# Journal of Elder Policy

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# Introducing the *Journal of Elder Policy* during the COVID-19 pandemic: Why policies that protect older adults are more important than ever

Editorial: Eva Kahana, PhD, Editor-in-Chief

Welcome to the inaugural issue of the *Journal of Elder Policy (JEP)*. This journal was initiated in 2019 during a period of relative calm and stability in the US. Our goal as a journal is to showcase cutting-edge scholarship in the field of aging and the social sciences that offers guidelines for practice and policy benefiting and protecting older adults.

For our first issue, we invited contributions from seven eminent scholars, whose work spans issues of intergenerational family support, long-term care, financing healthcare for frail older adults, public guardianship, age-friendly cities, ageism in society, and living with vulnerabilities such as HIV/AIDS. The authors represent diverse disciplines and theoretical orientations and include international and US-based scholars. We can thus view social policy issues through different lenses and gain a glimpse into diverse societies' ways of addressing the needs of older adults. I am pleased to report that the papers in this volume are creative, thought provoking, and highly relevant to the unprecedented global challenges we face today. In this editorial, I highlight the relevance of each of the papers included in our first issue to concerns affecting older adults during the current 2020 pandemic.

As we planned this first issue, little did we know that when our articles would go to press we would be in the midst of a COVID-19 pandemic, which puts the life and death of older adults at the center of social upheaval. This pandemic disproportionately threatens the lives of older people. Rather than focusing on policies that can benefit and protect older persons, the discourse has precipitously shifted to concerns about the social costs of protecting older persons, people with disabilities, and those with health-related vulnerabilities (Grzelka, 2020). This has resulted in militant manifestations of ageism and resentment directed toward older adults.

In a timely paper, expressions and consequences of ageism are addressed by **Ayalon**. Her essay focuses on ageism toward older adults at the macro-institutional level in policies or politics, at the meso level of interpersonal relations, and at the micro, intrapersonal level. She skillfully uses several contexts to demonstrate how ageism is manifested within policies, healthcare systems, workforces, and our ageist attitudes toward ourselves. Ayalon's article concludes with creative ways to combat such ageism.

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As a counterpoint to ageism, environmental initiatives to promote age-friendly environments within cities are addressed by **Phillipson** and **Buffel.** Their paper reviews age-friendly initiatives and points to areas where these policies can be developed and improved so as to be more inclusive for different groups of older adults and to enhance their quality of life within cities. At a time when COVID-19 is striking cities across the world, Phillipson and Buffel place ageism in an ecological context that is highly relevant to the current stay-at-home orders enacted in many countries to ensure social distancing.

Investing in bettering life for the old often comes with costs that threaten alternative social policies (Kahana & Kahana, 2017). Indeed, unlimited funds are seldom available for programs and services. Yet, in normal times, the competing needs of different segments of society do not come in as stark relief as they do during this pandemic. Older people and those with health-related vulnerabilities are at high risk for severe complications and mortality during the COVID-19 pandemic. There has been a major concern that the large numbers of severely ill patients requiring hospitalization in ICUs and placement on ventilators may overwhelm capacities of the healthcare system (Emanuel et al., 2020).

These concerns are reminiscent of the panic created in society at the time of the HIV/AIDS crisis. In our current issue, **Emlet** and **Brennan-Ing** address the long-term effects of aging with HIV/AIDS. While much progress has been made in the treatment of this disease, their article reminds us of the physical and psychosocial issues that impact older persons living with HIV. This thought-provoking article provides concrete policy recommendations that can improve the lives of this population, if implemented. We can only hope that similar progress will be achieved in the future treatment of COVID-19 infections.

At the writing of this editorial, during late April 2020, most states in the US are on lockdown, with schools and "non-essential" workplaces close and public gatherings canceled. In the US, tens of thousands of citizens, who are predominantly older, have already succumbed to COVID-19 and the future is unknown. The article featured in this issue by **Lynn** and **Franco** highlights the need for restructuring public policies to accommodate the increasing number of disabled older adults. Their focus is on factors such as finances, housing, medical care, food, transportation, and the direct-care workforce that provide insufficient support for older adults. This manuscript relates directly to issues of COVID-19: "Communities vary greatly in their readiness to assist disabled elderly people. Many cities now have more than six-month waiting lists to get home-delivered food, and most do not offer door-to-door transportation. Some have active 'Villages' that help with neighborly services like getting groceries, making minor repairs and upkeep, and providing companionship, while other communities have no such services." Based on these arguments, we can say that the pandemic has not only produced new problems for older adults, but has also exacerbated and made visible already existing problematic conditions.

While the lockdown is necessary to save lives, especially of older adults, the elderly encounter unique hardships in obtaining food, medicine, and services as they stay at home. The concrete policy reforms that Lynn and Franco advocate are more important than ever if we want to avoid the hardships created by this pandemic for future generations of older adults. While it is important for older adults to self-quarantine in order to avoid exposure to the virus, many older adults are caregivers for grandchildren and/or live in multi-generational households (Brooke & Jackson, 2020). The article by **Harrington-Meyer** and **Abdul-Malak** focuses on the power of intergenerational ties within the family. They also argue for the importance of policies that support parents in caring for their children, especially those with special needs. Programs, such as paid parental leaves, would diminish the need for grandparental caregiving. Today many older adults in the US are financially responsible for grandchildren with disabilities and are direct caregivers to such children. The demands on such elders pose serious stressors during the threat of COVID-19.

Even as social distancing and self-isolation are key to protecting older adults during the COVID-19 pandemic, such shutdowns come with staggering economic costs that may be associated with protecting older adults. In the US and other countries, there has been great public demand for diminishing restrictions of social distancing and an "opening up" of the economy. It is increasingly argued, even by political leaders, that the financial harms to the working poor and the psychological harm of social isolation of the young justify putting the old and vulnerable at risk (Thunstrom et al., forthcoming).

These arguments reflect negative attitudes toward older persons, who may now be viewed as expendable and a burden on society. The requirements for scarce and costly ventilators in treating severe COVID-19 complications have also raised questions about the rationing of healthcare based on projected life expectancy and success of treatment. The difficult choices made in caring for the severely ill have been documented in Britain (Merrick, 2020) and Italy (Cesari & Proietti, 2020). Age has been used in extreme situations as a factor in withholding treatment.

The loss of life among older adults due to COVID-19 has been most staggering in nursing homes and long-term care facilities, which have become epicenters of infection and death (Barnett & Grabowski, 2020). In the context of normal times, the changing profile of the long-term care system based on geographic context is by **Applebaum, Nelson, Straker,** and **Kennedy**. Their paper explores long-term services policy over time, focusing on data from Ohio. They show that despite an increase in Ohio's older population, nursing home use has declined. They note that frail older adults are increasingly opting for home care and non-institutional alternatives and relate this phenomenon to state policy and industry change. Their analysis offers useful insights about the challenges faced by long-term care delivery systems even in normal times. Given the devastation of residents in nursing

homes and other long-term care facilities and allegations of negligence in some cases, we might anticipate that demand for such facilities may further decline as a result of the pandemic. Creative solutions will be needed to find safer alternatives in caring for frail older adults (Kahana & Kahana, 2017).

With early signs of some benefits from social distancing, there appears to be a strong push to prioritize protecting livelihood and personal freedoms, even at the expense of protecting lives. In the US, there have been demonstrations protesting the loss of civil liberties during social distancing directives. Older adults find themselves the objects of scorn and disapproval rather than of caring. Suddenly, the theoretical issues we explore in *JEP* are imminent and personal for older adults. The COVID-19 pandemic calls for younger people, who feel that they are far less threatened by this crisis than are their elders, to change their way of life. They must reluctantly do so to protect the old and the vulnerable, who are at greater risk of mortality if infected.

The threat of COVID-19 has occurred against a backdrop of institutional ageism in the global health priority setting (Lloyd-Sherlock et al., 2020). Protection of the most vulnerable older adults is explicitly tackled in **Teaster** and **Chamberlain's** paper on public guardianship. Their article focuses on the successes and failures of the court system in the US in implementing public guardianship programs for those older adults who are unable to make decisions for themselves. Teaster and Chamberlain provide a detailed description of the guardianship system and available research while highlighting the flaws in the system that still leave the most vulnerable older adults unprotected. During a crisis, like the COVID-19 pandemic, such problems are likely to result in a lack of attention to tending to the needs of older adults who are quarantined, comforting those suffering from COVID-19, and ascertaining their end of life wishes.

Voices that question policies of physical and social distancing are not unique to the US. A recent position paper, written by health policy experts in Germany (Pfaff, 2020), laments the harms to society of enduring social distancing. The authors point to economic harms and growing inequality as a result of social distancing orders. They emphasize that continuing social controls that affect the economy are likely to lead to social unrest because they are damaging the mental health and lives of residents. Indeed, such arguments have led to steps to return to work both in Europe and the US. Many public health officials consider these initiatives premature. Given the uncertainty regarding antibody testing and potential for reinfections, there are fears of further serious flare-ups in infections.

Acceptance of placing the sick or the old at risk is antithetical to the values of protecting the old with social policies. These generational conflicts remind scholars of social policy that age matters as a social, political, economic, and historical category. Intergenerational solidarity is likely to benefit all age groups. Indeed, the young benefit in many ways from interactions with members of the older

generation. Elders serve as family historians and provide roots and values for the younger generation.

