations about community resilience in the disaster planning stages and during long-term post-disaster recovery (Chandra et al., 2018).

## **Future Steps for Research, Policy, and Practice**

**Research** Social work researchers conducting studies about disaster response and recovery can have challenges to ensuring rigorous approaches are used, but there are preemptive strategies that can be taken to ensure quality research (e.g., having an Institutional Review Protocol approved prior to a disaster event when possible, deploying multiple researchers to ensure ample information is gathered post-disaster). There is an urgent need for this research to enhance services and supports for older adults affected by disasters (e.g., Gibson & Hayunga, 2006). First, there is a need for more inclusion of practices that are rooted in evidence. Many of the approaches utilized in disaster response have limited evidence to support them as best practice. This is especially true for older adults because what limited evidence there is does not include research done with older populations (Gerdin et al., 2014; Gibson et al., 2017; Mahapatra, 2014).

Second, research should look to better understand older adults' motivations, behaviors, and experiences of disaster planning and response. Many disaster response and recovery organizations (e.g., the American Red Cross) have implemented scientific advisory councils to assist in ensuring planning and response efforts include evidence-based and best practice approaches (American Red Cross, n.d.). Third, there is a need to build on existing interventions to best determine how they could be adapted to be more efficient, to serve other diverse older adult groups, or be implemented utilizing varying approaches (e.g., an online tool or as a group intervention). As research continues to suggest that older adults have diverse needs in disaster events, social workers need to advocate for the inclusion of diverse perspectives in disaster planning and response so that disaster responders and mental health professionals consider cultural differences and individualized needs for disaster support and services among the aging population.

Finally, it is important that social work researchers take part in interdisciplinary teams conducting disaster-related research across the country. Agencies, such as the National Science Foundation, the National Institutes of Health, and the National Oceanic and Atmospheric Administration, have calls for proposals to address disaster risks and impacts, and these teams include engineers, emergency managers, community planners, and policy makers. As key members of these teams, social workers can ensure that the needs of older adults and individuals with disabilities are considered and that best practices are identified and utilized when designing disaster response and recovery plans.

**Policy** With each new natural disaster, policies are introduced to better prepare for, and mitigate the effects of, disasters. In some communities, older adults and those with disabilities can sign up for a registry so that emergency operations managers know where they are and what they may need in an emergency. For example, in Rhode Island, enrolling in the registry ensures that first responders and emergency management officials can identify those who may need assistance during a disaster (Rhode Island Department of Health, 2018). Social workers interacting with

community-dwelling older adults can help to ensure socially isolated individuals, particularly those who have any of the identified risk factors for serious threats to health and safety during a disaster, sign up for these types of registries (Elmore & Brown, 2007). While government entities are strongly encouraged to implement these registries, individuals in areas highly prone to disasters are reluctant to sign up because they do not self-identify as having "special needs" or "assistance needs" (Gibson & Hayunga, 2006; Renne, Sanchez, & Litman, 2008). While assistance registries are excellent for identifying individuals in the case of emergency, they do not guarantee priority access in response and recovery (i.e., priority power restoration). Thus, it is even more essential for social workers to assist in identifying highrisk individuals in the community to ensure they have an individualized plan for disaster preparedness and recovery.

On the federal level, the US Congress introduced a bill to help encourage those in affected disaster areas, including older adults, to evacuate with the passage of the Pet Evacuation Transportation Standards (PETS) Act of 2006. Following Hurricane Katrina, the PETS Act authorized the Federal Emergency Management Agency (FEMA) to provide rescue, care, shelter, and essential needs for individuals with household pets and service animals as well as household pets (The White House, 2005). While this supports the facilitation of pets in the evacuation process, social workers must continue to advocate for the inclusion of pets in evacuation and shelter planning (Banks, 2013).

Social workers should help to develop additional policies to support older adults affected by disasters, such as requiring disaster planning and response efforts to adopt and implement evidence-based approaches to disaster risk reduction; to develop policies targeting environmentally induced migration and population displacement; and to strengthen equity-oriented resilience policies and proactively engage marginalized communities in adaptation planning within both urban and rural areas (Sears, Kemp, & Palinkas, 2017).

**Practice** Many social workers feel unprepared to respond in the immediate aftermath of disasters. Some social workers have only learned about the role of social work in disasters first hand when their communities are affected by disaster events. Continuing education trainings that review disaster planning and response will enhance the social work profession's capacity to assist in preparing and responding disasters. Social workers should share stories about their experiences in disaster planning, response, and recovery. The social work profession needs first-hand accounts about what happened, what went well in a disaster, and what did not go well. Learning from mistakes will provide guidance about best practices for assisting older adults in disasters. The importance of having well-trained and aging-competent professionals to support older adults affected by disasters cannot be overstated.

Further, social workers should educate and support older adults in disaster preparedness. Social workers often help older adults and their families plan and prepare for disasters through psychoeducation. One such approach, PrepWise, is a

disaster preparedness training program specifically for older adults (see Ashida, Robinson, Gay, Slagel, & Ramirez, 2017). The program instructs older adults to complete a personal and household assessment, develop a personal emergency network, compile emergency information and important documents, keep an emergency supply of medications and medical supplies, and build an emergency kit. In a study by Ashida and colleagues (2017), following participation in the PrepWise program, rural older adult participants on average identified three new sources of emergency support.

#### Conclusion

Social workers can learn from the experiences of those affected by past disasters as well as other social workers that have worked with clients affected by disasters. Social workers have the training, knowledge, and experience to advocate for the unique needs of older adults disproportionately affected by the environment and need to take on this important challenge.

#### **Discussion Questions**

- 1. What are the risk factors, needs, and strengths of older adults in disasters? Do social workers have the skills to assess and address them?
- 2. Explain diversity factors of older adults that might affect their needs during a disaster.
- 3. Compare and contrast the needs of older adults in disaster events with those of the general population (i.e., adults and children)
- 4. A family caregiver of an older adult comes to you to ask for help in preparing for a disaster. What tips and resources would you provide to help them prepare for disasters with their loved one?
- 5. What is important for nursing homes to consider in preparing for, and responding to, disasters?
- 6. How would you suggest that social workers get involved in disaster preparation and response in their communities?
- 7. Find a recent news story that addresses issues of older adults during disasters. Based on the information in this chapter, identify two to three ideas that could have helped prevent the issues faced during the event.

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# **Chapter 8 Harness Technology for Social Good**



Paul P. Freddolino and Fay Keys

#### Overview

Social media and other information and communication technologies (ICTs) have the potential to change the lives of older adults and how we provide social work services to them. The Grand Challenge to harness technology for social good incorporates two different yet interconnected ideas, one focused on "practice innovation" and the other on "big data." These are introduced at a time when social work itself has finally begun to acknowledge technology's impact on client services and the need to address ethical concerns and to develop practice standards (National Association of Social Workers (NASW), Association of Social Work Boards (ASWB), Council on Social Work Education (CSWE), & Clinical Social Work Association (CSWA), 2017). The "practice innovation" document (Berzin, Singer, & Chan, 2015) addresses current and future possibilities for the application of ICTs to social work practice. Although there is also a second document on "big data" (Coulton, Goerge, Putnam-Hornstein, & de Haan, 2015), these authors' own estimate that "meaningful and measurable progress can be made in a decade" (p. 10 emphasis added) diminishes its value for the discussion of technology and the contemporary aging context. Thus, it is not included here.

In the "practice innovation" document, Berzin and colleagues (2015) argue that ICT "is transformational in its power to connect, create access to, and embolden new opportunities to rethink social work practice" (p. 3). The authors note that while social work lags behind other sectors like business, it has more recently taken up the challenge, responding to the need to support social good and yet not

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"replicate or amplify existing inequalities" (Goldkind & Wolf, 2015, p. 85). This is where ICT's power to improve access to social work services can become a major driver of change. Berzin and colleagues (2015) provide numerous examples of "flexible and on-demand services" and "personalized and individually paced services" as potential benefits to society. In the context of older adults, examples include providing services by cell phone, the Internet, or other technologies instead of requiring travel to specific clinics and using interactive computer-based programs to help older adults identify the services they need and then provide a technology tool to receive the services when they want them. All of this requires hardware, software, and skills to use the technology.

Social workers who serve older adults and their family systems will be faced with the challenge of technology, which is increasingly important in providing services. As Berzin and colleagues (2015) suggest, technology can be harnessed to support and engage older adults aging in place as well as assist families and service providers who constitute their care network. Furthermore, a recent study concluded that older adults' quality of life is improved when they have access to ICTs (Damant et al., 2013).

In some ways, older adults have never been better positioned to take advantage of technology-mediated approaches. According to Anderson and Perrin (2017) based on data from several nationally representative surveys conducted by the Pew Research Center:

Around four-in-ten (42%) adults ages 65 and older now report owning smartphones, up from just 18% in 2013. Internet use and home broadband adoption among this group have also risen substantially. Today, 67% of older adults use the internet – a 55-percentage-point increase in just under two decades. And for the first time, half of older Americans now have broadband at home. (p. 2)

This unprecedented digital engagement, which gives every indication of growing, suggests that gerontological social work services building on the emerging ICT resources described in the Grand Challenge to harness technology for social good will increasingly fit the capacity and interest of the older adult population, creating the opportunity to "rethink social work practice" (Berzin et al., 2015, p. 3). At the same time, however, Anderson and Perrin (2017) note that despite the positive findings from these nationally representative surveys, "many older adults remain largely disconnected from the digital revolution" (p. 3), with considerable variation in embracing technology among older adults based on age, income, and education. Considering race, the pattern is somewhat more complex. According to Smith (2014a, p. 1), who reports results from a 2013 survey of 6010 adults 18 and older, older African Americans have much lower Internet adoption rates than whites (45% compared to 63%). This is not true among younger generations. Young African Americans are as likely as their white counterparts to use the Internet and have broadband service in their homes. One of the important social justice issues to consider is the possibility that in harnessing new ICT tools and ICT-based services, the existing "digital divide" may be sustained or even worsened, at least among some demographic groups (Rainie, 2017).

The literature suggests older adults face several unique barriers and challenges when it comes to using new technologies, and yet these conditions also frame opportunities for the application of digital interventions. The challenges include but are not limited to the new digital divide, social isolation, and physical and mental health issues.

The New Digital Divide In the past, the digital divide was generally viewed as the technology gap between rich and poor based on their ability to access or purchase the physical tools of technology – computers, smartphones, and Internet access. What appears to be emerging today is a new digital divide, defined by three dimensions of access to ICTs. Physical access to ICT tools can be tied to income (Smith, 2014b) and thus similar to the old notion of the digital divide, and it can also relate to where one lives. Older adults represent a larger percentage of the population in rural areas, a pattern expected to increase (Baernholdt, Yan, Hinton, Rose, & Mattos, 2012), and there are many rural areas that still have no broadband Internet access or in some cases no cellular service. Many older adults do not have the skills and knowledge base to be able to use ICT tools. This is not due to ability or eagerness to learn, but may be related to access to the people and services to help them conquer the technology divide that exists. Some older adults may have retired from jobs where computers were not needed, while others may have an inherent fear of technology due to lack of exposure. The speed with which technology evolves exacerbates the problem, leaving many older adults to feel they can never catch up or feel comfortable. Finally, the absence of relevant content is one of the primary reasons given by the 34% of older adults who did not go online in 2017 (Anderson, Perrin, & Jiang, 2018).

Isolation As adults age, social isolation becomes more common, resulting in psychological difficulties, such as feelings of loneliness, depression, anxiety, and lowered self-esteem (Chaumon, Michel, Tarpin, & Croisile, 2013; Chopik, 2016; Cotterell, Buffel, & Phillipson, 2018; McMellon & Schiffman, 2002). These conditions may lead to reduced use of the Internet and other technologies that enable social contact (Papacharissi & Rubin, 2000). According to the Administration on Aging (AOA), Administration for Community Living, US Department of Health and Human Services, about 28% (13.8 million) of all noninstitutionalized older persons in 2017 lived alone (AOA, 2018). They represent 34% of older women and 20% of older men (AOA, 2018). To curb social isolation in older adults, researchers have studied ICTs as an intervention strategy (Khosravi, Rezvani, & Wiewiora, 2016; Woodward et al., 2012). For older adults who are isolated, the Internet, Skype, Facebook, and other similar services can help alleviate isolation and have an impact on the physical and mental health of older adults and their caregivers (Arumuganainar, 2017).

*Health and Mental Health Challenges* Health and mental health conditions may impact access and utilization of ICT resources (Delello, Rochell, & McWhorter, 2017). At a basic level, the extent to which older adults are facing deficits in activities

of daily living (ADLs), basic self-care tasks such as eating and bathing; and the more complex instrumental activities of daily living (IADLs) like managing finances and meal preparation (American Psychological Association, 2018) impacts technology access and utilization.

Physical and mental health conditions associated with aging (e.g., reduced hearing, mild cognitive impairment, and memory loss) may challenge the ability to utilize ICTs (Barley, Fritz, Van Son, & Schmitter-Edgecombe, 2019; Choi & DiNitto, 2013). In addition, sometimes there is less access to technology resources, such as access to the Internet, telehealth services, new innovative devices for older adults, and associated cost. However, assessing needs and uncovering ICT resources may prove to be important to quality service delivery. A recent study found that technologies for social connectivity and emotional health could promote health and mental well-being among older adults (Chopik, 2016). For example, sensory loss is a common problem, with higher rates of loss for the oldest old, males, and African Americans (Correia et al., 2016; University of Chicago Medical Center, 2016). So, addressing issues of sensory loss by enhancing adaptive computer access, ICT, and innovative yet cost-effective devices may assist with addressing and promoting overall health and well-being.

Assessing how ICTs can be integrated to address health and mental health needs is an important aspect of care and services for older adults. In addition, accident and fall prevention, overall safety issues, and social isolation can be addressed with technology. ICTs can, and will, play a significant role in addressing the health and mental health challenges faced by older adults today and in the future.

#### **Case Presentation**

Dominic Caputo is an 80-year-old white male veteran living alone in a rural area. He has no children and only one sibling, a sister who lives 500 miles away with whom he maintains contact. He is on Medicare and Medicaid. He currently lives independently, but has multiple chronic health conditions that are impacting his mobility and quality of life. He receives Meals on Wheels. In terms of technology, Mr. Caputo has a smartphone, but no computer or tablet even though high-speed Internet is available in his community.

Mr. Caputo's sister is his main source of social support, and she worries about his increasing health problems and the potential for falls. While he is a member of a local church, he is rarely able to attend services or participate in other church activities. His limited contact is with the caregiver the local Area Agency on Aging (AAA) provides 2 hours per week, the Meals on Wheels volunteer, and a driver he hires for medical appointments and other errands. Due to a new program at the AAA that is designed to increase independent living support through technology, two social work staff members trained in technology options have started coming

to Mr. Caputo's home to conduct a technology assessment and identify needs. The following options were determined:

- Options for a computer/tablet can be explored along with computer training.
- AAA staff can help with the Federal Communications Commission's (FCC) Lifeline program application.
- Mr. Caputo can be informed about a free pendant alarm to call for help in case of emergency and asked if he would be interested in one.
- Low-cost sensors that detect falls can be explored for home installation.
- With additional training, the Meals on Wheels driver could make sure that Mr. Caputo is linked with his sister for a video chat each day – or on scheduled days each week.
- With additional training and support, the AAA-provided caregivers can spend a
  few minutes during each of their visits providing a mini-lesson on one or more
  of the new technology tools Mr. Caputo could be encouraged to use. These minilessons would provide reinforcement and help improve sustained use of the
  technologies.

#### **Assessment and Intervention**

Social work assessment in the case of Mr. Caputo must consider both (1) a complete picture of the environment and daily living needs of older adult clients and (2) a current technology assessment that includes what older adults know, have, and use, as well as their openness to considering technology-supported tools and interventions. The assessment of the environment and daily living needs is part of basic good practice. This is likely standard procedure in most agencies that work with older adults, with frequently lengthy, detailed forms to document that all relevant areas have been covered (Chonody & Teater, 2017; Evans & Keamey, 2016; Parker, 2017). The results of the assessment form the basis of the intervention plan developed in cooperation with clients, where the proposed components of the plan are related to items identified in the assessment (Chonody & Teater, 2017; Evans & Keamey, 2016; Parker, 2017). In addition, for the worker schooled in technology-supported tools, these basic questions provide information that can help identify potential ICT-based solutions.

An essential area of assessment is the determination of clients' capacities and deficits in ADLs and IADLs. These assessments provide guidance for developing interventions that might be required to sustain clients' ability to live alone. While perhaps only robots can help directly with ADLs, other tools on phones, tablets, or even computers can assist with reminders, and a tech-savvy social worker can identify digital tools and services that can assist clients in dealing with the IADLs (National Center for Biotechnology Information, 2013; Rashidi, 2012).

Because of the serious negative consequences of falls (Centers for Disease Control and Prevention (CDC), 2016; National Institute on Aging, 2017), a thorough

assessment must include documenting potential fall hazards (CDC, 2005). For the tech-savvy social worker, fall hazards would suggest discussing ICT-based tools such as fall detection devices (Medical Alert Advice, n.d.) and alarm systems that can be activated in case of falls as noted in Mr. Caputo's case presentation.

As part of an in-home assessment undertaken to determine client capacity to continue independent living, two essential areas are mobility and cognitive capacity (Davis et al., 2015; Mlinac & Feng, 2016). If mobility challenges are identified, the proposed interventions are likely to be assistive devices like canes, walkers, or wheelchairs, rather than any ICT-based tools. However, there is a need to incorporate technologies. Assessing cognitive capacity, and identifying a range of digital options (i.e., brain games that are available on cell phones and tablets that may potentially improve cognitive functioning) (Weir, 2014), are examples.

A thorough assessment will generally include a full listing of family and friends, as well as trusted neighbors – all people who could become, or already are part of, clients' social support networks (Chonody & Teater, 2017; Kropf & Cummings, 2017; Royse & Badger, 2015) and who could assist with caregiving. To be complete, such a listing must include contacts engaged only online or by telephone, such as Facebook friends and similar virtual connections.

The final essential part of the overall assessment process is the status of technology in the lives of clients. In order to be able to determine what digital tools might meet clients' needs and/or enhance their quality of life, the assessment must cover three aspects of technology: what clients *have*, what they *know about*, and what they *actually use*. Clients' openness to using ICT-based tools must also be determined.

Determining what clients *have* will generate an inventory that will influence the types of digital resources they can potentially utilize. For example, whether or not the client has Internet access, or even decent cellular service, will have an impact on possible options. Determining *clients' knowledge and skills* to be able to use the technology they have is a second dimension. For example, if older adults have Internet access, do they know how to actually get online and interact online safely? Clients may own technology tools and even know how to use them – like a laptop connected to the Internet – but the final dimension is the *extent to which clients actually use* these devices. Use depends on a number of factors from perceived ease of use, perceived value (such as entertainment or information), and perceptions of online risks such as scams and identity theft. Many of these factors are incorporated in the Technology Acceptance Model and related perspectives (Lai, 2017). For all of these dimensions, the technology capacity of caregivers should also be included in the assessment.

As the extent of technology ownership by clients becomes clear, agencies will need to identify resources for some basic technology for clients or potentially develop connections with other agencies that can provide devices and Internet access. Agencies must also determine their roles in providing, or at least developing partnerships that can provide, instruction in technology use. This may involve intergenerational programs where tech-smart teens can assist older adults or engaging peer support teams in which older adults are trained to provide technology instruction

and support to other older adults (Freddolino, Lee, Law, & Ho, 2010; Woodward et al., 2012). Finally, data on actual utilization of the technology clients already possess can assist agencies in defining action plans for client instruction and support, particularly where these tech tools can be useful in accessing ICT-based tools and services that address client needs.

Not all clients will be open to exploring ICT-based tools and services. Thus, a complete technology assessment will determine clients' willingness to use the options that might address clients' needs. Lack of willingness is not limited to older adults by any means (Statista, 2017), but the literature suggests there will be less openness among older adults (Mitzner et al., 2010). Rather than indicating that no tech-supported interventions should be reconsidered, clients' responses should point to areas where the agency has to undertake technology education, support, and training activities, either alone or with partners. Such efforts would be consistent with the earlier 2005 social work practice technology standard 9:2 that states "Social workers shall advocate for the adoption and use of relevant technologies that will enhance the well-being of communities." (ASWB and NASW, 2005, p. 16). The centrality of technology in the basic assessment of older adults highlights the parallel responsibility of the social worker and the agencies to have adequate training to conduct appropriate assessments – to know what to ask. Social workers also need to be aware of the potential tools and services that might address client needs, and their agencies must have – or partner to obtain – adequate resources to provide appropriate tools and services. These components together will make it possible to develop intervention plans that incorporate ethical and appropriate use of technology.

A complete assessment, including the technology component, provides the starting point for determining appropriate interventions. Where this ultimately leads will be influenced by the social workers' awareness of tech-based tools and services as well as by the agency's own resources and partnerships. In Mr. Caputo's case above, tech-savvy social workers were able to identify feasible interventions including a computer or tablet together with training and support in its use, a pendant alarm, and potentially a fall detector.

Several appropriate examples of technology tools that can be utilized alone or as part of broader intervention strategies are suggested by the digital tools described in Goldkind, Wolf, and Freddolino (2018). While their case studies involve a wide range of clients, many of the tools noted have direct applications for older adults. Virtual reality applications (Krueger, 2018), for example, provide older adults with opportunities for immersive world travel from the comfort of their residence and can also provide training opportunities for caregivers (Dementia Australia, 2016). Digital storytelling (Sage, Singer, LaMarre, & Rice, 2018) could be used as a therapeutic tool with older adults living in residential care. At the organizational level, geographic information systems (GIS) can assist agencies in a range of tasks from identifying areas with the highest concentration of negative incidents or features (such as the neighborhoods with the highest concentrations of clients with no computer or tablet) to deciding where to locate new service centers to reach clients (Felke, 2018).

Thus, as Berzin and colleagues (2015) suggest, digital tools and ICT-based services that might help address the needs and problems of older adults are becoming increasingly available. The challenge for social work is to determine what knowledge, skills, and resources are needed to be able to use technology ethically and appropriately in practice.

## **Future Steps: Policy, Practice, and Research**

There is reason to believe that early assessment of the needs of older adults who are at risk of losing their ability to live safely in the community has the potential to improve outcomes for both them and their caregivers through increased utilization of both technology-supported and traditional tools and services (Culo, 2011). Earlier adoption of technology-supported tools and services may well lead to maintaining capacity for independence longer (Center for Technology and Aging, 2009) as well as reduced levels of caregiver stress (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012).

**Policy** An important implication for policy would be to ensure that adequate resources are available to social work agencies for skill development of staff to conduct technology assessments and for the purchase or lease of technology hardware, software, and Internet access. Those tasked with this responsibility must have adequate assessment skills and knowledge of available technology-related options to be able to match the needs of older adults and caregivers with ICT-based tools and services. Because these options will change rapidly, a policy decision may involve establishing a fully accessible database of resources available to those completing the assessments as well as to the public. By design this list must cover tools and services broadly, not tied to any one vendor.

Public policies are critical in narrowing the digital divide for older adults and ensuring more accessible broadband access (Lee, 2017). The Lifeline program, a federal program established in 1985, addresses the affordability gap for low-income populations (FCC, 2018). This federal program provides subsidies to buffer the cost of first wired telephone service, later updated to include wireless cellular service and recently moved to subsidies for broadband services.

Broadband access should be viewed as one of many fundamental civil rights (Lee, 2017). Older adults, for example, are impacted by the current and future healthcare system, which is using more technology in patient care. Older adults are often asked to consume telemedicine practices and tools, which facilitate healthy aging in place and physical independence. Guaranteeing that all older adults have unencumbered Internet access will assist in promoting healthy aging and assure that they are not further disadvantaged in the technology revolution. In addition, efforts to directly tackle scams that target older adults must be undertaken by the Consumer Financial Protection Bureau. They should also provide tailored consumer education for older adults.

**Practice** Social workers will need to evaluate clients' knowledge and use of technology as part of their full psychosocial assessments. Gerontological social workers will also have to be informed of existing and developing technology tools that can benefit their clients and families. This may also include teaching families how to use the tools, particularly ones that can maximize independence. In addition, social workers will need to advocate for access for clients that live in rural areas or for clients that cannot afford broadband.

**Research** The implications for research range from the ideal to the practical. While there is considerable literature that describes tools that can assist older adults and their caregivers, as well as emerging technologies to assist in the future, there is a dearth of research on effectiveness and quality of life outcomes. In the ideal world, resources would be available to support randomized controlled trials to compare efficacy and cost-effectiveness of various tools and treatment with no tools. While this would provide the type of evidence generally demanded by those who serve as gatekeepers to services, such as physicians and government bodies that pay for services, gathering such evidence is very expensive and requires considerable time, during which the available technology options will have increased in number, variety, and hopefully quality. The clear danger is that "the best" becomes the enemy of "the good" alternative.

Because of this challenge, a strong case must be made for expanded studies using solid research methods and maximizing the potential of existing data from agencies that serve older adults as much as possible. This approach would be an improvement over the types of studies encountered in the literature, which were done in limited "laboratory" environments, rather than the real world of service delivery. Such research could then inform the practice community by providing meaningful lists of technology-supported tools and services that seem best suited for older adults with varying levels of need, as well as for their paid and unpaid caregivers and professionals, both at home and in residential facilities as appropriate.

#### Conclusion

Two recent publications point to the critical forces influencing how social work will respond to the technology challenge. The recently published technology standards (NASW et al., 2017) focus heavily on ethical and legal challenges that might limit potential applications of these new tools. The Council on Social Work Education's (2018) recent *Envisioning the Future of Social Work* report describes four future contexts in which gerontological social work may operate, determined by two primary forces: "the level of leadership and influence social workers will have within or beyond the profession, ...and...the degree to which social work will harness and leverage technology to advance its work" (pp. 4–5). While not ignoring the importance of ethical and legal challenges, this document considers an environment in which social workers use "cutting-edge technologies to advance social justice and improve health outcomes" (CSWE, 2018, p. 6).

#### **Discussion Questions**

- 1. In what ways can information and communication technologies (ICTs) support client engagement?
- 2. What are the unique challenges and opportunities in using ICTs with diverse populations?
- 3. What skills and knowledge would you need to acquire to be able to conduct an appropriate technology assessment of an older adult client?
- 4. If Mr. Caputo were your client, what additional technology-based tools or services would you include in your intervention plan? If you would not recommend any tech-based tools or services, what is your rationale for this decision?
- 5. What are other policy and ethical issues to consider when incorporating technology to an intervention plan with Mr. Caputo?

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## Chapter 9 Smart Decarceration



Meredith L. Stensland and Sara Sanders

### **Grand Challenge: Promoting Smart Decarceration**

The number of individuals living in prisons is growing and has been increasing at staggering rates as criminal justice policies have changed to emphasize more stringent sentencing guidelines. The United States has the longest prison sentences and largest prison population of any country (Pew Research Center, 2018a, b; World Prison Brief, 2019). While individuals have discussed the need to look at decarceration strategies, effective strategies have yet to be employed. The Grand Challenge of promoting smart decarceration calls on social workers to assume a leadership role in considering how to reduce the prison population in the United States and addressing the racial segregation of the criminal justice system and to look for new strategies for addressing public safety.

## **Overview**

The Graying of US Prisons As the number of older adults grows in the United States and globally, systems that have not historically been considered to be part of the gerontological service system are now seeing an influx of individuals 55 and older. One such system is the correctional system, specifically state prisons, which are experiencing a radical transformation, as more individuals are aging in place behind bars (Leob, Penrod, McGhan, Kitt-Lewis, & Hollenbeak, 2014). Followed

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by El Salvador and Turkmenistan, respectively, the United States incarcerates individuals at the highest rate in the world, specifically 7% higher than the next closest country at 655 inmates per 100,000 (Pew Research Center, 2018a, 2018b). In 2016, there were over six million individuals involved in the correctional system, which included not only individuals residing in correctional institutions but also people in community correctional programs, such as probation (U.S. Department of Justice, 2018). While the total number of individuals in the correctional system has decreased, the number of individuals incarcerated has only slightly declined and is now at approximately 2.2 million individuals (Pew Research Center, 2018a, 2018b; U.S. Department of Justice, 2018). Of the 2.2 million individuals, 1.5 million are housed in federal or state prisons (Pew Research Center, 2018a, 2018b).

The prison system in the United States is graving at a rapid pace. Due to lifestyle choices, poor medical care, and the overall stress of incarceration, age 50 is considered to be old age for individuals residing in the prison system (Leob & AbuDagga, 2006). This is in line with research demonstrating that compared to the general population, offenders experience rates of death that would be expected for individuals at least 15 years older (Kouyoumdjian, Andreev, Borschmann, Kinner, & McConnon, 2017). By 2030, one-third of the prison population will be over 55 years old (Osborne Association, 2018). According to the Osborne Association (2018), an advocacy organization in New York focused on criminal justice, the population of older adults in prison continues to grow. Between 1980 and 2030, the prison population of older adults will have grown by 4400%. Due to greater medical needs, the costs of keeping older adults behind bars are twice as expensive as it is for younger offenders (American Civil Liberties Union, 2018). As cautioned by the Osborne Association, the criminal justice system is at risk of collapse because the sheer growth of the aging prison population and its profound disease burden are surpassing correctional facilities' capacity to finance effective and humane care provision, an issue referred to as a "crisis" by numerous scholars (e.g., Maschi, Viola, & Sun, 2012; Williams, Goodwin, Baillargeon, Ahalt, & Walter, 2012). The rising costs threaten prisons' ability to ensure high-quality care, as they are not equipped to meet the needs of this population. The fallout of this crisis may lead to poorer treatment of ill and elderly offenders, living conditions not appropriate for older adults, and grossly underfunded healthcare budgets. Many factors converged which led to the growth of older adults in prisons. Most research cites the policies of the 1980s and 1990s that were focused on assuming a more stringent, tougher stance against crime through stricter sentencing laws. Three-strike laws, mandatory minimum sentencing criteria, and an increase in life sentences, which account for 10% of all offenders in prison (Moore, 2009), have contributed to offenders having little to no options for release back into the community. Challenges associated with these laws are affecting states differently, with states, such as Iowa, Illinois, South Dakota, Pennsylvania, Louisiana, and Maine, seeing greater growth of older offenders than other states with less stringent sentencing guidelines (Nellis & King, 2009). One of the greatest challenges with these laws is that offenders were being sentenced while in their teens and early 20s without the long-term impact of these sentences on the 9 Smart Decarceration 127

correctional system being considered. Additionally, the long-term medical and psychosocial needs of the offenders are also not receiving needed attention.

The state of the literature on older adults in prison is relatively sparse with much of it citing the challenges associated with managing an older adult offender in a system that was not designed for this population. Specifically, this population has increased medical and psychosocial needs due to declining physical and mental health status, such as chronic health conditions and cognitive decline. As a result, they will require greater assistance with activities of daily living (Bai, Befus, Mukherjee, Lowy, & Larson, 2015; Stewart et al., 2015; Trotter & Baidawi, 2015). The body of literature that has grown over the last 15 years has examined the provision of end-of-life care for older prisons. This literature has developed due to the greater awareness of how prisoners have historically died behind bars, specifically in isolation and without proper pain management and care (Dubler, 1998), and the growth of the prison hospice industry due to the Guiding Responsive Action in Corrections at the End-of-Life (GRACE) initiative. Another growing body of literature pertains to advance care planning in prison settings and factors associated with honoring the end-of-life wishes of dying offenders (see Sanders & Stensland, 2018; Sanders, Stensland, Dohrmann, Robinson, & Juraco, 2014; Stensland & Sanders, 2016).