Being old and vulnerable is very personal to the editor. I am writing this editorial soon after celebrating my seventy-ninth birthday and am still much involved in productive work as a teacher, researcher, and mentor. I spent three months this past winter at Miami Beach with my eighty-six-year-old husband, who just retired last January after fifty-four years as a psychology professor. We traveled to Florida to avoid the health risks associated with the cold weather in Cleveland. We delayed our return from Florida to our home, because of the health risks of flying during this pandemic. We found the encounters with TSA and getting on the flight particularly frightening. None of the personnel we encountered were wearing masks. During our fourteen days of quarantine after returning home, we felt great anxiety about the threat to our lives if we were to catch this malevolent virus.

While we were in Florida, we witnessed no voluntary avoidance by young adults to protect the old. The beaches were full of young revelers for Spring Break 2020 until they were closed down due to rising infection rates and outside pressure. The young could not or would not comprehend the need for "social distancing." Did they need to stop having fun in order to protect a bunch of frail old folk? This concretizes the critical questions asked by *JEP* about implementing age-friendly social policies. The current pandemic brought into dramatic light the potential conflict of generations that often undergirds social policies (Binstock, 2010).

The mistaken belief that COVID-19 only poses a threat to the old helps support the ageist attitudes highlighted in this editorial (Brooke & Jackson, 2020). In their most extreme forms, these beliefs suggest that the old are a homogenous and dispensable group. If social distancing measures are relaxed or stopped too soon, the lives of older persons will be put in danger. Even as social distancing is institutionally supported, not all older persons can be protected. Social inequality and financial hardships play important roles in putting older adults at risk during the pandemic. Recommendations to have food delivered are not feasible for those without credit cards. Drive-in testing is not feasible for those without a car. Some people live in areas far from hospitals and away from essential services. Furthermore, the lack of internet access can further isolate older adults who may have difficulty communicating with family or healthcare providers (Ahmed et al., 2020)

This essay calls attention to the unique challenges for society in valuing and protecting older adults. While reflecting on the current health crisis, it is important to put things into perspective. It is reassuring to know that the majority of the US public does indeed support protections for the old and the frail. Therefore, I want to conclude by recognizing positive forces that have become visible during the pandemic. For instance, students and teachers inquiring online about each other's welfare and grandchildren calling grandparents, even as personal contact and hugs are discouraged. Compassionate love is a palpable currency as neighbors

check on one another to ensure the availability of food. Here humanity must stand in for social policy.

At this time, no one knows the timelines or degree of devastation ultimately to be wrought by this virus. The hope is that as a society we will survive and even come out stronger and more caring in the aftermath. Survivors of prior traumatic events, such as the Holocaust, have demonstrated social strengths and resilience (Kahana, Harel, & Kahana, 2013). I, myself, am a child survivor of the Nazi Holocaust and learned early to value efforts that better the lives of vulnerable members of society. For social scientists, there will be many valuable lessons about social forces and individual coping that come from this challenge.

We hope that you enjoy our inaugural issue of the *Journal of Elder Policy*. We believe that these articles, and the articles to come, raise important policy considerations that can be drawn from during uncertain times and times of calm in order to benefit the lives of older adults. Articles have been invited and are currently being received for our second issue. They present exciting additional topics related to aging and policy, such as elder abuse, financial security, healthcare advocacy and communication, future care planning, pension policies in China, and justice-involved older adults.

Lastly, we would like to mention that our journal has issued a Call for Papers to explore provocative issues in the social sciences brought to light during this pandemic. We hope that our readers will contribute to the scholarly discussion that considers both the problems and solutions regarding promoting the welfare of older adults that are brought to light by this unprecedented pandemic.

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# Presentamos el Journal of Elder Policy durante la pandemia COVID-19: ¿Por qué las políticas que protegen a los adultos mayores son más importantes que nunca?

Editorial: Eva Kahana, PhD, Editora Principal

Bienvenido a la edición inaugural del Journal of Elder Policy (JEP). Este diario se inició en 2019 durante un período de relativa calma y estabilidad en los EE. UU. Nuestro objetivo como revista es mostrar una beca de vanguardia en el campo del envejecimiento y las ciencias sociales que ofrece pautas para la práctica y la política que beneficia y protege a los adultos mayores.

Para nuestro primer número, invitamos a contribuciones de siete eminentes académicos, cuyo trabajo abarca temas de apoyo familiar intergeneracional, atención a largo plazo, financiamiento de atención médica para adultos mayores frágiles, tutela pública, ciudades amigables con la edad, edad en la sociedad y vivir con vulnerabilidades. como el VIH / SIDA. Los autores representan diversas disciplinas y orientaciones teóricas e incluyen académicos internacionales y estadounidenses. De este modo, podemos ver los problemas de política social a través de diferentes lentes y echar un vistazo a las formas de diversas sociedades de abordar las necesidades de los adultos mayores. Me complace informar que los documentos en este volumen son creativos, estimulantes y altamente relevantes para los desafíos globales sin precedentes que enfrentamos hoy. En este editorial, destaco la relevancia de cada uno de los documentos incluidos en nuestro primer número para las preocupaciones que afectan a los adultos mayores durante la actual pandemia de 2020.

Cuando planeamos este primer número, poco sabíamos que cuando nuestros artículos salieran a la prensa estaríamos en medio de una pandemia de COVID-19, que coloca la vida y la muerte de los adultos mayores en el centro de la agitación social. Esta pandemia amenaza desproporcionadamente la vida de las personas mayores. En lugar de centrarse en políticas que puedan beneficiar y proteger a las personas mayores, el discurso se ha desplazado precipitadamente a las preocupaciones sobre los costos sociales de proteger a las personas mayores, las personas con discapacidad y las personas con vulnerabilidades relacionadas con la salud (Grzelka 2020). Esto ha resultado en manifestaciones militantes de discriminación por edad y resentimiento dirigido hacia adultos mayores.

En un documento oportuno, Ayalon aborda las expresiones y consecuencias de la discriminación por edad. Su ensayo se centra en la discriminación por edad hacia los adultos mayores a nivel macroinstitucional en políticas o políticas, a nivel meso de las relaciones interpersonales y a nivel micro e intrapersonal. Ella usa

hábilmente varios contextos para demostrar cómo la discriminación por edad se manifiesta dentro de las políticas, los sistemas de atención médica, la fuerza laboral y nuestras actitudes que discriminan por la edad hacia nosotros mismos. El artículo de Ayalon concluye con formas creativas para combatir ese envejecimiento.

Como contrapunto a la discriminación por edad, Phillipson y Buffel abordan las iniciativas ambientales para promover entornos amigables con los mayores dentro de las ciudades. Su artículo revisa las iniciativas amigables con los mayores y señala áreas donde estas políticas pueden desarrollarse y mejorarse para ser más inclusivas para los diferentes grupos de adultos mayores y mejorar su calidad de vida dentro de las ciudades. En un momento en que COVID-19 está afectando a ciudades de todo el mundo, Phillipson y Buffel ubican el envejecimiento en un contexto ecológico que es muy relevante para las órdenes actuales de permanencia en el hogar promulgadas en muchos países para garantizar el distanciamiento social.

Invertir en mejorar la vida de los viejos a menudo conlleva costos que amenazan las políticas sociales alternativas (Kahana y Kahana 2017). De hecho, los fondos ilimitados rara vez están disponibles para programas y servicios. Sin embargo, en tiempos normales, las necesidades competitivas de los diferentes segmentos de la sociedad no son un alivio tan absoluto como durante esta pandemia. Las personas mayores y las personas con vulnerabilidades relacionadas con la salud tienen un alto riesgo de complicaciones graves y mortalidad durante la pandemia de COVID-19. Ha habido una gran preocupación de que el gran número de pacientes gravemente enfermos que requieren hospitalización en UCI y colocación en ventiladores puede abrumar las capacidades del sistema de salud (Emanuel et al. 2020).

Estas preocupaciones recuerdan el pánico creado en la sociedad en el momento de la crisis del VIH / SIDA. En nuestro número actual, Emlet y Brennan-Ing abordan los efectos a largo plazo del envejecimiento con VIH / SIDA. Si bien se ha avanzado mucho en el tratamiento de esta enfermedad, su artículo nos recuerda los problemas físicos y psicosociales que afectan a las personas mayores que viven con el VIH. Este artículo que invita a la reflexión ofrece recomendaciones políticas concretas que pueden mejorar la vida de esta población, si se implementa. Solo podemos esperar que se logre un progreso similar en el tratamiento futuro de las infecciones por COVID-19.

Al momento de escribir este editorial, a fines de abril de 2020, la mayoría de los estados en los Estados Unidos están cerrados, con escuelas y lugares de trabajo "no esenciales" cerrados y reuniones públicas canceladas. En los Estados Unidos, decenas de miles de ciudadanos, predominantemente mayores, ya han sucumbido a COVID-19 y se desconoce el futuro. El artículo presentado en este número por Lynn y Franco destaca la necesidad de reestructurar las políticas públicas para dar cabida al creciente número de adultos mayores discapacitados. Se centran en factores como las finanzas, la vivienda, la atención médica, la alimentación, el transporte

y la fuerza laboral de atención directa que proporcionan un apoyo insuficiente para los adultos mayores. Este manuscrito se relaciona directamente con los problemas de COVID-19: "Las comunidades varían mucho en su disposición para ayudar a las personas mayores discapacitadas. Muchas ciudades ahora tienen más de seis meses de listas de espera para recibir comida a domicilio, y la mayoría no ofrece transporte puerta a puerta. Algunos tienen "aldeas" activas que ayudan con los servicios de vecindad, como comprar víveres, hacer reparaciones menores y mantener y proporcionar compañía, mientras que otras comunidades no cuentan con dichos servicios ". Con base en estos argumentos, podemos decir que la pandemia no solo ha producido nuevos problemas para los adultos mayores, sino que también ha exacerbado y hecho visibles las condiciones problemáticas ya existentes.

Si bien el bloqueo es necesario para salvar vidas, especialmente de adultos mayores, los ancianos enfrentan dificultades únicas para obtener alimentos, medicamentos y servicios mientras se quedan en casa. Las reformas políticas concretas que defienden Lynn y Franco son más importantes que nunca si queremos evitar las dificultades creadas por esta pandemia para las futuras generaciones de adultos mayores. Si bien es importante que los adultos mayores se pongan en cuarentena para evitar la exposición al virus, muchos adultos mayores son cuidadores de nietos y / o viven en hogares multigeneracionales (Brooke y Jackson 2020). El artículo de Harrington-Meyer y Abdul-Malak se centra en el poder de los lazos intergeneracionales dentro de la familia. También abogan por la importancia de las políticas que apoyan a los padres en el cuidado de sus hijos, especialmente aquellos con necesidades especiales. Los programas, como las licencias paternas pagadas, disminuirían la necesidad de cuidar a los abuelos. Hoy en día, muchos adultos mayores en los Estados Unidos son financieramente responsables de los nietos con discapacidades y son cuidadores directos de dichos niños. Las demandas sobre tales ancianos plantean serios factores estresantes durante la amenaza de COVID-19.

A pesar de que el distanciamiento social y el autoaislamiento son clave para proteger a los adultos mayores durante la pandemia de COVID-19, tales cierres conllevan costos económicos asombrosos que pueden estar asociados con la protección de los adultos mayores. En los EE. UU. Y en otros países, ha habido una gran demanda pública para disminuir las restricciones de distanciamiento social y una "apertura" de la economía. Se argumenta cada vez más, incluso por los líderes políticos, que los daños financieros a los trabajadores pobres y el daño psicológico del aislamiento social de los jóvenes justifican poner en riesgo a los ancianos y vulnerables (Thunstrom et al., De próxima publicación).

Estos argumentos reflejan actitudes negativas hacia las personas mayores, que ahora pueden considerarse como prescindibles y una carga para la sociedad. Los requisitos para los ventiladores escasos y costosos en el tratamiento de complicaciones graves de COVID-19 también han planteado preguntas sobre el racio-

namiento de la atención médica en función de la esperanza de vida proyectada y el éxito del tratamiento. Las decisiones difíciles tomadas en el cuidado de los enfermos graves se han documentado en Gran Bretaña (Merrick 2020) e Italia (Cesari y Proietti 2020). La edad se ha utilizado en situaciones extremas como factor para retener el tratamiento.

La pérdida de vidas entre los adultos mayores debido a COVID-19 ha sido más asombrosa en hogares de ancianos y centros de atención a largo plazo, que se han convertido en epicentros de infección y muerte (Barnett y Grabowski 2020). En el contexto de los tiempos normales, el perfil cambiante del sistema de atención a largo plazo basado en el contexto geográfico es de Applebaum, Nelson, Straker y Kennedy. Su documento explora la política de servicios a largo plazo a lo largo del tiempo, centrándose en los datos de Ohio. Muestran que a pesar de un aumento en la población mayor de Ohio, el uso de hogares de ancianos ha disminuido. Señalan que los adultos mayores frágiles optan cada vez más por la atención domiciliaria y las alternativas no institucionales y relacionan este fenómeno con las políticas estatales y el cambio de la industria. Su análisis ofrece información útil sobre los desafíos que enfrentan los sistemas de atención a largo plazo, incluso en tiempos normales. Dada la devastación de los residentes en hogares de ancianos y otros centros de atención a largo plazo y las denuncias de negligencia en algunos casos, podríamos anticipar que la demanda de dichos centros puede disminuir aún más como resultado de la pandemia. Se necesitarán soluciones creativas para encontrar alternativas más seguras en el cuidado de los adultos mayores frágiles (Kahana y Kahana 2017).

Con los primeros signos de algunos beneficios del distanciamiento social, parece haber un fuerte impulso para priorizar la protección de los medios de vida y las libertades personales, incluso a expensas de proteger vidas. En los Estados Unidos, ha habido manifestaciones en protesta por la pérdida de libertades civiles durante las directivas de distanciamiento social. Los adultos mayores se encuentran a sí mismos como objetos de desprecio y desaprobación en lugar de preocuparse. De repente, los problemas teóricos que exploramos en JEP son inminentes y personales para los adultos mayores. La pandemia de COVID-19 hace un llamado para que las personas más jóvenes, que sienten que están mucho menos amenazadas por esta crisis que sus mayores, cambien su forma de vida. Deben hacerlo de mala gana para proteger a los ancianos y los vulnerables, que corren un mayor riesgo de mortalidad si están infectados.

La amenaza de COVID-19 se produjo en un contexto de edad institucional en el contexto de la prioridad de salud mundial (Lloyd-Sherlock et al. 2020). La protección de los adultos mayores más vulnerables se aborda explícitamente en el documento de Teaster y Chamberlain sobre la tutela pública. Su artículo se centra en los éxitos y fracasos del sistema judicial en los Estados Unidos en la implementación de programas de tutela pública para aquellos adultos mayores que no pueden tomar decisiones por sí mismos. Teaster y Chamberlain proporcionan una

descripción detallada del sistema de tutela y la investigación disponible al tiempo que destacan las fallas en el sistema que aún dejan a los adultos mayores más vulnerables desprotegidos. Durante una crisis, como la pandemia de COVID-19, es probable que tales problemas provoquen una falta de atención para atender las necesidades de los adultos mayores que están en cuarentena, consolar a los que sufren de COVID-19 y determinar sus deseos de fin de vida.

Las voces que cuestionan las políticas de distanciamiento físico y social no son exclusivas de los Estados Unidos. Un documento de posición reciente, escrito por expertos en políticas de salud en Alemania (Pfaff et al. 2020), lamenta los daños a la sociedad por el distanciamiento social duradero. Los autores señalan los daños económicos y la creciente desigualdad como resultado de las órdenes de distanciamiento social. Enfatizan que los controles sociales continuos que afectan la economía pueden conducir a disturbios sociales porque están dañando la salud mental y la vida de los residentes. De hecho, tales argumentos han llevado a medidas para volver a trabajar tanto en Europa como en los Estados Unidos. Muchos funcionarios de salud pública consideran que estas iniciativas son prematuras. Dada la incertidumbre con respecto a las pruebas de anticuerpos y el potencial de reinfecciones, existe el temor de nuevos brotes graves en las infecciones.

La aceptación de poner a los enfermos o los ancianos en riesgo es antitético a los valores de proteger a los viejos con políticas sociales. Estos conflictos generacionales recuerdan a los estudiosos de la política social que la edad importa como categoría social, política, económica e histórica. Es probable que la solidaridad intergeneracional beneficie a todos los grupos de edad. De hecho, los jóvenes se benefician de muchas maneras de las interacciones con miembros de la generación anterior. Los ancianos sirven como historiadores familiares y proporcionan raíces y valores para la generación más joven.

Ser viejo y vulnerable es muy personal para el editor. Estoy escribiendo este editorial poco después de celebrar mi septuagésimo noveno cumpleaños y todavía estoy muy involucrado en un trabajo productivo como maestro, investigador y mentor. Pasé tres meses el invierno pasado en Miami Beach con mi esposo de ochenta y seis años, que se retiró en enero pasado después de cincuenta y cuatro años como profesor de psicología. Viajamos a Florida para evitar los riesgos para la salud asociados con el clima frío en Cleveland. Retrasamos nuestro regreso de Florida a nuestro hogar, debido a los riesgos para la salud de volar durante esta pandemia. Encontramos los encuentros con TSA y tomar el vuelo particularmente aterrador. Ninguno de los miembros del personal que encontramos llevaba máscaras. Durante nuestros catorce días de cuarentena después de regresar a casa, sentimos una gran ansiedad por la amenaza a nuestras vidas si atrapáramos este virus malévolo.

Mientras estábamos en Florida, no fuimos testigos de la evasión voluntaria de adultos jóvenes para proteger a los ancianos. Las playas estaban llenas de jó-

venes juerguistas para las vacaciones de primavera de 2020 hasta que se cerraron debido al aumento de las tasas de infección y la presión externa. Los jóvenes no podían o no comprenderían la necesidad de "distanciamiento social". ¿Necesitaban dejar de divertirse para proteger a un grupo de viejos frágiles? Esto concreta las preguntas críticas formuladas por JEP sobre la implementación de políticas sociales amigables con los mayores. La pandemia actual trajo a la luz dramática el conflicto potencial de generaciones que a menudo apuntalan las políticas sociales (Binstock 2010).