Ethical Considerations As of 2016, 60% of offenders who die in prisons are over the age of 65 (BJS, 2016). Despite this and knowledge of the influx of older adult offenders, prison hospice programs are still relatively uncommon. According to the National Hospice and Palliative Care Organization (2018), there are only 75 prison hospice programs in the United States, despite there being 1719 state prisons and 102 federal prisons in the United States. For those prisons who do provide hospice care, this program is generally highly supported. In 2007, Bronstein and Wright (2007) found that end-of-life care in prisons was endorsed by prison administration and created community as offenders and prison staff worked side by side to care for those who were dying. However, end-of-life care in prison, even those with prison hospice programs, is laden with ethical issues. As White and colleagues (2014) found, the clash between safety and security in prison and the care and compassion of those who are promoting end-of-life care to dying offenders can create challenges for medical providers and staff, as well as offenders who take pride in helping their fellow prisons die peacefully. Reconciling a punishment-based model with a quality of life- and death-based model is one of the inherent challenges that prisons have to conquer.

Another ethical challenge facing end-of-life care in prison is that some offenders are moved from one facility to another for advance medical or end-of-life care. However, this does not guarantee that they will receive the end-of-life care they may require. For instance, long-term offenders create family structures within prison systems. Moving an offender from one prison to another at the end-of-life often separates him from his only support systems and the prison family structures that have been created (Sanders & Stensland, 2018). Research suggests that men who are moved to a different prison for advanced medical or end-of-life care experience

significant grief and consider stopping medical intervention in an attempt to be returned to their "home" prison and support systems; the separation from who they define as family creates psychosocial pain that complicates medical care decisions (Sanders & Stensland, 2018).

Another area of research that is beginning to grow is related to offender agency or control over their own end-of-life care. While advance care planning occurs commonly in the community, older offenders do not get routinely engaged in conversations about advance care planning (Williams et al., 2012), and researchers are only beginning to examine this issue in the prison setting. For example, studies have investigated offenders' preferences toward artificial nutrition, CPR, and palliative care (Phillips et al., 2011; Phillips, Allen, Salekin, & Cavanaugh, 2009; Sanders, Stensland, & Juraco, 2018). Given that advance care planning is considered a practice standard in correctional end-of-life care (GRACE Project, 2000), research into not only offender preferences but also administrative procedures for facilitating advance care planning within such a restrictive environment will grow increasingly essential.

The opportunity to complete advance care plans is complicated as older offenders often distrust staff and the system, which creates barriers for them believing their wishes will be actually honored (Sanders et al., 2014). Sanders and colleagues (2014) found that offenders did not trust that the medical providers were honest with them about their care, as they frequently did not have information about their diagnosis, medical appointments, and treatment options. Sanders and Stensland (2018) noted that older offenders clung to the hope of a possible release so they could have a piece of freedom before their deaths. Thus, offenders who had release dates several years out experienced difficulty accepting treatment options that were not associated with prolonging life and a possible cure. This further complicated the advance care planning process.

**Need for Change** With the growth of older adults in prisons and expanding ethical issues as the care of older prisons is considered, structural changes within the correctional system need to be considered as part of a smart decarceration plan. The Grand Challenges provides an opportunity for difficult, ethical conversations to be held about the types of policy and practice changes that need to occur to meet the needs of older, dying offenders. A smart decarceration process that takes into account the policy and practice issues of aging behind bars is just one critical step in this discussion.

#### **Case Presentation**

George Brown is an 83-year-old Caucasian male serving a life sentence without a chance of parole for two counts of first-degree murder. He is diagnosed with Parkinson's disease and has severe mobility limitations causing him to be wheel-chair bound. At age 19, George fatally shot a man and his brother while under the

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influence of drugs and alcohol after learning that the man had been spending time with his girlfriend a few nights prior. George has no memory of the murders; however, testimony from multiple eyewitnesses sharing the same story led him to assume it was true. During his 64 years in prison, George has been a "model offender," as evidenced by the following: He completed his GED and finished a bachelor's degree, he reestablished relationships with his family (including a son who was born after he was incarcerated), and he is actively involved in prison life. George sings in the prison choir and also spends time serving as a mentor to new offenders, a hospice volunteer, and a suicide watch participant on the mental health unit. George communicates his desire to show individuals "he had changed" and was a "new man."

George never had a "major offense or write-up" during his decades-long incarceration and believes that he was not the man he was at age 19 years old when he committed the crimes. George, on multiple occasions, reached out to families of the men he murdered asking for forgiveness. Despite his attempts, he never received a response. He knew that the parents and some siblings of the men who he killed had died, and he even attempted to reach out to their children and other relatives to reconcile what had occurred.

As George aged, he struggled with his life sentence given that he had changed and had demonstrated for 64 years he had the ability to live a productive life without crime. On multiple occasions, he petitioned for his sentence to be reconsidered, so he could be released to age with his family, who stated they would provide care for the duration of his life. Each request was denied due to the violent nature of his offense and the trauma his release could cause for the victims' family members. George knew that the primary family members of the men he shot had died years prior and that the family consultation was occurring from their children, some of whom never had met his victims. Despite his record in prison and supportive documentation from prison staff, George appealed the decision to the Governor who also denied his request for compassionate release. George died in prison 8 months later.

#### **Assessment and Intervention**

The following section presents a critical review of assessment issues for the aging prison population as it relates to the Grand Challenge of smart decarceration, including special needs and characteristics of older offenders, the collision of incarceration and care, and important fiscal considerations. Compassionate release is then described and evaluated for its potential as the leading macro intervention to support smart decarceration. Lastly, an application of compassionate release to the presented case study is made.

Special Needs of Older Offenders Perhaps the most defining characteristic of the older offender population is their heavy disease burden and high disability rates, thereby requiring special attention and assessment relative to other groups of

offenders. Older offenders demonstrate significantly greater rates of functional impairment and required assistance with activities of daily living than younger offenders (Trotter & Baidawi, 2015). Common chronic conditions among older offenders that often result in death include liver disease, cancer, and cardiac issues (Carson & Anderson, 2016). Cognitive impairment is an increasingly prevalent issue with older offenders as well (Maschi et al. 2012; Wilson & Barboza, 2010), in addition to frequent hospitalizations and medication use (Pew, 2018; Williams et al., 2010). Lastly, physical frailty and deficiencies in cognition can render older offenders especially susceptible to being victims of assault and manipulation at the hands of other offenders.

The extensive health needs of the older adult population have spurred a systemic shift in focus from an emphasis purely on confinement and punishment to an emphasis on care provision. The process of effectively managing complex chronic conditions in the correctional setting is fraught with difficulties (Bretschneider & Elger, 2014; Mann, 2013; Psick, Ahalt, Brown, & Simon, 2017; Williams et al., 2009, 2012), and macro-level healthcare concerns include issues such as off-site hospitalization, structural accessibility adaptations, security and staffing levels, and extra officer training for severe behaviors (Pew, 2017). Given the level of frailty and disability associated with chronic disease, the physical structure of prisons is a major consideration. Many prisons were not built with wheelchair accessibility in mind, and retrofitting showers and living spaces for individuals with limited mobility, for example, are complicated given the physical construction and design of prisons (Crawley, 2005). Perhaps one of the most salient examples of the conflicting objectives of incarceration and caring is the blurring of the line between institutional rule infraction and the behavioral manifestation of dementia, calling into question the inappropriate use of secure confinement (Maschi et al., 2012).

Resource Scarcity Given the constitutional mandate prisons must abide by regarding the provision of necessary healthcare to offenders (Estelle vs. Gamble, 1976), correctional workers and policymakers alike have grown acutely focused on the rising expenditures and cost containment efforts. As older offenders are considered a "high-cost population," their contribution to correctional healthcare costs is a critical assessment issue. Estimates indicate that housing an older offender in a facility built primarily for young offenders costs nearly \$70,000 per year in comparison to only \$22,000 for a young offender (Rikard & Rosenberg, 2007). Older offenders' greater utilization of off-site care is considered a major contributor to this cost discrepancy, for reasons such as inpatient hospitalizations, emergency and diagnostic services, and surgical procedures (Pew Research Center, 2018a, 2018b).

This off-site care contributes significantly to corrections departments' healthcare expenditures. A study on the state of Virginia's corrections department effectively illustrates this key issue, as it was found that just under half of the \$62 million spent on off-site healthcare during the 2016 fiscal year was attributed to less than 1% of the state's entire prison population, predominantly those aging and elderly offenders (Pew Research Center, 2014). As corrections departments continue to feel the strain

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of healthcare costs on slimming state budgets, prisons are pursuing different care models to limit costs while ensuring care adequacy. Strategies include telehealth, advancing care outsourcing, Medicaid financing, and medical/geriatric parole (also referred to as compassionate release) (Pew Research Center, 2014); of these four models, parole is the approach that aligns closely with and facilitates the aim of smart decarceration (see Gunst (2018) for differentiation of parole and geriatric parole).

Compassionate Release Compassionate release (CR) is a process outlined in a federal statute of the Sentencing Reform Act (1984) that allows for eligible individuals to be granted immediate early release from prison, thereby entering the community prior to serving one's entire sentence. Having been adopted by nearly all US states, CR laws are meant to be granted given "extraordinary and compelling circumstances" not present at the time of the original sentencing (Wylie, Knutson, & Greene, 2018). The establishment of CR as a sentencing option was based on the premise that severe health impairments alter the legitimacy of core justifications for incarceration, such as rehabilitation, deterrence, and incapacitation (Stensland & Sanders, 2016). That is, to the extent that offenders have such serious illness, severe cognitive impairment, and functional disability that they are unaware of the punishment they are receiving or are too impaired to actually pose a societal safety threat, these justifications are categorically undermined (Berry, 2009). As described earlier, older offenders demonstrate an especially heavy disease burden and are increasingly dying in prison, with greater needs for palliative and end-of-life care (Klock & Liantonio, 2018). CR is an alternative approach that will allow chronically and terminally ill offenders to receive appropriate treatment in the community setting, without unnecessary and costly security. As such, CR is a valid macro-level approach for reducing the number of older offenders who are high in healthcare needs and expenditures while being low in risk to potential danger to the general public.

The use of CR calls for policymakers, prison officials, and correctional social workers to make several critical considerations. In addition to alleviating prison overcrowding and promoting dignity in light of the scarcity of end-of-life care in prisons (Mitchell & Williams, 2017), financial benefits are expected of increased use of CR. For example, the US Department of Justice (2013) has advocated for clarifying and expanding the medical eligibility criteria for CR, and they estimate that \$5.8 million per year would be saved if 100 offenders with serious medical conditions were released from the medical referral centers each year. Proponents of CR struggle to provide data on the money-saving effects of CR, however, primarily because so few offenders are granted CR (U.S. Department of Justice, 2013) and state information documenting the use of CR is inconsistent and sparse (Wylie et al., 2018). Given the overrepresentation of racial minorities across all stages of the criminal justice system (Mechoulan & Sahuguet, 2015; Rehavi & Starr, 2014), including African Americans' markedly lower rates of being granted parole relative to Caucasian offenders (Bradley & Engen, 2016), it will become increasingly important to investigate racial disparities within the CR domain as data become available.

Another critical issue pertains to the larger discussion of offender appropriateness and eligibility for CR, for which an assortment of state laws and policies have been issued (Wylie et al., 2018). Recidivism appears to be the primary concern, and it may be noted that older offenders have a recidivism rate substantially lower than their younger counterparts once released back into the community (U.S. Department of Justice, 2015). Additional micro-level assessment issues include the following: illness severity, life expectancy, nature of original offense, potential threat to society, good behavior/rule infractions while incarcerated, and amount of sentence served versus amount of time remaining (Gunst, 2018; U.S. Department of Justice, 2013). Yet another important consideration is to assess older offenders' level of available social support and housing options in the community, given skilled nursing care facilities' reluctance to admit correctional patients (Maschi, Kalmanofsky, Westcott, & Pappacena, 2015).

Though financial and ethical benefits may result from the use of CR, very few offenders have actually been granted CR (Chiu, 2010; Wylie et al., 2018). Indeed, in a span of just under 10 years, the Colorado Department of Corrections released a total of only three offenders under its CR policy (Chiu, 2010). Likewise, approximately 6% out of the nearly 400 deaths that occurred in the Federal Bureau of Prisons in 2008 were granted CR, and six applicants died while awaiting approval (U.S. Bureau of Justice Statistics, 2014; see Williams, Sudore, Greifinger, & Morrison, 2011). A number of issues likely simultaneously contribute to this underutilization, including inherent bureaucratic complexities that stifle the process, unwillingness of prison officials to make risky decisions for fear of recidivism (Wylie et al., 2018), inadequate administrative protocols (U.S. Department of Justice, 2013), and fear of public backlash for releasing offenders prior to sentence completion (Granse, 2003).

Case Application As depicted by the presented case study on George, the implementation of CR requires prison officials to consider many factors in deciding whether or not to grant early release. While his original offenses are extremely violent in nature and indicate gross impulsivity, the following decades of prosocial behavior and sobriety suggest George may have achieved a level of rehabilitation appropriate for a lower level of supervision than a maximum security prison. Furthermore, his progressing Parkinson's disease rendered him wheelchair-bound and largely reliant upon others for meeting his basic needs; his physical frailty may be interpreted as significantly reducing his physical capacity and likelihood of committing more violent crimes upon being released. Further strengthening his appropriateness for CR is the availability of family support and housing, preventing the need for the prison to identify a skilled nursing facility willing to admit him for long-term care. As he continued to manage his Parkinson's disease and eventually required end-of-life care, George represents a particular profile of high-cost, low-risk offenders whom CR may provide better care quality and cost savings.

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### **Future Steps: Research, Policy, and Practice**

Research Implications The issue of smart decarceration spurs a great need for future research endeavors. First, extensive study is needed surrounding the issue of CR. Longitudinal research is needed to follow and evaluate the outcomes of offenders released though CR. Perhaps the leading concern of these investigations would be to understand and describe the recidivism that occurs among those offenders granted CR, particularly since most of these individuals are ill. Specific data on prevalence, sociodemographic and offense-related predictors, and nature of the recidivism are of critical importance in understanding the empirical risk that releasing offender prior to sentence completion poses to society. A particular focus should be placed on understanding how the safety of other skilled nursing home residents is impacted when a former offender is admitted into the facility. A deeper understanding of who tends to commit more crime upon release and how often this occurs may assist correctional departments in making the decision to grant CR and may also be used to help educate the community and general public about CR. In addition to recidivism, basic descriptive research is needed to understand issues such as post-release life expectancy, living arrangements/homeless rates, and healthcare utilization patterns.

Another imperative research focus is examining the fiscal impacts of greater utilization of CR. Lines of inquiry may involve comparing healthcare spending in states that utilize CR at a higher rate with states that underutilize CR, thereby examining relative annual expenditures and documenting trends in high-cost treatments such as surgical care, hospitalization, and emergency and diagnostic services. Another factor involves investigating the fiscal impact on programs such as Medicare and Medicaid. States must be able to report the quantitative impacts of CR to make stronger arguments for the benefits of greater CR utilization.

From a qualitative standpoint, researchers may seek to understand the personal experiences of offenders after they are released. Greater knowledge of the physical and psychological needs that arise upon leaving the prison setting, particularly of individuals who may have lived in the institutional setting for decades, is fruitful as it can help community social services better serve this population. When applicable, an important emphasis of this research will be to examine family processes of those providing support and caregiving including reintegration and communication styles.

**Policy Implications** Multiple policy issues must be considered when addressing the number of older adults in prisons. The Osborne Association (2018) defines the looming policy issues through a series of recommendations and action steps for leaders in the correctional systems and gerontological community to consider. While the Osborne Association was looking at issues impacting New York state, their recommendation has larger national relevance as decarcerations are considered for older adults. These five areas include:

1. Enhance conditions inside of prisons for aging individuals. This would consist of not only strengthening the prison infrastructure but also staff training and

knowledge of aging offenders. Similarly, it would involve systematic policy changes within the correctional system that are aging friendly.

- 2. Expand release programs for older offenders.
- 3. Increase the resources for and process of discharge planning and reentry preparations for older offenders.
- 4. Improve the reentry experience for offenders by strengthening the community-based formal support network, specifically the housing, physical and mental health, and financial and employment systems for how they can support the offenders and family members.
- 5. Switch the focus from excessively long sentences to greater rehabilitation to reduce the number of people aging in prisons.