La creencia errónea de que COVID-19 solo representa una amenaza para los viejos ayuda a apoyar las actitudes ageist destacadas en este editorial (Brooke y Jackson 2020). En sus formas más extremas, estas creencias sugieren que los viejos son un grupo homogéneo y prescindible. Si las medidas de distanciamiento social se relajan o se detienen demasiado pronto, la vida de las personas mayores se pondrá en peligro. Aun cuando el distanciamiento social se apoya institucionalmente, no todas las personas mayores pueden ser protegidas. La desigualdad social y las dificultades financieras juegan un papel importante para poner en riesgo a los adultos mayores durante la pandemia. Las recomendaciones de que se entreguen alimentos no son factibles para quienes no tienen tarjetas de crédito. Las pruebas de manejo no son factibles para quienes no tienen automóvil. Algunas personas viven en áreas alejadas de los hospitales y lejos de los servicios esenciales. Además, la falta de acceso a Internet puede aislar aún más a los adultos mayores que pueden tener dificultades para comunicarse con familiares o proveedores de atención médica (Ahmed et al. 2020)

Este ensayo llama la atención sobre los desafíos únicos para la sociedad en la valoración y protección de los adultos mayores. Al reflexionar sobre la actual crisis de salud, es importante poner las cosas en perspectiva. Es tranquilizador saber que la mayoría del público de EE. UU. Apoya las protecciones para los viejos y los frágiles. Por lo tanto, quiero concluir reconociendo las fuerzas positivas que se han hecho visibles durante la pandemia. Por ejemplo, los estudiantes y los maestros que preguntan en línea sobre el bienestar de los demás y los nietos que llaman abuelos, incluso cuando se desalienta el contacto personal y los abrazos. El amor compasivo es una moneda palpable ya que los vecinos se controlan entre sí para garantizar la disponibilidad de alimentos. Aquí la humanidad debe sustituir la política social.

En este momento, nadie conoce los plazos o el grado de devastación que finalmente causará este virus. La esperanza es que, como sociedad, sobreviviremos e incluso saldremos más fuertes y más cariñosos después. Los sobrevivientes de eventos traumáticos anteriores, como el Holocausto, han demostrado fortalezas sociales y resistencia (Kahana, Harel y Kahana 2013). Yo mismo soy un niño sobreviviente del Holocausto nazi y aprendí temprano a valorar los esfuerzos que mejoran la vida de los miembros vulnerables de la sociedad. Para los científicos

sociales, habrá muchas lecciones valiosas sobre las fuerzas sociales y el afrontamiento individual que surjan de este desafío.

Esperamos que disfrute de nuestro número inaugural de la Política de Journal of Elder. Creemos que estos artículos, y los artículos por venir, plantean importantes consideraciones de política que pueden extraerse durante tiempos inciertos y momentos de calma para beneficiar las vidas de los adultos mayores. Se han invitado artículos y actualmente se están recibiendo para nuestro segundo número. Presentan temas adicionales interesantes relacionados con el envejecimiento y la política, como el abuso de ancianos, la seguridad financiera, la promoción y comunicación de la atención médica, la planificación de la atención futura, las políticas de pensiones en China y los adultos mayores involucrados en la justicia.

Por último, nos gustaría mencionar que nuestra revista ha emitido un llamado a la presentación de documentos para explorar temas provocativos en las ciencias sociales que surgieron durante esta pandemia. Esperamos que nuestros lectores contribuyan a la discusión académica que considera tanto los problemas como las soluciones con respecto a la promoción del bienestar de los adultos mayores que salen a la luz de esta pandemia sin precedentes.

# COVID-19大流行期间介绍《中老年政策期刊》：为何保护中老年人的政策比以往任何时刻都更重要

社论：Eva Kahana，博士，主编

欢迎阅读《中老年政策期刊》（JEP）创刊第一期。本刊于2019年的一个相对平静和稳定时期在美国启动。期刊目标是展示老龄化和社会科学领域的领先学术，提供让中老年人受益并得到保护的实践与政策指南。

我们的第一期文章邀请了七位杰出学者投稿，他们研究了有关代际间家庭支持、长期护理、为脆弱中老年人资助医疗、公共监护、老年友好型城市、社会中的年龄主义、以及与例如艾滋病毒/艾滋病等缺陷共同生存的问题。作者代表了多样化学科及理论方向，并包括国际学者与美国学者。因此我们能透过不同实践看待社会政策问题并了解不同社会对中老年人需求的解决方式。我很高兴的是，本卷收录的文章具有创新性、启发性、并且与我们当前面对的前所未有的全球挑战高度相关。在这篇社论中，我强调了第一期收录的每篇文章，与在2020年病毒大流行期间影响中老年人的关切的相关性。

在我们计划第一期内容时，我们并不知道文章将在COVID-19 大流行期间出版，这次大流行将中老年人的生死置于社会动荡的中心。大流行极大地威胁着中老年人的生命。话语已突然转向了有关保护中老年人、残疾人士、以及那些有健康缺陷的人士所需的社会成本，而不是聚焦于那些能让中老年人受益或保护中老年人的政策 (Grzelka 2020)。这已导致年龄主义的激进体现，以及对中老年人的仇恨。

作者**Ayalon**在一篇即时的文章中研究了年龄主义的表达方式及结果。她的文章聚焦于政策或政治的宏观-制度层面上，人际间关系的中观层面上，以及微观-人际间层面上针对中老年人的年龄主义。她娴熟地使用几个情景证明年龄主义如何在政策、医疗卫生体系、劳动力、以及我们对自己的年龄主义态度中进行体现。Ayalon的文章结论提出了打击年龄主义的创新方法。

与年龄主义对比的是，作者**Phillipson** 与**Buffel**研究了在城市中推动老年友好型环境的相关环境倡议。他们的文章审视了老年友好型倡议并指出了这类政策能得以发展和提升的地区，以期更为包容地对待不同中老年人群体并提升其在城市中的生活质量。在COVID-19 强烈影响全球各城市时，Phillipson 与Buffel将年龄主义置于一个生态背景，后者与当前许多国家为确保社交距离而通过的居家令高度相关。

为老年人投资更好的生活时常带来对替代性社会政策构成威胁的相关成本(Kahana and Kahana 2017)。确实，项目和服务很少获得无限制的资金。然而，在正常时期，社会的不同部分之间相互竞争的需求不会像在这次大流行中一样成为强劲的帮助。中老年人和那些患有健康缺陷的人士在COVID-19大流行期间是严重并发症与死亡的高风险人群。主要的一项关切是，大量需要在ICUs住院的重症患者以及呼吸器的安置可能让医疗卫生体系不堪重负 (Emanuel et al. 2020)。

这些关切让人想起艾滋病毒/艾滋病危机期间社会出现的恐慌。在本期中，作者**Emlet** 与**Brennan-Ing**研究了伴随艾滋病毒/艾滋病衰老的长期影响。尽管在治疗该疾病上取得了许多进展，他们的文章让我们想起影响携带艾滋病毒的中老年人的身体问题与心理问题。这篇启发性文章提供了能提升该人群生命的具体政策建议，如果建议能落实的话。我们只能希望相似的进展将在未来治疗COVID-19感染时得以实现。

在2020年四月下旬撰写这篇社论时，美国大多数州都采取了行动限制，学校与“非必需”工作场所被关闭，公共集会被取消。在美国，成

千上万的公民，其中绝大多数是中老年人，已经被COVID-19感染，他们的命运是一个未知数。本期中作者**Lynn 与Franco**强调了需要重组公共政策，为越来越多的残疾中老年人提供住宿。Lynn 与Franco聚焦于例如财政、住房、医疗、食物、交通、以及那些无法为中老年人提供充足支持的直接劳动力等因素。这篇文章与COVID-19引起的问题直接相关："不同社区在其协助残疾老年人的准备上差异巨大。许多城市现在的获取运送到家食物的等待名单已超过六个月之久，并且许多城市不提供上门运送。一些城市有活跃的'乡镇'帮助提供邻区服务，例如购买杂货、提供小型修补和保养、提供陪伴，而其他社区则没有这类服务"。基于这些论证，我们认为大流行不仅为中老年人制造了新问题，还加重并让现有的不确定情况变得明显。

虽然行动限制对拯救生命，尤其是中老年人的生命而言是必需的，但当老年人待在家时其在获取食物、药物、服务方面遭遇独特困难。Lynn与 Franco倡导的具体政策改革比以往任何时刻都更重要，如果我们想要避免这次大流行为未来几代中老年人造成的困难。尽管对中老年人来说自我隔离是重要的，以期避免感染病毒，但许多中老年人是孙辈的看护者并且/或者居住在多代家庭中(Brooke and Jackson 2020)。作者**Harrington-Meyer**与**Abdul-Malak**撰写的文章聚焦于家庭中代际关系的影响力。作者还论证了那些帮助父母照顾子女、尤其是有特殊需求的子女的政策的重要性。例如带薪产假等项目将减少祖父母提供儿童看护的需求。现在许多美国中老年人都为残疾孙辈提供经济支持，并且是这类儿童的直接看护者。这类中老年人在面对COVID-19威胁时所需完成的各项任务要求对其造成了严重压力。

即使当社交距离和自我隔离在COVID-19大流行期间对保护中老年人而言至关重要，这类活动限制也会产生惊人的经济成本，这类成本可能与保护中老年人一事相关。在美国和其他国家，存在相当多的公众要求减少社交距离限制和"开放"经济。甚至政治领导人也日益论证认为，贫困工作者的经济损害和年青人因社交隔离而产生的心理伤害是将老年人和弱势群体至于风险之中的正当原因（Thunstrom et al. forthcoming）。

这些论证反映了对中老年人的消极态度，他们现在可能被视为社会中可被牺牲的部分和负担。在治疗严重COVID-19并发症时对稀缺和昂贵的呼吸器的需求同样已引起了有关基于预期寿命和治疗成功率的医疗配给的疑问。英国 (Merrick 2020) 和意大利 (Cesari and Proietti 2020) 已记录了照顾严重患者时做出的艰难选择。年龄在严重情况下已成为被拒绝治疗一个因素。

因COVID-19造成的包括中老年人在内的死亡情况在护理院和长期护理设施中最为严重，它们已成为感染和死亡的中心(Barnett and Grabowski 2020)。作者**Applebaum**、**Nelson**、 **Straker**、和**Kennedy**研究了在正常时期下，基于地理背景的长期护理系统的变化。他们的文章探究了随时间推移的长期护理服务政策，聚焦于俄亥俄州的数据。他们表明，尽管俄亥俄州中老年人口增加，疗养院的使用却出现下降情况。他们指出，脆弱中老年人正越来越多地选择居家护理和非机构替代物，并将该现象与州政策及产业变革相联系。作者的分析就长期护理交付体系面临的挑战（即使在正常时期）提供了有用见解。鉴于在疗养院和其他长期护理设施的居民所遭受的灾难，以及在一些情况下关于疏于护理的指责，我们可能预期的是，对这类设施的需求可能会因大流行而进一步下降。将需要创新性解决方案来找到更安全的替代措施，为脆弱中老年人提供护理 (Kahana and Kahana 2017) 。

随着社交距离的部分益处的早期显示，似乎出现了优先保护生计与个人自由，甚至以保护生命为代价的强烈推动力。在美国，不断出现示威游行抗议社交距离指令期间公民自由的损失。中老年人发现自己成为被蔑视和反对的对象，而不是被照顾。COVID-19大流行呼吁那些感觉自己比年老人更不受危机威胁的年轻人改变其生活方式。尽管迟疑，但他们必须这么做来保护老年人和弱势群体，后者一旦感染病毒则会面临更高的死亡率。

COVID-19带来的威胁出现在全球卫生重点设置下的制度年龄主义背景中 (Lloyd-Sherlock et al. 2020) 。作者**Teaster** 与**Chamberlain**就公共监护撰写的文章明确研究了对最脆弱的中老年人的保护。他们的文章聚焦于美国法律体系在为那些无法为自身做决定的中老年人执行公共监护项目时的成功与失败。Teaster 与Chamberlain详细描述了监护体系和可用的研究，同时强调了该体系的缺点，后者将让最脆弱的中老年人无法受到保护。在例如COVID-19大流行这样的危机中，这类问题很有可能导致在照顾被隔离的中老年人的需求、安慰COVID-19感染者、确定其遗言方面缺乏关注。

那些质疑身体距离和社交距离政策的声音并不只在美国出现。最近的一篇由德国卫生政策专家(Pfaff et al. 2020) 撰写的立场论文对忍受社交距离对社会造成的危害表示悲叹。作者指出了因社交距离法令而造成的经济危害及越来越多的不平等。他们强调，继续实行影响经济的社交管制很可能导致社会动荡，因为这些管制正在破坏居民的精神健康与生活。确实，这类言论已导致欧洲和美国实行返回工作的步骤。许多公共卫生官员认为

这些倡议过于仓促。鉴于抗体检测的不确定性和再次感染的可能性，存在进一步严重感染爆发的担忧。

接受将病人或老年人置于风险中，与用社会政策保护老年人的价值观背道而驰。这些代际冲突提醒社会政策学者年龄在社会、政策、经济、历史方面都具有重要性。代际间团结很有可能对所有年龄群体都有益。确实，年青一代在很多方面受益于与年老一代之间的互动。老年人充当家庭的历史学者，并为年轻人提供根源与价值。

作为一名编辑，处于老年与属于弱势群体是一件很私人的事。我在庆祝79岁生日之后不久撰写这篇社论，同时我还作为一名教师、研究者和导师处理诸多工作。去年冬天我与86岁的丈夫在迈阿密海滩度过了三个月，他在从事54年的心理学教授工作后于今年一月刚退休。我们到佛罗里达州旅行，避免因克里夫兰的冷天气而面临健康风险。由于这次大流行期间与飞行相关的健康风险，我们推迟了从佛罗里达州返回家的航班。我们发现与运输交通管理局的接触及搭上飞机的经历尤为可怕。没有任何一名工作人员佩戴了口罩。在我们返回家后的十四天隔离期间，我们对如果我们感染这一恶性病毒而造成的生命威胁感到极度焦虑。

我们在佛罗里达州期间目睹了没有一个年青人出于保护而主动避免接触老年人。海滩在2020年春假期间充满了年青的狂欢者，直到因感染率上涨和外界压力下海滩被迫关闭。年青人不能或不愿意理解“社交距离”的必需性。他们需要停止享乐才能保护一群脆弱的老人吗？这是JEP就落实老年友好型社会政策所质疑的关键问题的具体化。当前的大流行极大地暴露了潜在的代际冲突，这种冲突经常会加强社会政策(Binstock 2010)。

COVID-19仅对老年人造成威胁的错误观念助长了本篇社论所强调的年龄主义者的态度 (Brooke and Jackson 2020) 。这种观念最极端的形式认为，老年人是一个同质的且可被牺牲的群体。如果社交距离措施过快地放松或停止，中老年人的生命将被置于危险中。即使当社交距离从制度上被支持，也并非所有中老年人能被保护。社会不平等与经济困难在将中老年人在大流行期间置于风险一事中发挥了重要作用。对那些没有信用卡的人来说获得食物运送服务的建议并不可行。免下车检测对那些没有车的人而言并不可行。一些人所住的地区远离医院和基础服务。此外，缺少网络获取能进一步隔离那些可能在与家庭或医疗服务提供者沟通方面存在障碍的中老年人 (Ahmed et al. 2020) 。

这篇社论呼吁关注社会在重视和保护中老年人时面临的独特挑战。在反思当前卫生危机的同时，将事情进行透彻分析十分重要。令人安心的是，绝大多数的美国公众的确支持老年及弱势群体。因此，我想以承认那些在大流行期间出现的积极力量的方式作结论。例如，学生与教师通过网络形式相互问候健康，孙辈与祖父母通话，甚至是个人接触与拥抱都不被鼓励。当邻居相互探望确保彼此有食物时，这种充满同情的爱是一种可感受到的受欢迎之物。在这里人道必须代替社会政策（给予关怀）。

在这一时期，没有人知道病毒最终会造成的灾难的时间及程度。希望则是，作为一个社会我们将存活并在灾难后变得更为坚强和关爱。之前痛苦事件的幸存者，例如大屠杀等，已证明了社会的优势和韧性 (Kahana, Harel, and Kahana 2013) 。我本人是纳粹大屠杀的儿童幸存者，我很早就知道要珍惜那些为社会弱势群体的生活变得更好所作的努力。对社会科学家而言，将从这次挑战中的社会力量及个人应对中学到许多宝贵经验。

我们希望您享受阅读《中老年政策期刊》创刊的第一期。我们相信这些文章，以及今后的文章会引起重要的、能从不确定时期和正常时期得出的政策考量，以期让中老年人的生活受益。我们第二期内容已邀请了文章投稿并正在接收稿件。它们提出了令人兴奋的、有关老龄化与政策的相关话题，例如中老年虐待、财务安全、医疗卫生倡导及传播、未来护理规划、中国养老金政策、以及陷入司法纠纷的中老年人。

最后，我们想提到的是，我们的期刊已发出了“论文征集”，寻找这次大流行期间暴露的社会科学中的争议性议题。我们希望读者将对学术探讨作出贡献，衡量由前所未有的大流行所暴露的、有关推动老年人福利的问题和解决方案。

# Policy Does Matter: Changing an Unchangeable Long-Term Services System

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## Abstract

Because long-term services policy is largely driven by state decisions, this study examines the impact of state-level changes on Ohio's long-term services system. Using longitudinal data collected over twenty-six years, this paper tracks system changes, showing that despite a continued and dramatic increase in Ohio's older population, nursing home (NH) use has declined. The paper also documents the growth of in-home services, assisted living, and the increase in short-term institutional care. Advances in state policy, along with industry changes, such as the expansion of private pay home care and assisted living, have resulted in a changed long-term services and supports (LTSS) landscape. Driven by continued demographic changes and associated resource constraints, tomorrow's challenges will be even more difficult to address. The paper concludes with a discussion about how the system will need to be reformed to meet the challenges ahead.