Embedded in these policy recommendations are larger issues for social workers to address in collaboration with state departments of correction. For instance, the first policy recommendation calls for enhancing the current prison environment to make it more aging friendly. However, the costs of converting current prisons into environments that are conducive to older adults and their needs as they age would be significant. Current medical units are not equipped to handle the number of older offenders, causing some older individuals who have more significant medical needs to live in general population. This creates not only safety concerns but also situations in which inadequate care is being provided. Further complicating this situation is the need for dementia care. Prison environments are not designed for individuals with reasoning, judgment, and perception deficits characteristic of all forms of dementia. Thus, typical dementia-related behaviors may be misinterpreted as disobedience or aggression by correctional staff. Concern among advocates is that this may result in solitary confinement or other types of punishment that would be considered abusive and cruel for older individuals with cognitive impairment. Additionally, the types of behavioral medication programs and activity programs to promote quality of life for individuals with dementia are not offered or even developed in prisons. But like healthcare needs in general, the costs of creating a dementia-supportive environment in prisons are significant with state and federal funds not necessarily available for these infrastructure and staff needs. Through a strategic plan for smart decarceration of these offenders, the correctional system may see cost containment and greater offender care.

The second policy recommendation from the Osborne Association specifically pertains to the release options for older offenders, including compassionate release. This recommendation calls for a culture shift in the thinking of correctional parole boards toward not only understanding aging but considering how rehabilitation occurs. As release options are considered, states need to examine the impact of release of Medicaid programs and the larger gerontological service system to determine the types of programs and additional policies that would need to be developed to assist offenders upon release.

The third policy recommendation has significant impact on the social work profession as it calls for better planning around prison discharge and reentry. Social workers are not consistently used in correctional settings and specifically in prisons. Often a correctional counselor who is trained in criminal justice versus social work assists with discharge preparations. As the Osborn Association (2018) suggests,

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greater attention to discharge processes would need to occur to adequately assist older offenders return to the community. It is important to recognize that for offenders who have been incarcerated for decades, society on the "outside" has significantly changed, specifically related to technology and community infrastructure, which creates challenges for integration and re-assimilation. This may warrant great social work influence in prison settings and in criminal justice as a whole given the experience of social work in this area.

The fourth policy recommendation is associated with how to make the reentry process successful. This recommendation consists of the large ethical issues that have yet to be fully considered prior to implementation. For instance, while community-based care may seem more cost-effective, organizational policies, as well as state laws, may complicate service access. A prime example is with state sex offender laws, as offenders who have this type of conviction may experience challenges finding care providers and places to live. There are many unknowns to consider for the discharge and reentry process, such as admission issues for assisted living or nursing homes for individuals with sex-related or violent crime convictions, staffing concerns for both community-based and institutionally based staff with offenders with certain convictions, and how to provide care for offenders who may not have family or friends who could assist as decision-makers or caregivers. Likewise, for those individuals who are moving in with family members, state reporting and registering laws for individual with sex-related convictions need to be considered as this may impact family involvement. These areas of policy debate will not be easy but are essential for a successful decarceration process for older adults.

Finally, the fifth policy recommendation calls for greater public dialogue about sentencing and emphasizes the importance of survivors, researchers, and professionals being part of this process. As stated by the Osborne Association (2018), public dialogue should be focused on the findings from research associated with what crime victims and survivors desire as a fair sentence and alternative options rather than long prison sentences. Consideration of a "more compassionate, fair, and humane justice system" should be part of this process, shifting away from the harsh sentencing paradigm (Osborne Association, 2018, p. 45). Issues that may be of focus particularly for rehabilitation of older offenders are those that improve the biopsychosocial functioning of aging individuals. For example, substance abuse treatment, physical therapy for mobility issues, and social and technological skills training may facilitate greater ability to adapt to life in the community upon being released.

**Practice Implications** Social workers have expertise in both micro and macro practice that could assist in the decarceration of older offenders. Social workers can assume a leadership role with many of the abovementioned recommendations, particularly associated with creating an aging-friendly environment for aging offenders, staff training, and discharge/reentry planning. Additionally, social workers can be instrumental in assisting the prison system in addressing the needs of older offenders, including advance care planning and other end-of-life preparations, individual and family counseling, and adjusting to the physical health changes that accompany aging. While the social work profession has been historically underutilized in the correctional system, social workers need to be involved in advocacy efforts associated with prison policy reform. Social workers have an ethical mandate

to respond to social injustices which include unnecessarily long prison sentences, inhumane care of offenders, and survivor and victim preferences. In the face of harsh sentencing paradigms, social workers must advocate for humane treatment of an exceptionally vulnerable subpopulation, frail and ill incarcerated individuals, who remain relatively hidden within institutions across the United States.

### Conclusion

The number of aging offenders behind bars is growing; however, there are more questions than answers for how we adequately address this situation. The cost of changing the prison environments for this population is staggering. Values and biases toward people who commit crimes are deeply embedded into this discussion and any policy and program changes that could occur to better provide care to this population. Decarceration is a viable option and one that would reduce costs for the criminal justice system. However, the gerontological service system has yet to partner with the criminal justice system for how to make this possible. To effectively address the aging crisis and advocate for smart decarceration, the topic of aging behind bars must be at the forefront of policy discussions, and social workers must be included in these discussions.

### **Discussion Questions**

- 1. How might correctional departments safeguard against discriminatory practices with regard to ensuring racial/ethnic equity in the granting of compassionate release?
- 2. To what extent does compassionate release balance the objectives of public safety and cost containment?
- 3. How can social workers most effectively educate policymakers and the general public about smart decarceration in light of mainstream opposition to perceived sentence leniency?
- 4. What types of psychosocial needs should be considered as George ages in prison?
- 5. Considering the different systemic views of the purpose of prisons, what types of training do correctional staff need to help prepare them for the influx of older offenders?
- 6. How can social workers effectively advocate for policies such as compassionate release while also recognizing issues of trauma following crimes for survivors and family members?
- 7. What implications might greater use of compassionate release have on the larger gerontological service system?
- 8. Do nursing homes or other gerontological service providers have a responsibility to disclose if an older adult with a sex-related or violent criminal history requests services? Should other families, residents, patients, or staff be informed?

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# **Chapter 10 Reducing Extreme Economic Inequality**



Joan Davitt and Sol Baik

### **Grand Challenge: Extreme Economic Inequality**

Extreme economic inequality is a critical Grand Challenge for social workers as economic well-being is closely connected with many social problems. Extreme economic inequality refers to considerable imbalances between the highest and lowest economic strata in the distribution of both wealth and income in a nation. Wealth is a measure of one's assets minus any liabilities, while income is money received on a regular basis either as payment for labor or through investments. Inequality in either or both has lasting effects; for example, being poor throughout one's lifespan is associated with poorer health in old age, worse economic security in retirement, and greater risk of dependence on public welfare. Economic inequality has a substantial impact on national economic growth as well (Organization for Economic Cooperation and Development (OECD), 2015).

This chapter focuses on the Grand Challenge of extreme economic inequality and how this manifests in older age. In order to understand how extreme economic inequality impacts older adults, one must first understand what extreme economic inequality in the United States looks like and what factors contribute to such inequality. Thus, the chapter begins with a description of extreme economic inequality and its contributing factors. The relationship between extreme economic inequality over the lifespan and income security in retirement is then discussed. Strategies for mitigating the effects of long-term poverty are presented. Finally, the chapter highlights international models that could be applied to the United States and the role of social workers in reducing extreme economic inequality and its negative effects in later life.

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### Overview

Wealth inequality has been on the rise for at least the past half-century. For example, the richest 20% of US households own 90% of all the wealth (Wolff, 2017). Between 2007 and 2016, inequality in wealth rose as did middle-class debt. Disparities in wealth by race or ethnicity have also risen since 2010 (Dettling et al., 2017). According to the Survey of Consumer Finances (Dettling, Hsu, Jacobs, Moore, Thompson, & Llanes, 2017), almost 20% of African American households had no or negative net worth compared to 13% of Hispanic and 9% of White households. In addition, women accumulate less wealth on average than men (Ruel & Hauser, 2013).

Income inequality has also been on the rise in the United States for many decades. SCF data from 2016 show that "the top 1% of families now receives nearly as large a share of total income (23.8%) as the next highest 9% of families combined, who received 26.5% of all income" (Bricker et al., 2017, p. 10). Between 1989 and 2016, the share of income of the bottom 90% declined to 49.7%. In fact, the United States performs worse than most OECD countries on income inequality, performing only slightly better than Turkey, Mexico, and Chile (OECD, 2015). As with wealth, there are also racial/ethnic and gender disparities in income. White families on average have higher incomes than all other racial or ethnic groups. For example, in 2016, the median income of White households was \$61,200 compared to \$35,400 for African American and \$38,500 for Hispanic families (Dettling et al., 2017). Moreover, women make, on average, 0.81 cents for every dollar men make (Hegewisch & Williams-Baron, 2017).

Extreme economic inequality has serious repercussions for both the individual and society. Research shows that living in poverty over the lifespan negatively influences individuals' health due to economic inequality (Kahn & Pearlin, 2006; Wilson, Shuey, & Elder, 2007). For example, according to a recent study, people aged 55 or older with low incomes (i.e., below 250% of the federal poverty level) were three times more likely to indicate their health status as fair or poor than those with high incomes (i.e., at or above 400% of poverty) (Syre, 2018). Similar results were found for impairments in activities of daily living, depression, and cognitive impairment. Extreme economic inequality increases societal costs for health and long-term care. Some, particularly low-income individuals, African Americans, Hispanics, and Native Americans, are at greater risk of developing multiple chronic conditions as they age. Research shows that this increased risk is a direct effect of cultural racism, inequality, and discrimination that leads to gaps in access to needed resources and higher stress levels throughout the lifespan (Williams & Mohammed, 2013). Therefore, some people are living longer, but not necessarily living healthier lives, which means they have greater need for services from the health sector as they age (Estes, 2001). This affects society in the form of less-developed human capital, higher health and long-term care costs, and reduced economic growth (OECD, 2015).

Extreme Economic Inequality: Contributing Factors In order to understand how economic disparities over the lifespan directly affect income security in later life,

one must first understand how extreme economic inequality arises in the United States. The increase in income and wealth disparities is influenced by political ideology that emphasizes macroeconomic policies favoring the wealthiest strata. Political forces have also sanctioned racially biased "policies and procedures that have reduced access to housing, neighborhood, and educational quality, employment opportunities" and other desirable resources (Williams & Mohammed, 2013, p. 1152), thus reducing income in minority households and undermining the potential of minority households to build wealth. Social forces have also supported gender-based economic discrimination by endorsing gendered norms about work, family, and caregiving (Estes, 2001). Each of these areas is addressed in greater detail in this section.

Historically, the United States has emphasized a laissez-faire form of capitalism, which assumes that the market should be allowed to function freely with little to no government intervention except to protect property rights and to maintain peace and order. In a laissez-faire economy, taxes should be kept to a minimum to cover only those absolute necessities of social existence. In theory, individuals should be "free to" invest their funds as they choose which will stimulate economic activity. In fact, tax policy changes enacted since the early 2000s have exacerbated existing economic disparities in favor of the wealthiest households, with the assumption that the wealthy will then reinvest these saved tax dollars in the economy and benefits will trickle down to lower strata via enhanced economic productivity. However, research has shown that tax cuts do not necessarily increase economic activity, nor trickle down to lower-income groups (Gale & Samwik, 2016). In fact, the after-tax wealth share of the bottom 90% has declined, while the after-tax wealth share of the top 1% has increased since 1992 (Looney & Moore, 2015). Yet the United States continues to reduce tax liability for the wealthiest citizens, making the federal income tax system less progressive and redistributive, which does little to curb extreme inequality.

Laissez-faire capitalism relies more heavily on market-based approaches to social welfare provided through individuals' employers, rather than universal public benefit systems. Unfortunately, work-based private benefits are not distributed equally to all workers. The US Bureau of Labor Statistics' data reveal that the higher the average wage at a firm or place of employment, the more likely that entity is to offer health coverage, retirement accounts, and life insurance (Morgan & Astolfi, 2013). Whites, men, and full-time and high-earning workers are much more likely to have employer-based health and retirement benefits than women, people of color, and those in low-wage jobs (Harrington-Meyer, 2010). In addition, market-based residual welfare programs concentrate risk and responsibility at the individual level, thus exacerbating inequality. In contrast, countries with coordinated market economies tend to offer universal public welfare systems that spread risk and costs across the entire population and are thus more effective in reducing racial, gender, and class inequality (Harrington-Meyer, 2010).

Moreover, tax cuts generate pressure on the system to cut public welfare programs. However, the focus of cuts historically has been to programs that mostly

benefit the poor [e.g., Temporary Assistance for Needy Families (TANF)], even though publicly funded welfare in the United States is not distributed proportionally by need. Only 32% of entitlement spending went to the bottom 20% of households. The largest forms of public welfare in the United States are directed at higherincome groups and corporations in the form of tax deductions (e.g., the mortgage interest and charitable contributions deductions) (Sherman, Greenstein, & Ruffing, 2012). This is because a free market economy needs an underclass to put constant downward pressure on wages. This underclass must be worse off than the lowest-paid workers, such that the workers are unable to demand higher wages because someone is always waiting to take their jobs. Any system of public welfare must therefore be minimal in order to incentivize work while staving off revolt among those who cannot find or perform work. Moreover, by keeping wages low, businesses in turn increase their profits. These profits, however, are not typically shared with workers in the form of higher wages, thus maintaining inequality.

Following the theory that governments should not artificially inflate wages but allow the market to determine the value of someone's labor, wage growth in the United States has stagnated. The federal minimum wage peaked in 1968 and has lost about 9.6% of its purchase power since then (DeSilver, 2017), resulting in a decline in real purchase power for most working-class families. Since 1938, the US Congress has increased the federal minimum wage only 28 times with the last increase to \$7.25 per hour occurring in 2009 (U.S. Department of Labor, 2018). More than half of those working for minimum wage are over age 24 and are supporting families. A full-time worker earning \$7.25 per hour would earn \$15,080 per year, which falls below the federal poverty threshold for a two-person household (\$16,460 in 2018) (Zipperer, 2018). Even in states that have raised their mandated minimum wage, increases have not typically risen as much as inflation. In fact, African American and Hispanic poverty rates would be 20% lower if the federal minimum wage had just kept up with inflation (Zipperer, 2018).

Added to these trends has been a continuous weakening of organized labor in the United States. Union membership has declined from 17.7 million workers in the United States in 1989 to 14.8 million in 2017 (U.S. BLS, 2018). Union workers make on average 20% more than nonunion workers (U.S. BLS, 2018). Unions benefit all workers when they raise pay for their members because their higher pay compels the system to raise wages even in nonunion jobs, particularly in a tight labor market. In addition, the right to organize has been persistently under attack. For example, the US Supreme Court decided in *Janus v. American Federation of State, County, and Municipal Employees*, 585 US (2018), that public employees choosing not to join a union cannot be required to pay dues that fund collective bargaining. This decision is likely to erode the capacity of unions to raise wages for members and nonmembers alike.

Institutional discrimination has also affected the earning potential of women and people of color. Much research has shown that employment discrimination is still a pervasive problem in the US employment sector. Not only do women make about 80% of what men make for equivalent work; for many years, women were restricted to mainly lower-paid occupations. These restrictions were not based on ability but

rather gendered norms about appropriate roles for women in the workforce. Moreover, social norms regarding family and caregiving have also helped to constrain women's earning potential because women are more likely to interrupt their careers for caregiving responsibilities (Estes, 2001).

African Americans and other people of color have experienced a history of institutional and cultural racism that negatively influences their socioeconomic status (Williams & Mohammed, 2013). Racism for many years afforded very restricted access to limited job opportunities for African Americans. Moreover, most unions did not integrate until the latter half of the twentieth century, excluding African Americans, other people of color, and women from many craft and trade unions where they could have earned a living wage and health and welfare benefits. In addition, both overt and covert racism continue to influence every type of employment decision, including hiring, firing, and promotions (Smith, Marsden, & Hout, 2011). Nosek and colleagues (2007) found that almost 70% of Americans, of all races, have implicit biases toward Whites over Blacks, and Whites continue to report discriminating against minorities (Pager & Shepherd, 2008).

Such economic inequality is further exacerbated for African American individuals via historic institutional discrimination in housing. Redlining, racially restricted housing covenants, and other forms of sanctioned discrimination have resulted in dramatically decreased access to home ownership and wealth accumulation for African American families (Williams & Mohammed, 2013). Redlining was a practice that began in the 1930s by the Federal Housing Administration (FHA) to reduce home foreclosures during the Depression. The FHA would determine whether a particular neighborhood was too risky for financial investment and would literally shade the risky area in red on a map. Often the FHA used the area's racial composition as a proxy for income to establish investment risk based on negative stereotypes about people of color. Because of this practice, banks and other investors completely abandoned many predominantly African American neighborhoods resulting in distressed communities with little access to retail businesses, grocers, financial institutions, and health-care providers (Williams & Mohammed, 2013).

Racially restrictive housing covenants were private contracts between homebuyers and sellers that generally were enforced by neighborhood associations and real estate boards. These contracts stipulated that the homeowner could not sell or lease their property to people of color or risk forfeiting the property if they did. These discriminatory policies and practices, which were legal until 1968, maintained a pattern of residential segregation by race in the United States that can still be seen today. African American families have historically been restricted to living in impoverished communities due to these discriminatory practices, which negatively affect access to high-quality educational institutions, healthy environments, and enhanced economic opportunities and networks (LaVeist, Pollack, Thorpe Jr., Fesahazion, & Gaskin, 2011; Williams & Mohammed, 2013). Moreover, US education has historically been funded by real estate taxes. Impoverished communities have fewer tax dollars to support their schools because the value of real estate in those neighborhoods is much lower. This affects the quality of education, which affects academic achievement and, ultimately, access to well-paying jobs and

careers for African Americans. Moreover, discriminatory practices affect the wealth of those families for generations to come because most middle- and working-class wealth comes in the form of equity increases in the value of one's family home. When one is barred from purchasing a home or from purchasing within higher-value communities, there is less wealth to pass on to heirs. All of these factors contribute to a vicious cycle of extreme economic inequality specifically for African Americans, people of color, and women. This cycle also affects income security in retirement; how this happens is discussed in the next section.

Extreme Economic Inequality: Effects in Later Years Extreme economic inequality contributes to economic insecurity in older age because it erodes capacity to accumulate financial resources and negatively affects health status over the lifespan (Estes, 2001). First, extreme economic inequality is carried over into old age because most forms of retirement income are in some way based on, or directly tied to, one's earnings as a worker. For example, to receive social security retirement benefits, one must have worked and paid wage taxes for a minimum of 40 quarters or about 10 years, and benefits are based on wages. Although the program replaces a higher ratio of earnings for lower-wage workers, higher earners still receive a higher monthly benefit. Employer-sponsored pensions, whether they are a defined benefit or defined contribution, are also generally based on wages (Hudson & Dinitto, 2016). Research shows that working-class African American men, and to a lesser degree Hispanic men with less education, are more likely to experience ongoing instability in employment or to receive lower pay throughout their lifespan. This tenuous labor force participation is influenced by discrimination in hiring, firing, and promotions; poor access to high-quality primary and secondary education; and residential segregation (Flippen, 2010; Williams & Mohammed, 2013). Women also experience more tenuous relationships to the labor market generally due to caregiving responsibilities that take them out of the labor market entirely for a period of time or cause them to dramatically scale back their paid work hours (Estes, 2001). Moreover, women earn less than men even in equivalent jobs. This increases risk that their wage history will result in very low monthly social security benefits and lower access to employer-based pension plans (Flippen, 2010). Thus, low wages are carried over into retirement.

Social security is an essential source of economic security for retirees. According to the Social Security Administration (SSA), in 2014, nearly 9 out of 10 older persons received social security income. Many folks rely on social security for the majority of their retirement income; 61% of all beneficiaries receive 50% or more of their income from social security, while 33% receive 90% or more of their income from social security. However, the highest-income quintile relies less on social security than those in the lowest-income quintile. Many in the highest quintile have income from assets and earnings because they are able to continue working. Moreover, women are more likely than men to rely on social security for half or more of their income (Social Security Administration (SSA), 2016). Yet, social security has dramatically reduced poverty, lifting over 22 million people of all ages out of poverty. Without social security, the poverty rate for older Latinos would be almost 45%, and for African Americans, it would exceed 50%. Still 18% of African

Americans, 17% of Latinos, and 10% of women fall into poverty in retirement even with social security benefits, due to historically low wages (Romig & Sherman, 2016).

Furthermore, many low-wage earners, generally, do not have access to any type of employer-sponsored retirement benefit that could supplement social security. The percentage of workers enrolled in a defined benefit pension plan (the gold standard for retirement security) has declined from a high of 35% in 1990 to 18% in 2011 (Wiatrowski, 2012). Some employers have switched to offering their employees defined contribution or 401(k) type retirement plans. The problem with such plans is that the risk rests with the worker and not with the employer because defined contribution plans are not a guaranteed annuity that will pay until one dies. Moreover, these plans are invested via mutual funds. If one retires during a stock market downturn, the amount of the investment can decline dramatically leaving many with insufficient funds to support their retirement security. In addition, many folks may outlive their 401(k) investments due to increased longevity, finding themselves with little to no supplemental income in late life. Also, workers in low-wage jobs and those working part time, working for smaller employers, or in the service or retail sectors are less likely to have access to employment-based benefits (Hudson & Dinitto, 2016; Wiatrowski, 2012). These individuals are more likely to be women or racial/ethnic minorities. Finally, low-wage earners are typically unable to save an adequate amount to support themselves in retirement because minimum wages have not kept up with inflation, further exacerbating the income inequality problem. If individuals add the rising costs of health care to this, many low-income older adults are unable to stretch their resources to pay for much needed support services as they age.

#### **Case Presentation**

Mrs. Althea Johnson is an 85-year-old African American woman who worked her entire career as a housekeeper at a Catholic convent earning minimum wage. Mrs. Johnson was passed over for promotion to housekeeping supervisor even though she had been the acting supervisor for 6 months when she was 48. This would have substantially increased her wages. Instead, they hired a White male, age 35, for the position. She retired at age 62 because she could no longer physically do the work due to multiple chronic health conditions. Between her social security benefits and her meager pension, Mrs. Johnson receives \$ 12,500 per year. Her married son (age 55) lives over 8 hours away and has two children in college. Mrs. Johnson currently rents a home in a neighborhood that lacks a grocery store or health services. She managed for many years to access these and other services from a nearby community by driving her own car. However, it became increasingly difficult for her to afford the insurance and upkeep on the car, so she sold it. Now she takes two buses to buy groceries or go to her doctor. However, her declining health from multiple chronic conditions (e.g., diabetes, high blood pressure, and glaucoma) is making it increasingly difficult for her to manage this. Mrs. Johnson is worried she will have to move from her neighborhood, where she has many friends through her church, to some kind of care facility if her health deteriorates.

### **Assessment and Intervention**

According to sociologist Carroll Estes, "...health and social policy interventions have largely focused on those factors that can be altered by the exercise of individual choice" (2001, p. 139). This can be seen in the proliferation of financial literacy programs. Much research shows that most US citizens regardless of age are financially illiterate and in many cases are not aware of how little they know (Lusardi & Mitchell, 2014). Demographic characteristics associated with lower financial literacy include being female, lower education levels, lower wages, being unemployed, being African American or Hispanic, living in a rural area, and family financial literacy. Research shows that the least-informed individuals were more likely to have more costly mortgages, higher transaction costs on debt, and more credit card debt and are more likely to borrow from their pensions. All of these behaviors can result in tremendous financial losses or unrealized gains due to higher fees or foregone investment opportunities (Lusardi & Mitchell, 2014). Therefore, many programs have proliferated to promote financial literacy in the United States. However, research on the impact of such programs is mixed and does not focus on the longterm effects for decreasing poverty or economic inequality (Lusardi & Mitchell, 2014). Financial literacy programs are quite limited in their ability to reduce extreme economic inequality. Even when low-wage workers, such as Mrs. Johnson, do all the right things, when the cost of living is increasing faster than wages, those earning the least will never be in a position to save enough to assure a financially secure retirement.

On the other hand, the United States has some existing subsidy programs that mitigate the impact of extreme economic inequality for older adults like Mrs. Johnson. For example, the Medicare Low-Income Subsidy, or Extra Help, assists low-income Medicare beneficiaries to pay for their prescription drugs. The Medicare Savings Programs provide assistance with paying Medicare premiums, copayments, coinsurance, and deductibles, for low-income beneficiaries. Other federal subsidy or income assistance programs include Supplemental Nutrition Assistance Program (SNAP), Low-Income Home Energy Assistance Program (LIHEAP), and Supplemental Security Income (SSI), as well as senior housing subsidies and Medicaid. Social workers need to be aware of these programs, their income eligibility criteria, and application procedures, some of which vary between states. Also, many states, municipal governments, and private organizations offer subsidies or discounted services as well as in-kind benefits. However, these programs are not focused on preventing extreme economic inequality but rather on mitigating some of the negative effects of living in poverty.

Although there is economic inequality even in the most generous nations, for many OECD countries, the difference between the highest and lowest economic strata is much smaller than in the United States. Therefore, some of the interventions currently used in Europe may hold promise for the United States. For example, many OECD countries have higher minimum wages than the United States' \$7.25. For example, Sweden's negotiated minimum wage is \$9.94 per hour, Ireland's is

\$9.25, and Germany's is \$8.84. Moreover, most European countries have more workers in unions than in the United States. Over 66% of workers are in unions in Denmark, Sweden, and Finland (Matthews, 2017). A sectoral-based organized labor system, such as in France, could be the answer to the decline in union members in the United States. In this system, all workers in a sector (e.g., restaurant workers) belong to one national union that negotiates on their behalf. Strong unions support enhanced wages as well as progressive tax systems that enable the development of universal welfare programs. Such systems also help to reduce extreme economic inequality.

US welfare state spending falls in fifth place in comparison to other developed economies, when using a net social expenditure model developed by the OECD (Morgan & Astolfi, 2013). Yet taxes and transfers in the United States only decreased poverty rates by 10%, while taxes and transfers in the United Kingdom decreased poverty by 20% and in France by 25%. Therefore, US spending on public welfare is large, while redistribution is small (Morgan & Astolfi, 2013). This is because in many other OECD countries, low-income families receive a much more generous and comprehensive array of tax subsidies and income transfers that work together to reduce economic inequality. Most importantly, the majority of these public welfare programs are universal, meaning everyone receives the benefit regardless of income (albeit sometimes on a sliding scale). Such benefits include paid family caregiving leave, child allowances paid directly to the family for each child, retirement tax credit for time spent out of the labor market as a family caregiver, publicly financed health care, publicly financed higher education, and publicly subsidized childcare. For example, all countries in Europe provide between 14 and 20 weeks of paid maternity leave for all workers, providing between 70% and 100% of earnings during the leave. Moreover, because the parent is still being paid, they continue to pay taxes, including into their retirement systems. They do not lose in terms of present earnings or future retirement benefits for caring for their children. Some countries also provide retirement tax credits for those who take time out to care for other family members. Social workers need to understand how this approach is different from the US approach. First, in these other countries, benefits are provided in the form of transfers or tax credits. Second, benefits are universal, provided by the government regardless of one's labor force attachment. In the United States, welfare benefits tend to be selective and provided through the private market or via tax deductions that mainly go to those with greater income, thus exacerbating inequality.

Many OECD countries' pension systems lift a greater proportion of retirees out of poverty as compared to the United States. For example, the OECD average earning replacement rate for a median earner is 52.9%, while the US social security system replaces only 35% of earnings (Van de Water & Ruffing, 2017). The results of this lower benefit can be seen in older adult poverty rates in the United States (20.9% for those 66+) compared with the average for OECD nations (12.5%) (OECD, 2017). The key factor enabling these systems to raise more older adults out of poverty is higher tax rates in general, more progressive tax systems, and higher taxes on employers, which enhances redistribution and addresses inequality albeit in a delayed fashion.

Another threat to economic security in retirement is the financial health of existing social insurance programs in the United States. US Social Security Trustees estimate that the Social Security Trust Fund faces potential depletion in 2034. If nothing is done before then to modify the program, the system would only be able to pay 75% of benefit claims. In order to resolve this impending shortfall, policy-makers will have to choose between benefit cuts, tax increases, or some combination. Any cuts to benefits will likely hit the lowest-income retirees the hardest, due to their reliance on social security for a majority of their income. Likewise, raising payroll taxes on lower-wage workers will make it even harder for them to save for their future. Social workers should critically evaluate any proposed changes to Social Security and how they will affect low-income workers and retirees. We discuss one possible solution in the next section.

Likewise, many politicians have raised concerns about the federal deficit and the need to cut entitlements in order to reduce the deficit. This has fueled recommendations to privatize Social Security. One has merely to consider the housing crash of 2007 and the dramatic declines in all types of publicly traded investments to understand the risk to completely privatizing retirement income security. Those who retire during a market downturn could see their investment accounts dramatically reduced at the very point when they need to begin drawing out income. Moreover, privatization does not address the impending shortfall. Social workers need to carefully evaluate any proposals to privatize the existing system.

Finally, the United States spends more on health care than most other developed nations but achieves worse outcomes related to health status and coverage. In fact, as a percent of gross domestic product (GDP), the United States spent about double the OECD average, and yet US coverage is not universal. Universal coverage is a key factor in reducing health care and health outcome disparities. Moreover, universal coverage reduces both individual and societal costs and plays a major role in reducing economic inequality (Morgan & Astolfi, 2013).

In the meantime, the United States faces a similar problem in the Medicare program as in Social Security. In 2018, the Medicare Trustees projected that the Part A trust fund could be exhausted by 2026 (Cubanski & Neuman, 2018). Social workers need to be aware that this will therefore require some policy intervention, such as an increase in taxes, a reduction in benefits, or a combination of both, to maintain this program. However, many older adults already struggle to cover the cost sharing components in the Medicare program. This could add further burden on low-income Medicare beneficiaries and their families if fewer services are covered or taxes are increased to pay for services.

# Future Steps: Research, Policy, and Practice

Proposal 1: Make federal income taxes more progressive by increasing rates for the wealthiest modeled after most developed nations, and enhance support for the neediest Our federal income tax policy has become increasingly less progressive

since the 1960s with the top 1% benefiting the most from tax breaks. In 1970, the highest 1% of households contributed 47% of their income to federal taxes, but as of 2004, they were only paying an average of 30% (Piketty & Saez, 2007). In fact, the majority of tax cuts (65%) enacted since 2000 have gone to the richest 20% of the US population (Wamhoff & Gardner, 2018). Moreover, the estate tax is only triggered on estates worth over \$22 million, benefiting the wealthiest families. Finally, corporate taxes have also been reduced down from an average of 32% before 2017 to 21%, putting us well below the 27% average for OECD countries (Hungerford, 2013). In addition, more of our tax breaks should be refundable as opposed to deductions that lower individuals' tax liabilities. This would result in more benefits flowing to those at the lower end of the income distribution that truly need them (Morgan & Astolfi, 2013). If necessary, tax subsidies could be adjusted by income, where some credits are reduced as individuals' incomes climb. Social workers should use research from other OECD countries with higher and more progressive tax systems that fund more generous and universal public welfare systems to educate the general public on the economic benefits of such tax systems, including economic productivity gains due to a healthier workforce and better educated and thus more productive workers.