***Keywords:*** long-term services system reform, re-balancing long-term services, future long-term services policy

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# La política importa: cambiar un sistema de servicios a largo plazo inmutable


## Resumen

Debido a que la política de servicios a largo plazo depende en gran medida de las decisiones estatales, este estudio examina el impacto de los cambios a nivel estatal en el sistema de servicios a largo plazo de Ohio. Utilizando datos longitudinales recopilados durante veintiséis años, este documento rastrea los cambios del sistema, mostrando que a pesar de un aumento continuo y dramático en la población de ancianos de Ohio, el uso de hogares de ancianos (NH) ha disminuido. El documento también documenta el crecimiento de los servicios en el hogar, la vida asistida y el aumento de la atención institucional a corto plazo. Los avances en la política estatal, junto con los cambios de la industria, como la expansión de la atención domiciliaria privada y la vida asistida, han dado como resultado un cambio en el panorama de los servicios y apoyos a largo plazo (LTSS). Impulsados por los continuos cambios demográficos y las limitaciones de recursos asociadas, los desafíos del mañana serán aún más difíciles de abordar. El documento concluye con una discusión sobre cómo será necesario reformar el sistema para enfrentar los desafíos futuros.


***Palabras clave:*** reforma del sistema de servicios a largo plazo, reequilibrio de los servicios a largo plazo, política futura de servicios a largo plazo

# 政策确实重要：改变一个无法改变的长期（护理）服务体系


## 摘要

鉴于长期服务政策在很大程度上由各州决策所驱动，本研究检验了州级变化对俄亥俄州长期服务体系产生的影响。通过使用长达26年的纵向数据，本文追踪了体系变化，并表明尽管俄亥俄州中老年人口出现持续且显著的增长，护理院（NH）的使用却有所下降。本文还记录了居家护理服务和辅助生活服务的增长情况，以及短期机构护理服务的增加。州政策的进步，加上产业变革，例如私人支付家庭护理和辅助生活服务的扩大，已造成长期服务及支持（LTSS）局面发

生变化。受持续的人口变化和相关资源限制的驱动，今后的挑战将更难解决。本文结论探讨了该体系将如何需要改革以应对未来挑战。

关键词:长期服务体系改革，重新平衡长期服务，未来长期服务政策

## Background

The debate in western society about whether to provide care in an institutional setting (indoor relief) or community-based location (outdoor relief) dates back to the Elizabethan Poor Law of 1601 (Axinn & Stern, 2005). Evaluation research has accompanied the indoor versus outdoor relief controversy, with the first US study completed by Josiah Quincy in 1821. The Quincy Report concluded that indoor relief was the most efficient means of support since conditions were so unpleasant in the almshouse that only those truly in need would use the assistance (Poverty USA, 1971). Swinging back and forth in pendulum fashion for more than 400 years, the arguments about efficiency and effectiveness of how best to provide services are ongoing. As nursing home (NH) care expanded alongside a growing older population, the home care versus institutional care controversy broadened in scope from basic societal welfare to the aging and disability policy arenas.

Federal and state policy in the 1960s and 1970s leaned heavily toward institutional long-term care as the primary approach to serving older people with disabilities. While incentivized through federal legislation, for many decision-makers the development of a formal NH option was viewed as an improvement over the small care homes that had grown across the state and nation. Driven by a desire to protect older people and to create more health-care-like facilities, the industry expanded dramatically. Accompanying the growth of the NH industry was the development of professional associations that dedicated substantial resources to educating and influencing policymakers, particularly state legislators. This resulted in policy changes at the state level that contributed to a further preference for "indoor" institutional care rather than services provided in the community. By the middle of the 1990s, concerns about the lack of balance between settings in the LTSS system were common, and Ohio, the focus of our study, was ranked as one of the least balanced LTSS states in the nation (forty-seventh) (Burwell, 1999).

In response to the criticism that federal and state policy gave preference to institutional care, beginning in the 1980s, the federal government respond-

ed with a series of policy changes, including the 1981 Medicaid Home- and Community-Based Waiver Program, with Oregon becoming the first state to be granted waivers, and the 1990 Americans with Disability Act and the Olmstead court decision, both setting the stage legally for improved access to long-term services. Despite these efforts, many states were slow to expand home- and community-based services (HCBS), with concerns that such options would merely increase the numbers served, an idea referred to with the pejorative term "the woodwork effect." However, considerable efforts by aging and disability advocates, combined with federal policy changes, made it more difficult for states to resist balancing pressures in the LTSS arena.

Even with the strong political position experienced by the NH industry in Ohio, community-based care advocates, spurred on by the state's participation in the National Long-Term Care Channeling Demonstration, began to make political inroads with efforts to create a more balanced system. In response to the concerns about costs and balancing in the long-term services system, Ohio initiated a study in 1993 to track state long-term system changes. Over the past twenty-six years the study has collected data on in-home services, residential care - including assisted living - and NH care, with a focus on how cost and use patterns have evolved over time. Today Ohio's LTSS system has changed substantially. Ohio has a large HCBS waiver program for individuals age sixty and older called PASSPORT, an assisted living waiver covering all adults, a separate waiver for adults with disabilities under age sixty, and several waivers for individuals with developmental disabilities. Since 2014, Ohio also has participated in a Center for Medicare and Medicaid Services (CMS)-approved integrated care demonstration called MyCare, which has been implemented in the urban counties of the state. This paper describes these LTSS shifts and addresses the new policy issues that have arisen as a result of today's system structure. Reshaping the long-term services delivery system did not happen quickly or easily, but a transformation has occurred, indicating that policy can matter.

## Study Methods

This study is unique in that it uses data from an array of sources to form a detailed picture of long-term services use over an extended period of time. To collect data from long-term care facilities in Ohio, we surveyed all operating NH and residential care facility every other year since 1993. The Biennial Survey of Long-Term Care Facilities has recorded consistently high response rates over the thirteen waves of data collection, ranging between 90 and 96% for NHs and from 85% to 93% for residential care facilities (Applebaum et al., 2019; Mehdizadeh et al., 2007; Mehdizadeh et al., 2011; Mehdizadeh et al., 2013; Mehdizadeh et al., 2017; Nelson et al., 2015). The most recent NH survey achieved a 91% response rate (Applebaum et al., 2019). This survey records facility characteristics, payer mix, admissions, and occupancy rates.

The longitudinal biennial survey data have been combined with a series of other LTSS data sources. The Nursing Home Minimum Data Set (MDS, 3.0), records the characteristics of nursing facility residents and is used to calculate the length of stay for all NH admissions, both long- and short-stay residents. The Ohio Medicaid Cost Report supplements the occupancy rate calculations and Medicaid and Medicare utilization rates. The Ohio PASSPORT Information Management System tracks service use and costs for HCBS participants and includes the full array of waiver services paid for under the program. Finally, the federal Certification and Survey Provider Enhanced Reports data provided additional characteristics about long-term care facilities in the state and is used to examine the Medicare-only facilities that do not complete the survey. Data cover the time period from 1993 through 2017.

## Results

A review of the long-term services system for the past two decades shows an industry in significant transition. Our data indicate dramatic changes in where and how older people with impairments receive LTSS. Major trends identified include considerably higher numbers of admissions reflecting shorter resident stays driven by increasing proportions of Medicare residents, declining overall occupancy rates in NHs, despite a growing older population with severe disabilities, a dramatic expansion of HCBS, and changes in the profile of individuals using NHs.

### *Increasing Numbers of Medicare Residents*

As shown in Table 1, over the twenty-five-year time period of the study, the number of NH beds in service has remained relatively constant, decreasing slightly from 91,500 in 1993 to 90,500 in 2017. Despite stability in the supply of beds in service, the number of short-term admissions has grown substantially. Short-term care surged across the nation motivated by an array of industry and policy changes, including the 1983 Medicare prospective payment system; ongoing cuts to Medicaid reimbursement rates, which made Medicare a more attractive financing source; and continued growth in HCBS options (Morrisey, Sloan, & Valvona, 1988; Tyler et al., 2018).

In Ohio between 1993 and 2017, the number of NH admissions nearly tripled, from 71,000 annual admissions to 206,000. Most of that increase came from individuals entering facilities with Medicare support, with those annual admissions increasing from 30,000 to 147,000. This increase in the proportion of residents admitted for post-acute care occurred across the US, with the average share of residents whose care was reimbursed by Medicare increasing from 9% to 15% between 2000 and 2015 (Fashaw et al., 2019). A shift in the proportion of beds certified for both Medicaid and Medicare also occurred during this time period, reflected in the growth of dually-certified NHs to 97% in 2015 from 33% in 1985 (Fashaw et al., 2019). In Ohio, 41% of NH beds in 1993 were Medicare certified, and by

**Table 1. Ohio Nursing Facility Admissions, Discharges, and Occupancy Rates, 1993-2017**

| | 1993 | 1999 | 2001 | 2005 | 2009 | 2011 | 2013 | 2015 | 2017 |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| Total beds in Service | 91,531 | 95,701 | 94,231 | 91,274 | 93,209 | 94,710 | 92,787 | 91,503 | 90,464 |
| Medicaid certified | 80,211 | 93,077 | 87,634 | 87,090 | 90,876 | 90,724 | 89,063 | 88,479 | 88,016 |
| Medicare certified | 37,389 | 47,534 | 62,088 | 86,701 | 91,928 | 91,650 | 90,730 | 89,555 | 89,307 |
| **Number of Admissions** | | | | | | | | | |
| Total | 70,879 | 149,838 | 149,905 | 190,150 | 197,233 | 207,148 | 218,992 | 211,338 | 206,636 |
| Medicaid resident | 17,968 | 28,150 | 24,442 | 34,432 | 27,040 | 31,212 | 36,859 | 35,182 | 35,647 |
| Medicare resident | 30,359 | 78,856 | 90,693 | 116,810 | 109,315 | 148,426 | 144,959 | 146,756 | 147,194 |
| **Occupancy Rate (percent)** | | | | | | | | | |
| Total | 91.9 | 83.5 | 83.2 | 86.4 | 84.7 | 83.2 | 83.9 | 84.7 | 81.0 |
| Medicaid resident | 67.4 | 55.4 | 58.5 | 58.8 | 55.4 | 54.9 | 54.3 | 54.3 | 53.6 |

2017, almost all (99%) had dual certification. Some of the push for this expansion came from states that wanted to ensure that residents who could be supported by Medicare were receiving this benefit. Facilities themselves also were incentivized to add Medicare as a funder, since states had begun to restrict Medicaid funding growth, and Medicare as an acute care funder and social insurance had been a more generous payer. Finally, since Ohio has been involved in the integrated care MyCare demonstration, those eligible for Medicaid and Medicare must enroll in a managed care health plan. The MyCare health plans are funded through a capitated rate with a financial incentive to reduce the use of institutional care. Limited evaluation data exist on the impacts of this demonstration, but it has resulted in increasing the proportion of Medicare Advantage enrollees in the state to about 40%. The sum of these changes meant that for many residents, NH care was no longer long-term care, but rather a short rehabilitation stay as they transitioned back to the community (Saliba et al., 2018; Xu & Intrator, 2019).