Proposal 2: Reduce reliance on the private market to provide social welfare benefits. Benefits need to be universal to address extreme inequality. In order to reduce reliance on private market welfare, we will need to boost public revenues to cover the cost of benefits. A more progressive federal income tax system will generate revenue to pay for additional public benefits that go to all, not only to those with strong labor force attachment. These revenues could be used to subsidize education, thus ensuring quality regardless of where one lives, job retraining and relocation services, caregiving support in the form of family supplements, universal health care, and much more. Moreover, increased revenues could be used to shore up the Medicare program. Social workers need to continue to demonstrate, through research, the benefits of universal public welfare programs and the relationship between selective, residual programs and income inequality and the costs to society when all are not included.

**Proposal 3: Raise the federal minimum wage, and tie future increases to inflation** Not only would this increase income of the lowest-paid workers in the United States; it would also increase both payroll and income tax revenue, helping to pay for some of the above proposals. Increased payroll tax revenues would help to delay exhaustion of the Social Security and Medicare trust funds. Simulation studies could help to demonstrate how minimum wage laws can reduce societal costs by raising more citizens out of poverty.

**Proposal 4: Make Social Security more progressive and redistributive** Several factors make the current Social Security tax system regressive. First, the tax percent is the same for all wage earners. Second, Social Security taxes are only applied to wage income. Finally, there is a cap on the maximum wages, which in 2019 is

\$132,000, that can be taxed to support Social Security. In other words, an individual earning \$500,000 does not pay Social Security taxes on \$367,000 of wages. Wage inequality in the United States has caused incomes to grow much faster above the wage cap; thus, the wage tax currently applies to only 82% of taxable wages down from 90% in 1977 (Romig, 2016). If the United States either raised the wage cap to cover 90% of earnings or eliminated the cap, it would make the system more progressive, as higher-income workers would pay taxes on most or all of their earnings. This new revenue could erase 90% of the predicted trust fund shortfall. Even if the benefit formula was modified to account for these contributions, the shortfall could be substantially reduced. In addition, all forms of income should be taxed to support Social Security (and Medicare), including investment income and corporate profits, particularly from S-corporations. Some of the increased revenue could be used to assure all workers a minimum benefit that raises them above poverty. This would make the program even more redistributive, thereby reducing extreme economic inequality.

Proposal 5: Proactively address institutional racism and discrimination For the above proposals to be successful, the United States must address the institutional racism and discrimination that have prevented certain citizens, particularly people of color and women, from fully participating in the economy on equal footing and advancing their own economic interests. Such discrimination affects all aspects of one's life, including longevity and morbidity (LaVeist et al., 2011). Therefore, ongoing research should focus on things such as the effects of residential segregation on educational achievement, income, wealth, and well-being. Moreover, social workers need to advocate for modified eligibility criteria for public welfare programs, funding for access to equal educational systems, and employment-based training on racial and gender bias, to counter institutional racism and gender discrimination.

#### Conclusion

Social workers need to organize and engage in advocacy campaigns to shore up programs, such as those run by the National Committee to Preserve Social Security and Medicare and AARP. Education will be another critical role for social workers, helping the general public to better understand the existing tax system and how other industrialized nations provide for the welfare of their citizens. In order to engage in conscientization processes, social workers will need to critically evaluate public policy and its impact on inequality. Finally, social workers will need to be involved at the political level in everything from voter registration campaigns to running for office.

### **Discussion Questions**

- 1. If Social Security benefits are decreased, what might happen to Mrs. Johnson?
- 2. If Social Security payroll taxes are increased, how will this affect low-wage workers?
- 3. How would you modify Social Security to reduce the shortfall without harming low-income workers or retirees like Mrs. Johnson?
- 4. If Medicare services are cut to address the impending trust fund deficit, how might this impact Mrs. Johnson's or her family's ability to meet her health-care needs?
- 5. How might benefit cuts affect overall health-care costs, health-care providers, and population health?
- 6. In what ways might an increase in the minimum wage have potentially affected Mrs. Johnson's economic security in retirement?

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# **Chapter 11 Financial Capability in Later Life**



Cal J. Halvorsen and Stephanie Skees

### **Grand Challenge: Build Financial Capability for All**

The Grand Challenge to "Build Financial Capability for All" argues that in order for individuals to achieve financial security, they must become financially capable and be able to accumulate assets (Sherraden et al., 2015). Two concepts key to financial capability are *ability* and *opportunity*, which align with the person-in-environment approach to social work (Kondrat, 2002; Sherraden et al., 2015). Using this lens, financially capable people have the abilities (i.e., personal) to save and accumulate assets, such as having good financial literacy, as well as the opportunities (i.e., environmental) to pursue improved financial well-being, such as access to banking services and retirement savings plans (Grinstein-Weiss, Guo, Reinertson, & Russell, 2015; Sherraden et al., 2015). Both are necessary for full financial capability. As such, pursuing a society that promotes financial capability in later life involves changing both individual behavior and larger institutions.

### Overview

The threat—and reality—of financial insecurity in retirement is a key concern for those in, and approaching, later life. The long-running Retirement Confidence Survey, for example, shows that two in five (40%) American workers do not feel confident that they are doing a good job preparing for retirement (Employee Benefit

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Research Institute & Greenwald & Associates, 2018b). Among workers closest to retirement—those aged 55 and older—nearly one in five (19%) have less than \$1000 in savings and investments (Employee Benefit Research Institute & Greenwald & Associates, 2018a). These statistics are sobering and, to make matters worse, are inclusive of the savings of respondents' spouses.

The ability for those in, and approaching, later life to experience their advanced years without poverty and with economic and social engagement opportunities should be of major concern to social work practitioners and researchers. Indeed, the Social Work Code of Ethics promotes this principle, stating, "Social workers should promote the general welfare of society....[and] advocate for living conditions conducive to the fulfillment of basic human needs and should promote social, economic, political, and cultural values and institutions that are compatible with the realization of social justice" (National Association of Social Workers, 2018, Section 6.01).

Building financial capability is important in later life, just as it is in the early years. Regardless of the age group of a social worker's primary client population, it is important to promote financial capability and to understand its link to individual, family, and societal well-being. For example, gerontological social workers may work on behalf of lower-income older adults in a variety of agencies and organizations, such as area agencies on aging and long-term care settings. However, those who work primarily with younger people will often count older adults as their secondary or tertiary client populations. For example, child welfare social workers may work with grandparents providing care. Although gerontological social work has an important function in the lives of retirees and in long-term care and end-of-life settings, it is also important to consider the abilities and opportunities of those who have not yet reached traditional retirement age or who do not require ongoing caregiving. Many social work scholars define older adults as those aged 50 and older (e.g., Halvorsen & Morrow-Howell, 2017; Pitt-Catsouphes, McNamara, James, & Halvorsen, 2017). Relatively speaking, this is young; however, it introduces a broader range of settings and policies in which micro, mezzo, and macro factors can influence financial capability and asset accumulation in later life, including the workplace.

Although the incoming generation of older adults, baby boomers, has been called the richest generation to ever advance to old age (e.g., Steverman, 2016), older adults face a range of financial realities. The Federal Administration for Community Living and the Administration on Aging (2018) report that the median income for people aged 65 and older in the United States in 2016 was \$23,394, with less than one-quarter (22%) of older adults reporting incomes of \$50,000 or more. Discrepancies by gender and race persist, with the median income for older men more than \$13,000 above that of older women and households headed by older non-Hispanic white individuals having a median income more than \$16,000 above those headed by older Hispanic and African American households. The agencies also revealed that about one in seven (14.2%) older adults lived below the poverty line (9.3%) or between the poverty line and 125% of it (4.9%) in 2016. In fact, about one-quarter (24.7%) of those 65 and older in 2015 lived in households that relied on

Social Security to provide at least 90% of their family income; those aged 80 and older, as well as women and those who had not graduated from high school, were unmarried, or were African American or Hispanic, were even more likely to rely on Social Security for the vast majority of their income (Dushi, Iams, & Trenkamp, 2017). This is simply not enough, considering that the Social Security program was only intended to provide about one-third of a person's retirement income as part of a larger "three-legged stool" of individual savings, employer retirement benefits, and Social Security (DeWitt, 1996).

Asset accumulation is a key area of focus for this Grand Challenge. While older households, on average, have higher levels of wealth than their younger counterparts, a substantial portion of older households have relatively little saved. Data from the Federal Reserve's Survey of Consumer Finances revealed that the net worth of households headed by white or Asian individuals aged 62–69 in 2010 was \$54,004 at the 20th percentile, foretelling a financially insecure retirement (Emmons & Noeth, 2015). Unfortunately, this is higher than other groups: among older households headed by African Americans or Hispanics of any race, the authors found that net worth at the 20th percentile was \$6972 for those aged 62–69, while households headed by those aged 70 and older had a net worth of just \$830. While the wealth statistics for both groups at the 20th percentile is low, the gap between white or Asian households and African American or Hispanic households clearly indicates larger issues at play, such as the interplay between systemic racism and wealth accumulation. Gerontological social workers must respond to these issues at all levels in the system, from the micro to macro.

Clearly, social workers who engage with clients, whether they be individuals, groups, communities, or larger systems, have a role to play in ensuring a financially capable populace in later life. The remaining sections of this chapter will help to elucidate a few of those roles, with the caveat that there are far more opportunities for social workers to lead on this issue than can fit into these few pages.

#### **Case Presentation**

Gail W., 52, has worked hard her entire life. Her first job was as a part-time restaurant host at 16. She worked full time during college as a waitress and met her future husband, John, through a mutual friend. John did not attend college, but worked for a local housing contractor. After graduating in 4 years, Gail found a job in sales at a small, locally owned bookstore and married John that summer.

Within a few years, Gail worked her way up in the bookstore and became the store's assistant manager. She loved her job and had aspirations for becoming the store's manager and, perhaps further into the future, buying the store from the owner when he retired. Yet, she and her husband also hoped to become parents. After 5 years, she became pregnant with her first child. The store's owner stressed that Gail would have a job once returning from her unpaid maternity leave, yet after careful consideration, she and her husband decided that it would make the most

financial sense for her to raise her son full time, given the prohibitive costs of child care. And for the next 25 years, Gail was a caregiver, first, for her four children—two sons and two daughters—and then for her own parents as they struggled with chronic and acute illnesses in later life. During this time, John started his own small construction company, riding the ups and downs of the housing market and being the sole source of income.

At 52 and after 30 years of marriage, Gail and her husband divorced; neither felt that their marriage had been working for some time. As part of the divorce settlement, Gail received some spousal support and half of their retirement savings. Yet, she still needed to find a job to cover her living expenses and build her emergency and retirement savings, something that she nor her husband had prioritized. They always seemed to have other pressing expenses and prioritized paying for the majority of their children's college education. They also received no pension or employer match for their retirement savings; after all, her husband employed himself. Although the local bookstore had closed, she found a temporary job as a sales associate at a chain bookstore for the busy season and is hoping that the store will keep her on so that she can join the company's healthcare plan and begin saving in earnest. While her income is low, she is unsure what, if any, programs are available to help her make ends meet.

### **Assessment and Intervention**

Financial Skills and Knowledge for Social Workers At the micro, mezzo, and macro levels of practice, gerontological social workers should stay current in the changing financial landscape, including the laws, regulations, and available benefits regarding savings and retirement. Additionally, gerontological social workers must be financially capable themselves, as these skills and knowledge areas will enhance their social work practice with clients. This is important, as many of the populations that social workers serve have lower levels of financial capability and often did not have access to formal financial education themselves (Sherraden, Laux, & Kaufman, 2007). Social work students can boost their own financial capability in several ways. First, they can take advantage of the Clearinghouse on Economic Well-Being in Social Work Education, a free, online platform launched by the Council on Social Work Education. While designed for social work educators, students can also take advantage of this website's resources, tools, and readings on household economics and financial management, as well as to ask their schools to include related content https://www.cswe.org/Centers-Initiatives/Initiatives/ (see Clearinghouse-for-Economic-Well-Being to learn more). Further, students can utilize the free, online resources provided by the National Endowment for Financial Education, a national nonprofit organization that provides financial education for people throughout the life span. Example resources include financial calculators, quizzes, worksheets, videos, and guides regarding savings and investments, insurance, credit and loans, and retirement (see https://www.nefe.org to learn more).

Considering the case presentation, Gail and John likely had sound shorter-term financial management skills, given the management of his business and their ability to pay for much of their children's college education. However, they may have benefited from further financial education on the importance of saving for emergencies and retirement at a younger age to take advantage of years of compound interest.

There are three important financial organizations for gerontological social workers to understand that regulate various aspects of the financial system. These include the Office of the Comptroller of the Currency (n.d.), which falls under the US Department of the Treasury and is tasked with regulating all national banks and federal saving associations. This and the Federal Trade Commission (n.d.), which works to protect consumers from "anticompetitive, deceptive, and unfair business practices" (para. 1), play vital roles in consumer protection and disseminating resources to help individuals manage their finances. Another important organization for gerontological social workers to follow is the Financial Industry Regulatory Authority (FINRA) (2018), a nonprofit, nongovernmental organization authorized by the US Congress to ensure fair and honest operations by broker-dealer services. In 2009, FINRA launched the first national survey of financial capability, which was repeated in 2012 and 2015 (Lin et al., 2016). The latest comprehensive survey of more than 30,000 individuals found that only a minority (46%) of Americans had set aside 3 months' worth of living expenses, and less than that (39%) had attempted to figure out how much they needed to save for retirement (Lin et al., 2016). Indeed, the case presentation highlights how Gail nor her husband had prepared for either. Further, this FINRA study highlights how those from our most historically vulnerable populations are more likely to show lower levels of financial capability, including women, those who have lower incomes and educational attainment, those from racial and ethnic minorities, and those who care for dependent children (Lin et al., 2016). As such, gerontological social workers must possess a high level of financial capability while understanding the specific benefits available to lower-income older adults to be effective advocates.

Person-Centered Approach to Casework After meeting the clients' immediate needs, social workers should work to develop plans for strengthening clients' personal safety nets, which might include a mix of personal savings and public benefits. Developing and implementing this plan of action can be daunting for an individual in need, especially if other issues seem more salient. For example, the expenses that Gail and her husband had before their divorce in the case presentation felt more salient than saving for emergencies or retirement. At the micro level, a strength that gerontological social workers can bring to the field is the personcentered approach to case management, which places the individual at the center of the planning process and integrates what is most important for the person in that plan, utilizing both formal and informal supports and services (Hooyman, Mahoney, & Sciegaj, 2013).

One helpful resource to begin these conversations is the Consumer Financial Protection Bureau (CFPB) Financial Well-Being Scale (CFPB, 2015). This free

questionnaire, accessible online and complete with a practitioner user guide and scoring worksheet, asks respondents about their abilities to handle major unexpected expenses, concerns about how long their money will last, and other financial issues. This scale also takes respondent age into consideration, an important factor for gerontological social workers.

The National Council on Aging (NCOA) is another resource for gerontological social workers. NCOA has advocated for taking a person-centered, holistic approach to casework by completing comprehensive reviews of older adults' financial situations (Firman, Nathan, & Alwin, 2009). Using this approach, gerontological social workers would, in partnership with clients, coordinate services that are traditionally obtained through a difficult-to-navigate set of providers, including determining eligibility for, and securing enrollment in, public benefits, health insurance counseling, credit and debt counseling and consumer protection, and housing options counseling, among others.

Gerontological social workers do not need to start from scratch. Indeed, NCOA created *BenefitsCheckUp*, a free, online tool that helps to connect older adults to benefits they may be eligible for on topics such as medication and healthcare, food and nutrition, housing and utilities, veterans, employment, education, and income assistance and tax relief, among others (National Council on Aging, 2018). NCOA also offers the free, online *EconomicCheckUp* program, which provides location-based resources for older adults on retirement planning and money management, employment and training, and avoiding scams, among others (National Council on Aging, n.d.). Resources like this might be helpful for Gail, for example, when exploring how to strengthen her own personal safety net.