## *Declining Occupancy Rates*

Despite a growing older population, there has been a national decline in NH occupancy, driven by the expansion of in-home services, the development and phenomenal growth of the assisted living industry, and a shift into serving more short-term residents (Applebaum et al., 2019; Castle, 2008; Castle, Liu, & Engberg, 2008; Tyler et al., 2018). The National Investment Center (NIC, 2019) reported that national NH occupancy rates decreased from about 88% in 2012 to 83% in 2019. While this data source is not a census of all US NHs, the pattern of declining occupancy is reflected in the monthly sample of 1,389 NHs in forty-seven states and from historical data. A study using a nationally representative sample of NHs similarly found a decline in the average occupancy rates from about 87% in 1995 to 81% in 2015 (Fashaw et al., 2019). This decline in occupancy rates appears to be the result of a combination of factors. For example, the expansion of the Medicaid HCBS waiver programs has been dramatic, with many states now serving more old people with severe disabilities in the community than in NHs (Eiken et al., 2018). Private payment for home care services and the development of the assisted living industry created a much wider range of options to enable older adults to age in place, even with increasing functional or cognitive declines (Hahn et al., 2011; Kwiatkowski & Gyurmey, 2019; Walters, 2012).

In Ohio, the annual nursing facility occupancy rate declined by 11 percentage points from 91.9% to 81.0% between 1993 and 2017 (see Table 1), despite an increase of more than 150,000 older people age eighty-five and older. As shown in Figure 1, the decline in average daily census was fueled by changes in two areas. Ohio experienced a substantial drop in the number of long-term residents supported by Medicaid, going from an average daily census of more than 54,000 in 1997 to an average daily census of 47,000 in 2017. Access to private options is reflected in a big drop

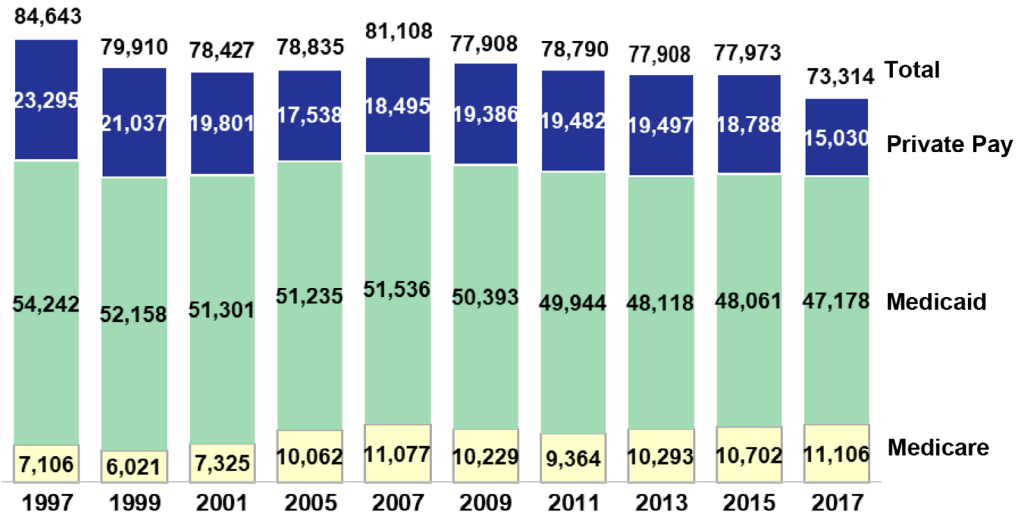


*Figure 1.* Average Daily Nursing Facilities Census, 1997-2017

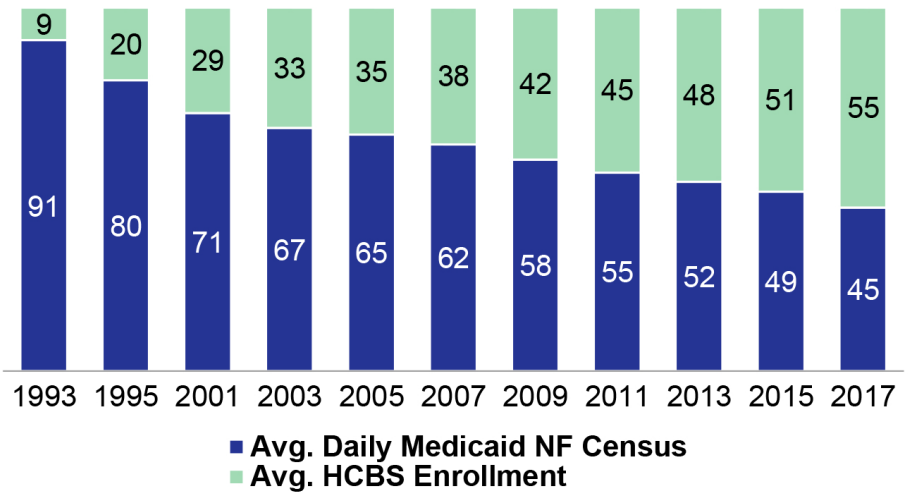


*Figure 2.* Proportion of Ohio's Medicaid HCBS and Nursing Facility Use by People Age 60 and Older, 1993-2017

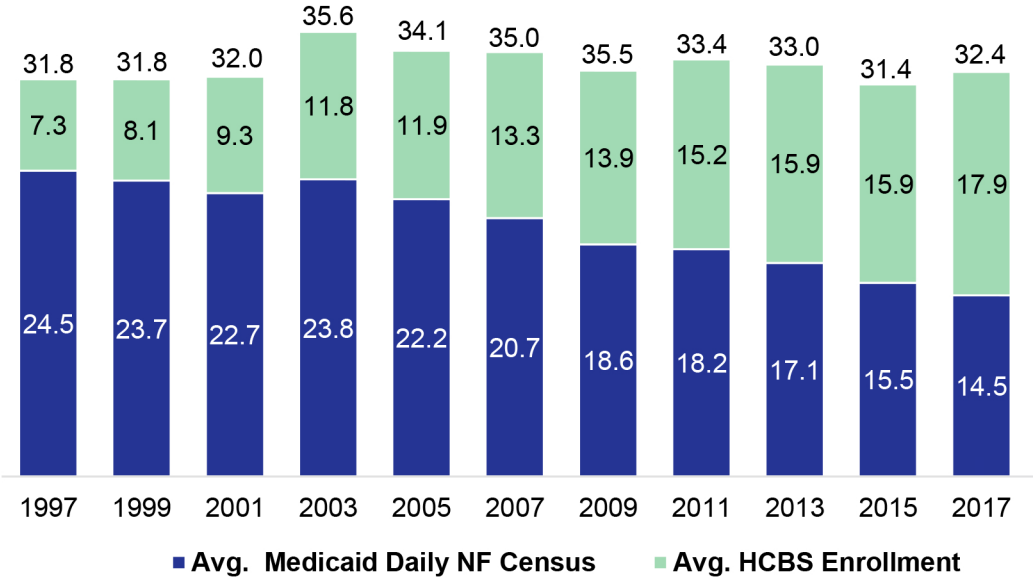


***Figure 3.*** Number of People Age 60 and Older on Medicaid Residing in Nursing Facility or Enrolled in HCBS (including MyCare) per 1,000 Older Persons in Population, 1997-2017

in private-pay residents, declining from 23,000 average daily census in 1997 to about 15,000 in 2017.

## *System Balancing*

The expansion of HCBS combined with reductions in NH use means that Ohio has substantially changed its approach to providing long-term services over the past two decades. Figure 2 illustrates the dramatic shift in LTSS utilization, going from fewer than 10% of older Ohioans on Medicaid using HCBS in 1993 to over half of Medicaid LTSS recipients age sixty and older receiving services in the community in 2017.

A second way to examine system balancing is by tracking Medicaid expenditures. Expenditure data is more readily available for national comparisons, and while NHs are generally more expensive than HCBS, the trends are similar. In 1994, 7.5% of Ohio's Medicaid expenditures for individuals age sixty and over were spent on HCBS. By 2017, the proportion had increased to 37%. Ohio recorded the third highest increase in state HCBS spending (12.7%) between 2012 and 2016 (Eiken et al., 2018).