Social workers can also use behavioral economics techniques to help clients increase their financial capability. Behavioral economics is a broad field of research that combines economics and psychology to explain, predict, and change individual behavior (Camerer & Loewenstein, 2004). In one study of low- to moderate-income tax filers who used the online tax preparation software, TurboTax, those who received on-screen messages regarding the importance and choice to place all or part of their refund into a savings account saved more than those who did not receive these messages (Grinstein-Weiss et al., 2017). Considering the case presentation, had Gail and her husband received similar messages about the importance of saving at tax time, they might have started saving for emergencies and retirement earlier in life. In practice, social workers might consider using similar tactics to encourage clients to save part of their income as the "default" choice after meeting priority expenses, such as housing and food.

Understanding the Diverse Needs and Histories of Older Adults While the need to raise financial capability for all is important, there is an added element of urgency for addressing the unique financial concerns within the increasingly diverse older population. Using the life course perspective (Elder, 1994), gerontological social workers can better understand the diverse needs and histories of their older clients. Using this perspective, gerontological social workers can consider their clients in relation to the historical times and places in which they have lived, such as the existence of

government-sanctioned discrimination on segments of the population and birth cohort effects; the timing of key events and roles in one's life, such as the age at which people marry, have children, or retire; the social relationships and interdependence developed at key points in one's life, such as an adult child moving back home due to being unemployed; and individuals' own abilities to shape their lives, such as an older gay couple being unable or fearful to live together in assisted living. These life course factors can contribute to, and exacerbate, financial disparities well into later life, often due to the effects of cumulative advantage and disadvantage that have increased over the past few decades (Crystal, Shea, & Reyes, 2016).

When working with older clients and their families, gerontological social workers must understand that older adults are not a homogenous group. They are an incredibly diverse population with different lived experiences. Using the person-centered approach discussed in the previous section, gerontological social workers can assess the specific needs and histories of their older clients to create an individualized plan for future financial capability. Considering the case presentation, a social worker might assess Gail's interest in earning a certificate in an area of vocational interest from the local community college while discussing how the skills she learned as a full-time caregiver for the past 25 years can transfer to the paid work environment. These actions might help Gail to secure a higher paid job that aligns with her interests, making it easier to work later in life.

Assessing Financial Capacity and Preventing Exploitation As the field has progressed in acknowledging the complex issues around financial capability, researchers have begun to develop instruments to aid in measuring this phenomenon. Here, we outline two that can be used in the field.

Financial capacity, defined as an individual's ability to start and finish financial tasks and make informed financial decisions, is often one of the first areas to show decline due to Alzheimer's disease or related disorders (Gerstenecker et al., 2016). This presents a problem for many professionals, including social workers, who are obligated to uphold their fiduciary duty to act in the best interest of the client (Kutchins, 1991). One instrument that has been created to assist in the field is the Financial Capacity Instrument-Short Form, which was developed to evaluate an older adult's ability to complete financially related tasks and decision-making, including questions geared towards task-based and judgment skills (Gerstenecker et al., 2016). This 37-item instrument is designed for clinical use with an average completion time of less than 15 minutes.

Gerontological social workers wishing to assess an older adults' abilities to make financial decisions may also use the 10-item Lichtenberg Financial Decision Screening Scale (Lichtenberg et al., 2016). The scale is particularly useful in cases where a social work professional needs to briefly assess a situation identified as suspected financial abuse or exploitation. It is unique in that it is applied to the specific financial request of the older adult and not a hypothetical scenario, like previous instruments, although limitations still exist, such as its inability to screen for identity theft (Lichtenberg et al., 2016).

Especially for older adults who are no longer in the workforce and less familiar with changing technologies, a major concern related to lower financial capability is increased vulnerability to financial fraud and exploitation. While federal law is limited, state laws have become a major mechanism for determining protections and sanctions (Carey, Hodges, & Webb, 2018). There are notable examples of financial institutions working to decrease financial fraud and exploitation of older adults where gerontological social workers can play key roles. In June 2014, for example, Wells Fargo Advisors (WFA) started the Elder Client Initiatives (ECI) team, becoming the first brokerage firm to form such a specialized internal group (Long, 2016). A gerontological social worker played a key role on this team. Using the personcentered approach, the social worker helped team members to understand older clients' fears and expectations, as well as any physical or cognitive changes that might make them more susceptible to fraud. The social worker also educated the ECI team on content areas important to their work, such as dementia (Long, 2016).

While most gerontological social workers will not work within financial institutions, they can still learn how to spot financial exploitation and advocate for increasing education on this topic at banks and other financial institutions. Again, gerontological social workers do not need to start from scratch: they can use the resources provided by the AARP Public Policy Institute's BankSafe Initiative that aims to reduce financial exploitation, empower financial caregivers, and make the banking environment more accessible (Gunther, 2018). Example resources include a tip sheet on spotting financial exploitation and case studies of banks that are leaders in the prevention of financial exploitation.

# **Future Steps**

**Research** As previously documented, a sizeable group of present and future older adults are financially ill prepared for covering the costs of emergencies, such as losing one's job or experiencing a major illness and retirement. Using the ability-opportunity framework of financial capability (Sherraden et al., 2015), future scholarship should continue to investigate how to make it easier for people to save for emergencies and for retirement.

An area in need of additional research is employer-sponsored and automatic "rainy day" savings accounts, which, for many employees, could be relatively quick to accumulate (in comparison with the larger sums needed for retirement) while resulting in higher employee retention (Beshears et al., 2017). Further, behavioral economics techniques, such as creating social norms, calling forth intrinsic and extrinsic motivations, removing barriers to participation, developing commitment devices, and setting defaults that require one to "opt out" instead of "opt in," are all areas ripe for exploration that aim to address the *ability* part of the framework.

<sup>&</sup>lt;sup>1</sup>The second author of this chapter served as that gerontological social worker.

Exploration of innovations within organizational and governmental policies and programs to provide *opportunity* for people to build their assets is also an area of needed research. One example is within self-employed older adults, who must save for their own retirement without the aid of their employers. Just as Gail's husband in the case presentation did not save enough for retirement, empirical research shows that older self-employed adults are far less likely to have access to pensions (Zissimopoulos & Karoly, 2007).

**Policy** Sherraden and colleagues (2015) called for building "a universal, progressive, and lifelong system of asset building that would begin with a Child Development Account opened automatically for each newborn" (p. 3). Although the research is still too new to assess these accounts' effects 50, 60, or 70 years into the future, these accounts have been found to decrease disparities in asset accumulation among the young recipients (Sherraden et al., 2015). We echo their calls for building these universal accounts, as the child recipients who grow into adulthood and enter later life will likely be more financially capable well into retirement. We also acknowledge that for current and future older adults who do not have access to these accounts, more needs to be done.

Of particular importance to many gerontological social workers is family caregiving. In the case presentation, Gail became a caregiver for her parents, a role that prevented her from rejoining the workforce after she finished caring for her children. Few workers have access to paid family leave, which means that they risk losing valuable income, and an opportunity to save for retirement, when they have a family member in need of care (James & Greenfield, 2017). That is why more than 100 scholars in aging, including gerontological social workers, sent an open letter to Congress that called for a national paid family and medical leave policy (James & Greenfield, 2017). This policy would create a national insurance system paid into by every worker that protects those who provide family caregiving. Gerontological social workers can contact their representatives to advocate for such a system at both the state and national level, as well as work with groups that have taken up this cause, such as the National Partnership for Women and Families.

**Practice** As discussed earlier, there is a need for social workers to gain more specialized skills and knowledge in financial management, with a particular focus on building financial capability and assets (Sherraden, Birkenmaier, McClendon, & Rochelle, 2017). This will help gerontological social workers that work at the micro, mezzo, and macro levels of society.

Gerontological social workers should also gain additional skills in navigating the complexities of public benefits that are often used by lower-income older adults. Using the holistic, person-centered approach advocated by the National Council on Aging (Firman et al., 2009), they can coordinate financial services from several agencies using tools that have already been developed, such as *BenefitsCheckUp* (National Council on Aging, 2018). They can also become more aware of financial exploitation in later life and use the resources provided by AARP's *BankSafe* initiative (Gunther, 2018) to help their clients. Gerontological social workers can also

advocate for changes in employer-sponsored savings plans that make it easier for employees to save for emergencies and retirement. To help, they can review behavioral economics techniques, such as those used by Benartzi and Thaler (2013), to increase savings among workers.

### **Conclusion**

Social work scholars have been at the forefront of advancing research, policy, and practice to build financial capability among our most vulnerable populations. Gerontological social workers have the opportunity to leverage this important body of work for those who are closest to or already in retirement, promoting financial security throughout the arc of life. As covered in this chapter, ensuring financial capability in later life involves leading change at micro, mezzo, and macro levels, which gerontological social workers are in the perfect positions to facilitate.

### **Discussion Questions**

- 1. How would you define financial capability in later life, and how would you contrast aspects of both the *ability* and *opportunity* for current and future older adults to be financially capable?
- 2. Reviewing the case presentation, what situations and events may have had the most impact on Gail's current financial state?
- 3. How would you rate your financial capability, including aspects of financial literacy, management, and asset building, and how might that relate to how you work with clients?
- 4. What connection is there between cognitive decline and financial exploitation, and what are some tools to prevent financial exploitation in later life?
- 5. How might gerontological social workers, human and social service organizations, and governmental organizations work together to promote financial capability in later life?

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# **Chapter 12 Achieving Equal Opportunity and Justice**



Laneshia Conner

## **Grand Challenge: Achieving Equal Opportunity and Justice**

Disparities in access to services and opportunities exist throughout society. The Grand Challenge associated with "Achieving Equal Opportunity and Justice" examines the barriers/issues associated with access to education, housing, and employment that affect millions of individuals in the United States. It also focuses on the challenges associated with societal issues that result in continued discrimination and stereotyping that prevent individuals and communities from reaching their fullest potential. This chapter will look specifically at transgender older adults, a population that is frequently not discussed among providers and has faced many historic societal injustices due to values and believes about the LGBT population.

While this Grand Challenge is not focused on older adults, using an aging lens brings to light how older adults of underrepresented populations have encountered and endured injustices and inequalities over the life course. The cycle of limited access, stigma, internalized negative stereotypes, and the lack of opportunities influences whether an older adult has access to needed services and an ability to function fully and uninhibited in society. For example, older adults who are not technology literate and cannot navigate the complexities of the Internet, cannot afford Wi-Fi in their home, live where Wi-Fi signals are weak, or do not have the opportunity to access technological resources are at a disadvantage. Social workers need to understand how exposure to advantages versus disadvantages over the life course or historic oppression in the life of older adults is part of addressing the inequities caused by structural discrimination and institutional racism and its impact on the aging process.

Social workers are in a prime position to examine structural inequality over the life course (Venkatapuram, Ehni, & Saxena, 2017). Public education, affordable health insurance, food security, and many other systems help people achieve their maximum potential. Despite the perception that opportunities advantage all people, many systems are in fact unequal and create barriers to some individuals while advancing others. Understanding the imbalance of access to systems will better inform practitioners about the historic and current experiences of older adults. Operating under the notion that inequality is not a result of individual actions and choices, but instead is structurally generated, is an important point when factoring in accumulated experiences in older adults.

#### Overview

Older adult demographics are changing, including those who identify as members of the LGBT community. Approximately 2.4% of adults over 50 identify as LGBT (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013; Fredriksen-Goldsen & Kim, 2014; Fredriksen-Goldsen, Hyun-Jun, Chengshi, Goldsen, & Emlet, 2015). By 2030, there will be five million older LGBT adults (Fredricksen-Goldsen, 2014). As compared to same-age heterosexuals, older LGBT adults are more likely to experience poor mental and physical health and disability (Foglia & Fredriksen-Goldsen, 2014; Fredriksen-Goldsen et al., 2015; Fredriksen-Goldsen et al., 2013; Wallace, Cochran, Durazo, & Ford, 2011). Some behaviors that negatively impact health, such as smoking, excessive drinking, and obesity, have been means in which older LGBT adults may maladaptively cope with lifelong stigma and lifetime victimization (Emlet, 2016). These behaviors can lead to chronic disease and disability (Emlet, 2016). Reasons for health disparities in the LGBT population are tied to internalized stigma, institutional discrimination, denial of civil and human rights, limited access to health care, financial barriers, and victimization across the lifespan (Fredriksen-Goldsen & Kim, 2014; Emlet, 2016; Zelle & Arms, 2015).

Perhaps one of the more understudied and often most discriminated subsets of the aging population is older adults who identify specifically as transgender. A recent study reported that an estimated 1.4 million (0.6%) individuals in the United States identify as transgender based on data from the 2014 Behavioral Risk Factor Surveillance System (BRFSS) and the Population Estimates Program from the Census Bureau (Flores, Herman, Gates, & Brown, 2016). This figure doubled a widely used previous estimate of 700,000 (0.3%) people from a report released in 2011 (Gates, 2011) and demonstrates the difficulty in obtaining estimates for this population. Within the LGBT population, older adults who identify as transgender have significantly poorer physical and mental health than their gay, lesbian, and bisexual counterparts (Fredriksen-Goldsen, 2014; Fredriksen-Goldsen et al., 2013). There is a paucity of health information about older transgender adults due to limited research on this population and their specific needs as they age. Reasons for this limited knowledge stem from grouping all sexual minorities together in studies,

lack of national studies asking about gender identity, limited funding for research studies that focus on gender identity among older adults, difficulties in recruiting participants, conflation of terms used to define gender identity, and fear of disclosure (Stroumsa, 2014).

Healthy aging has become a growing priority from both a public health and population health standpoint. While *Healthy People 2020* stated an overall goal of improving health and quality of life for older adults, not as much data exists on LGBTQ populations. Two of the noted gaps identified by both *Healthy People 2020* and the CDC are (1) identifying health disparities related to gender identity using nationally representative data and (2) focusing on older adult health among those that identify as LGBTQ (CDC, 2011; ODPHP, n.d.). Older adults who identify as transgender are a part of a "hidden" group of older adults who have unique mental and physical health needs and have received limited attention.

There are a number of health disparities for individuals identifying as LGBTQ. These individuals are less likely to obtain preventive service; have higher risk for HIV and other STDs, particularly in communities of color; are more likely to be overweight; have mental health issues; report higher tobacco, alcohol, and other drug use; and are less likely to have health-care insurance (Buchmueller & Carpenter, 2010; Dilley, Simmons, Boysun, Pizacani, & Stark, 2010; Donovan, 2008; Grant, Mottet, & Tanis, 2011; Kenagy, 2005; Lee, Griffin, & Melvin, 2009; Struble, Lindley, Montgomery, Hardin, & Burcin, 2010; Wheldon & Kirby, 2013; Xavier, Honnold, &Bradford, 2007). For older adults who identify as LGBT, managing chronic disease has become increasingly challenging and costly, not because preventive services are inaccessible, but because this population is highly stigmatized, under-resourced, and underserved (Crisp, Wayland, & Gordon, 2008; Wheldon & Kirby, 2013).

Cultural Humility and Cumulative Equity Theory Cultural humility, a philosophy coined by Tervalon and Murray-Garcia in 1998, postulates that in order to fully acknowledge and accept diversity in its many presentations, individuals need a process-oriented approach to competency. Additionally, it postulates that individuals cannot arrive to a full place of knowing, but should instead act on the premise that knowledge is based on ongoing transactions of attitudes and behaviors between the client system and practitioners. There are three main tenets of cultural humility: (1) participants are involved in lifelong learning that is coupled with critical self-reflection; (2) there is a desire to fix, or mitigate, power imbalances between client systems and practitioners; and lastly, (3) partnerships with institutions will be established with the focus of holding those institutions accountable to creating positive change (Tervalon & Murray-Garcia, 1998).

Cumulative inequality theory, which begins with an examination of inequality across the life course, can be instrumental in working with older adults who identify as a sexual minority, as it offers a comprehensive examination of factors that shape older adult lives. Cumulative inequality theory is a contemporary extension of Dannefer's (1998) cumulative advantage/disadvantage theory, a salient perspective that introduces a way to understand how social structures influence human behavior and interpersonal relationships. Cumulative inequality theory states that inequality

for individuals accumulates over the life course. More precisely, "inequality is not primarily the result of individual choices and actions, but is structurally generated" (Ferraro & Shippee, 2009, p.334). Estes (2001) also examines inequality and aging from a political-economic perspective and posits "many complex social, political, and economic forces...may contribute to the production of dependency (rather than a reduction in dependency) in old age" (p.139). This dependency, or exposure, has also manifested as forms of institutional disadvantage with dire consequences for groups, such as older persons of color and women (Estes, 2001, p.139). The five domains of this theory are useful in order to understand and describe behavioral processes in aging populations, particularly among older women of color and sexual minorities, and can be instrumental during the intervention phase, when trying to understand how systems of oppression have unfavorably affected certain populations and are explained in more detail below.

The Five Domains of Cumulative Inequality Theory The first domain of cumulative inequality theory states that social systems generate inequality and that this experience manifests over the course of individuals' lives. This helps to understand how behavior in later life is shaped by events experienced in early life or childhood (Ferraro & Shippee, 2009, p.335). The second domain is that "disadvantage increases exposure to risk, and advantage increases exposure to opportunity" (Ferraro & Shippee, 2009, p.335). This can be used to look at issues, such as poverty or low educational attainment among subpopulations of transgender older adults, which are associated with participating in high-risk behaviors for sustainment. Underemployment and unemployment have risen in the last few years and have caused an increased burden on groups of sexual minorities who are economically dependent on their partners. In addition to this, other factors that impose a disadvantage to this group as a whole and increase their participation in HIV risk behaviors are types of hazardous lifestyle patterns such as sex trade work, (Nyamathi & Shuler, 1990), sexual abuse (Lewis, Melton, Succop, & Rosenthal, 2000), or having multiple sex partners (Wagstaff, Kelly, & Anderson, 1995). Conversely, it would appear that advantages, or exposures to opportunity, would include older sexual minorities having more income, more education, and higher levels of employability. Due to variability among older adults who identify as transgender or a sexual minority, there is a unique historical context based on "when" they transitioned, and in turn, this could have led to their risks increasing through disadvantages, such as living in hostile environments or suppressing their gender identity (Porter et al., 2016).

The *third* domain is that life course trajectories are dependent upon how risks are accumulated over time and how resources and human agency shape how individuals address these risks. The way in which individuals respond to stimuli greatly differs with some being able to better tolerate harmful treatment more than others (Thoits, 1989). This domain has the capacity to address how older transpersons, especially persons of color, have *responded* to risks or opportunities and how that influences their behavior. Hess (1990) points out that any gender or racial/ethnic minority's life experiences vary from the majority's life experiences because of lifelong stratification systems that maintain gender and racial inequality.

The *fourth* domain states that people use subjective norms to gage whether they are on or off track in relation to others and the life course. Those who feel they are ahead may have more self-efficacy, and conversely, those who feel they lag behind would have less self-efficacy when it comes to participating in high-risk behaviors. For instance, the development of a sexual self is based on an understanding of the messages and meanings individuals are given about sexual roles and behavior over time (Stephens & Phillips, 2003, 2005). Self-efficacy plays a significant role in communicating about individuals' own sexual health, and given the large cultural and societal formations that older transgender adults have faced, those played major roles in shaping both individual and societal understanding of this group.

Finally, the *fifth* domain in this theory states that when studying age cohorts based on limited age ranges (e.g., focusing on people over 50, over 65), it should be considered that population truncation has occurred. In other words, individuals may miss some accumulation of risk factors that has occurred if they begin their investigation later in life because factors that accurately reflect accumulated inequality may be excluded. For example, the question was posed if gerontologists should only study older people, because there are limitations set by not having data on the accumulation of risk factors up until the age of interest, which would be considerably older. Limiting a study by age can limit the consideration of the experienced disadvantage at different points over the life course. While focusing on older adults can be viewed as objectionable according to this domain, the benefit in looking at older cohorts is that those within that cohort share a common experience at the same time, allowing for insight about the relationship of age cohorts of older adults and social structures over time (Levy et al., 2003).

Taking into consideration the tenets of cumulative inequality theory will further support the understanding of older persons who are a part of the sexual minority, as it provides a breakdown of how the lack of exposure to advantage can suppress attitudes and behaviors, as well as encourage poor coping mechanisms and place people at heighted risk.

#### **Case Presentation**

Margie is an 85-year-old African American, cisgender female. She resides at Bluegrass Estates Nursing Home. She was widowed several years ago. She has three adult children; one died several years ago, leaving her with one daughter, Nancy, and one son, Willis. While able to make most decisions, Margie's most recent score on the Mini-Mental Status Exam yielded a 22, suggesting mild cognitive impairment. This score has dropped two points in the past 6 months. Her daughter, who is also her power of attorney, makes regular visits to the facility to pick up her laundry and bring her treats. Her son lives over 400 miles away and only visits when he comes into town, approximately six to seven times a year.

Nancy received a call from the nursing home social worker, requesting she come to her office during her next visit as she wanted to review some documents from her

mother. The next day, before going to the social worker's office, Nancy stopped by her mother's room, to find her mother sitting on her bed, cuddling with another resident. Nancy felt embarrassed and confused, but stood quietly near the door, to listen to her mother's conversation with the other resident. She overheard her mother tell the resident, "I wish we could be like this always." Until this point, Nancy had not considered the possibility of her mother developing feelings for another man.

Once in the social worker's office, Nancy told the social worker what she had just observed. After she shared her experience, the social worker informed her about several things that surprised Nancy. Her mother had given the social worker a list of requests that she wanted the day before, which prompted the meeting:

- 1. Margie had put in a request to be placed in a room with this individual.
- 2. Margie wanted to add this individual to her last will.
- 3. She wanted to make a few changes to her advance directive, making this same individual power of attorney for health-care decisions.

After hearing these requests, Nancy became visibly upset and expressed her refusal to change any part of Margie's documents to suit "some stranger." Nancy began talking about what her deceased father would think about this request and that it was simply not going to be entertained. In a fury, Nancy stood up to exit the office, when the social worker gently explained the impetus for Margie's request. The individual, known as Sam, was on the verge of being discharged from the facility for financial reasons and did not have any family or friends as optional placements. Based on Sam's income, the only viable option would be a personal care home. The social worker leaned into Nancy and softly stated that while a common alternative for many older adults, Sam was unique because he was a transgender male, and finding an inclusive environment had proven to be challenging for the social worker. The social worker explained the stigma associated with non-heteronormative identities in some of the aging communities; Sam was bound to face discrimination. She shared with Nancy that Sam and Margie had been "together" for a few months and that many of the staff had observed a steady connection between the two of them. As Nancy became noticeably upset, the social worker suggested that the three of them sit down for a meeting to talk about Margie's list and requests and even offered to call in Nancy's brother on the phone for a family meeting. Suddenly, Nancy found herself thinking about all of this news in a different way, as the issue of her mother's sexuality had not been in question as were the changes she was requesting. Nancy left the social worker's office confused, conflicted, and unsure what her thoughts were about anything she had just seen and heard.

### **Assessment and Intervention**

Sexual identity and sexual orientation among older adults who identify as transgender or gender nonconforming (TGNC) have characteristics that are distinct from those who identify as LGBT (Porter et al., 2016). In addition, appreciating the intersection of different forms of discrimination or disadvantage, intersectionality,

as well as the role of family beliefs and dynamics are important considerations. A heterosexist lens would lead one to target Margie and her family as the client system; however, operating under a lens of cultural humility, an aware practitioner would focus the plan of assessment and intervention around norming alternative lifestyle patterns and educating both staff and family members on understanding and accepting the choice of the resident. Additionally, a social worker practicing from a lens of cultural humility would consider the intersection of race and sexual identity.

Prior to working with a family, it would be imperative that the practitioner considers the severity of the problem as a pre-intervention marker. To assess the degree of severity, one could administer a frequently used scale in behavioral health, a ruler for readiness where clients select from 0 to 10 to determine how much the issue is affecting them (0 = not at all to 10 = extremely). This assessment will dictate the type and level of intervention offered to address the situation. The target population would be all those who have direct contact with the client system, including staff as well as family. Practitioners would use current markers that their facilities use to assess how much distress the current situation was causing.

Intervention: Organizational Level For service providers, particularly at a nursing home, employee education programs would be a way to influence the formal organizational structures. In the case of Margie, the social worker could contact a local university's social work program to find out about continuing education workshops, or they could create a collaboration to host a lunch and learn tailored to this topic area. Additionally, providing support programs for families and caregivers can enhance communication, decrease service fragmentations, and, most importantly, identify unmet needs. Nancy could be provided a list of LGBT support services that help family and friends by providing information, support, and resources. Given the history of care coordination, there are many models to choose from. A key to the effectiveness and sustainment of such a program would be enlisting help from stakeholders and identifying a coordinated system of care that could easily integrate this new information. Examples of existing programs include care coordination programs, respite programs, and programs that have partnerships with entities, such as the US Veterans Affairs Medical Center, a local Alzheimer's Association chapter, or other community agencies that partner with Area Agencies on Aging. Advocacy and Services for LGBT Elders, also known as SAGE, is dedicated to the advocacy and pursuit of human rights for older persons who are LGBT. They have a number of resources, programs, and initiatives that are dedicated to policy and macro-level issues that older LGBT persons face.

# Future Steps: Policy, Practice, and Research

**Policy** A lack of policies that address the barriers that persons who identify as transgender face as a whole exists, not to mention the barriers that older persons will encounter. For example, consider transgender bathroom access. Bathroom access is

already an issue for some older adults who have limited physical function, depend on a caregiver, or reside in an institutional setting. Proposed legislation across multiple states wants to deny bathroom access based on individual gender identity. This further jeopardizes an already vulnerable population (Porter et al., 2016; Transgender Law Center, 2005). Based on the likelihood of accumulated disadvantage of older trans-adults, there may be more of a reliance on social services due to economic disparities. Documents, such as birth certificates, are needed for applying for many government benefits. While there are stated policies on the process of changing one's identity, there are also some regulations from insurance companies regarding gender reassignment processes, requiring levels of documentation from medical personnel and recommending counseling in the event that hormone treatment is sought after, which makes this complex (Coleman et al., 2012; Porter et al., 2016).

Conversations about long-term care planning for older trans-adults will include establishing criteria or protocol on determining one's gender or how to house an individual based on their identity. Without these policies in place, further perpetuation of discrimination is highly likely, in addition to older adults recloseting, reversing their transition, or inflicting harm on themselves to avoid placement in a long-term care facility altogether (Ippolito & Witten, 2014; Porter et al., 2016). Lastly, transgender older adults may be less likely to have documents such as advance directive, last wills, and power of attorneys for health-care decisions than their cisgender counterparts. Policies are less likely to cover other concerns, such as posthumous handling of their bodies and gender identity on a death certificates. End-of-life concerns are a matter of treating one respectfully, and as an issue related to having equal opportunity to be represented in death as the person they were alive, policies will need to be revised and adopted.

Prevention Programs While funding for prevention programs lies heavily upon the groups being categorized as high risk (National Center for HIV/AIDS, Viral Hepatitis, STD, & TB Prevention, 2011), older adults are under the radar. Given the rate of growth of the older population, ethnic minorities, and the ratio of professionals who are trained in gerontology and geriatrics, this identifies the need for older adults to become a priority population. It has been identified that there is more knowledge that is needed regarding older adults and HIV risk that multilevel approaches should be used and to also consider successful prevention interventions that have been used among younger populations (CDC, 2008). These programs include education to increase knowledge, skills training, culturally sensitive messages, and strategies for older women to negotiate safer sexual behavior (CDC, 2008). Prevention strategies should include the exploration of risk behaviors, specifically among older communities of color, older women, and older persons who identify as LGBT, because of the diverse and age-specific needs that are present yet unexplored. Prevention strategies should also be explored among health and helping professionals, as they can serve as educators and perform risk assessment to identify the need for interventions, referrals, and related services. Given what we know about mistrust of the medical community among populations of older adults (Ahmed et al., 2001; Palacios-Ceña et al., 2011), prevention strategies will need to expand to clinicians and medical professionals, providing training on issues of mistrust and how to maximize their interactions with consumers when it comes to risk assessments and education

Data sources, such as the US Census, have included questions specific to same-sex households, yet there have not been specific questions for those who identify as transgender. Popular media has followed this issue, as the US Census is required to list the categories 3 years prior to conducting the survey. It appeared hopeful in 2017 that gender identity would be included in the 2020 US Census. However, in a statement released by the US Census Bureau, the initial report released had been corrected; the section on sexual orientation and gender identity had been removed (O'Hara, 2017). This is not the first time that information about the LGTBQ population has been removed from national surveys. The National Survey of Older Americans Act Participants had questions of this very nature removed just 1 week prior to the above US Census incident, under the auspices of the Trump Administration (O'Hara, 2017).

**Practice** Gerontological social workers are in prime positions to serve as brokers of information. While guided and mandated by interagency policies, practitioners act on behalf of clients to obtain resources and services that would otherwise not be provided. The question remains: how many social work practitioners are willing to deliver workshops to older adults in the community on identifying sexual risk behaviors, discussing sexual health and preferences prior to engaging in sexual activity with a partner, or thinking about end-of-life planning with a partner in mind?

Practitioners can take several steps to maximize their position in older adults' lives to address this issue. A primary step is for social workers to use research evidence that is interdisciplinary in nature to inform them about best practices regarding behavior change, as it is well known that this is critical to changing attitudes and behaviors (Crosby et al., 2009). Secondly, practitioners will need to request trainings and continuing education efforts that cater to this topic. This includes identifying what they need to know and how to access the information and then finding experts to provide in-service trainings, hosting workshops, and launching online or face-to-face continuing education courses. A local university may be a good resource. To support this route, a third step is becoming familiar with and using public databases, such as the Campbell Collaboration, the Cochrane Collaboration, SAMHSA's National Registry of Evidence-Based Programs and Practices, and the CDC Compendium of Evidence-Based HIV Behavioral Interventions. These databases and sites contain systematic reviews and behavioral interventions that have been deemed as best practices. The social worker from the case presentation could engage in these steps to strengthen her service delivery.

**Research** Research that is inclusive of race, ethnicity, and culture as well as environmental factors adds to the methodological quality of studies because they address the criticisms that research has not paid enough attention to social interactions and culture (Levy et al., 2003; Logan et al., 2002). In addition to what was explored in

this chapter regarding gender identity, intersections of race, ethnicity, and culture should be considered, as older ethnic minorities are a population that have accumulated experiences related to race, ethnicity, and culture which should be accounted for as it affects their quality of life (Ferraro & Shippee, 2009). Therefore, adults who identify as both an older ethnic minority and as LGBT experience cumulative layers of stigma and oppression. Some things to be considered for future studies of older adults who are sexual minorities include examining different cohorts of older adults (i.e., baby boomers, the Silent Generation), using longitudinal studies, using an appropriate level of analysis that considers the cultural and social aspects related to aging, replicating existing studies with diverse older populations to assess for fit and identify cultural adaptations, using more qualitative inquiry to identify concepts that need further investigation, and lastly successfully disseminating study findings to academic and non-academic communities (Levy et al., 2003).

#### Conclusion

Mature and aging populations of adults in this nation are unique in their experiences. Their existence is a point made all on its own: we are still here. While this evergrowing cohort continues to be active, utilize technology, and live in the community, how prepared are social workers to support older adults who identify as transgender? The answer to this question stems from understanding the meaning of opportunities this group has experienced and addressing how both historic and current prejudices truncate the effort of addressing the challenge of creating and sustaining opportunities that provide equal opportunities for older adults including those who are among a sexual minority.

#### **Discussion Questions**

- 1. Discuss the role of sexual identity in older age as it relates to estate planning documents.
- 2. Discuss how the impact of structural inequality and injustices that have accumulated over the life course and intersectionality may be important in the case presentation.
- 3. Considering the NASW Code of Ethics, which ones are applicable to this scenario? If the social worker was in supervision and brought this case up, how should they be advised?
- 4. Discuss institutional and personal bias as it can relate to this scenario. How can applying lens of cultural humility address these biases?
- 5. What therapeutic approach can be used to work with family emotions?
- 6. What are training needs of staff persons who have clients who have gender identities different than perceived?

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