In the past, a common concern from policy-makers was that an expansion of HCBS would add costs to the LTSS system. Essentially, some argued that expanding HCBS by adding to an already high-cost system was bad policy. Figure 3 shows that, despite an increase in the population eighty-five and over—the group most likely to need LTSS—the proportion of adults age sixty and over relying on Medicaid LTSS has remained stable during an

era of tremendous home care expansion (31.8/1,000 age sixty and older in 1997 to 32.4/1,000 age sixty and older in 2017). This provides clear evidence that the hypothesized "woodwork effect" did not occur (Berish et al., 2019). While findings demonstrate that the Medicaid utilization rate for individuals age sixty and older remained constant over the twenty-year time period, the way Medicaid spent funds changed. The NH utilization rate of 24.5/1,000 older individuals in 1997 dropped to 14.5/1,000 in 2017, while the HCBS rate went from 7.3/1,000 to 17.9/1,000.

### *Profile Changes of the Nursing Home Population*

A review of the profile of NH residents reinforces industry changes. The shift to more short-term care has been coupled with a change in the profile of residents. As shown in Table 2, today's nursing facility residents are less likely to be female (63% vs. 74% in 1995), and more likely to be married (24% vs. 16%). One of the surprising trends has been an increase in facility use by individuals under age sixty-five, increasing in Ohio from 9% in 1996 to 19% in 2018. Nationally, the percentage of NH residents under the age of sixty-five has grown as well, increasing from 10% in 2000 to 16.5% in 2016 (Harris-Kojetin et al., 2019). Several factors contribute to this increase, including psychiatric hospital closures, a short supply of community behavioral health services, increased rates of obesity and associated chronic diseases, and limited housing alternatives for individuals with disabilities (Fashaw et al., 2019; Jervis, 2002; Kaldy, 2012; Mullins, Mushel, & Hermanns, 1994; Persson & Ostwald, 2009; Shapiro, 2010; Smith, 2004). Our review in Ohio also suggests that a sizable portion of the residents under sixty-five may not be in the best place to receive long-term services, with critics suggesting that the community mental health system has not kept pace with this growing population. About half of these younger Medicaid residents have a diagnosis of severe mental illness, a trend that has increased in recent years (Nelson & Bowblis, 2017). Over one-quarter of these individuals (28.0%) had zero or one impairment in activities of daily living, which appears to be below the eligibility threshold for Ohio's level of care qualifications for Medicaid NH care.

## Policy Challenges in a Changing World of Long-Term Services

These data paint a picture of an industry that has changed dramatically over the past two decades. Some of these shifts represent policy ideas that were part of bipartisan legislative and administrative initiatives designed and implemented by Ohio policymakers. Other changes were driven by federal policies, industry strategies, or facility reactions to the market. In sum, the LTSS system is dramatically different from the system of twenty-five years ago. While it is difficult to link specific policy decisions to specific outcomes, what we know is that these factors working in concert resulted in a dramatically changed LTSS system. Despite these impacts, our contention is that state and federal policies

**Table 2 Demographic Characteristics of Ohio's Certified Nursing Facility Residents over Time, 1996, 2006–2018**

| | 1996 (Percentages) | 2006 (Percentages) | 2012 (Percentages) | 2014 (Percentages) | 2016 (Percentages) | 2018 (Percentages) |
|---|---|---|---|---|---|---|
| **Age** | | | | | | |
| 45 and under | 2.6 | 2.7 | 2.3 | 2.1 | 2.1 | 2.1 |
| 46-59 | 3.8 | 9.1 | 10.4 | 10.4 | 9.9 | 9.5 |
| 60-64 | 2.6 | 4.5 | 6.4 | 6.5 | 7.1 | 7.6 |
| 65-69 | 4.4 | 5.9 | 7.9 | 8.3 | 9.6 | 9.7 |
| 70-74 | 8.1 | 8.1 | 9.5 | 9.7 | 9.9 | 11.0 |
| 75-79 | 13.1 | 13.2 | 12.0 | 12.1 | 12.3 | 12.9 |
| 80-84 | 18.7 | 19.2 | 16.4 | 15.3 | 14.5 | 14.4 |
| 85-89 | 21.2 | 19.4 | 18.2 | 17.6 | 16.7 | 15.3 |
| 90+ | 25.5 | 17.9 | 16.9 | 18.0 | 17.9 | 17.5 |
| **Average Age** | 80.7 | 78.4 | 77.3 | 77.5 | 77.2 | 77.0 |
| **Gender** | | | | | | |
| Female | 73.5 | 68.5 | 65.5 | 65.1 | 63.8 | 62.8 |
| **Race** | | | | | | |
| White | 88.3 | 86.3 | 86.0 | 85.5 | 85.3 | 84.5 |
| **Marital Status** | | | | | | |
| Never married | 13.8 | 15.1 | 16.1 | 16.7 | 17.9 | 19.0 |
| Widowed/Divorced/ Separated | 70.7 | 63.7 | 58.7 | 59.9 | 57.9 | 57.3 |
| Married | 15.5 | 21.2 | 25.2 | 23.4 | 24.2 | 23.7 |
| **Population** | 80,417♦ | 92,297♦ | 107,737* | 101,279* | 100,881* | 97,305* |

have not adapted to today's changed system or the challenges ahead. In fact, recent efforts to roll back federal regulations in the NH sector appear to be in direct conflict with the increasing levels of disability experienced by today's NH residents. On the financing side, while there has been a dramatic shift in how Medicaid funds are used, the reliance on Medicaid as the major long-term financing approach fails to reflect the fact that the majority of elders are not eligible for the Medicaid program. This structural lag in financing and regulatory behaviors create a problem as we look to develop a LTSS system that will work for the large wave of boomers coming down the road. Based on the changes experienced over the past two decades, we have identified a series of policy challenges that need to be addressed to ensure a high-quality long-term services system in the future.

## Implications for a New Long-Term Services System

### *Pre-Admission Screening*

As noted, one of the biggest policy challenges is that some traditional long-term services, such as the NH, are not long-stays for many residents. The dramatic increase in short-term NH stays has major implications for program policies and procedures. For example, in 1993, Ohio implemented an extensive pre-admission screening and resident review requirement for individuals being admitted to Ohio's skilled nursing facilities. At that time there was a concern that individuals were entering NHs inappropriately, because of limited HCBS options and limited information to consumers about possible HCBS alternatives. In 1993, when pre-admission screening was initially implemented, about 60% of those admitted continued to reside in the facility after three months, compared to 16% two decades later. Ohio continues to spend considerable resources conducting pre-admission reviews for individuals who will stay only a short period of time.

The challenge is that while the current approach needs modification, there are still individuals admitted to skilled nursing facilities who would benefit from a pre-admission screen. Sometimes these individuals enter as short-term rehabilitation admissions but become long-stayers; efforts to identify these individuals are critical. An improved method for identifying mental health needs of those being admitted is also important in today's system. Individuals with behavioral health conditions might enter facilities under appropriate circumstances, but there is no required post-admission review. A delayed assessment might be considerably more practical than a pre-admission review for admissions.

### *Quality and Regulation*

A second challenge involves the quality and regulatory models in place. For example, our state and national regulatory efforts for NHs remain anchored in the annual survey, which has become predictable for providers. Despite a number of federal initiatives, such as the creation of a Special Focus Facilities

program for low-quality NHs, the provision of public consumer information and quality measures through Nursing Home Compare, and the modification of the survey process to involve quality processes, poor quality facilities remain. In fact, recent trends indicate a shift in federal policies designed to reduce regulatory requirements and to limit resident litigation rights. With a resident population experiencing higher acuity rates and a higher proportion of long-stay residents experiencing dementia, improving regulatory approaches continues to challenge the system.

The expanded HCBS system means that improvements in quality approaches are needed also in this sector of the LTSS industry. HCBS and even assisted living are often limited in regulatory scope. For example, Ohio does not license HCBS providers, although most have an affiliation with a payer such as Medicaid or Medicare that does require specific structures and processes. Assisted living is largely private-pay, with individual states setting their own requirements for licensing. Despite a dramatic expansion of HCBS, quality approaches and measures are not systematically implemented across the nation. A recent, but unsuccessful effort by the National Quality Forum to develop uniform HCBS quality measures highlighted a continued lack of consensus in this area. While we celebrate the expansion of options for individuals to live in their setting of choice, improvements in HCBS quality strategies remain a priority for states and the federal government.

### *Reimbursement*

Another question involves the reimbursement approach. Medicaid has long been viewed as the long-term public funding mechanism for NHs, while Medicare was the short-term rehabilitation funder of services. One surprising finding from our work is that many Medicaid admissions are also for short stays, with 72% of these individuals discharged within three months. Should there be a differing reimbursement rate for short- and long-term individuals using Medicaid? Many states attempt to control Medicaid expenditures by either cutting reimbursement rates, or moving to managed Medicaid LTSS, leaving facilities unclear about state priorities for services. A review of financing and regulatory policies is necessary.

### *Workforce Challenges*

Long-term services, regardless of setting, will remain a labor-intensive and personal set of services. Our most recent survey of NHs found an annual average retention rate of 60% of state-trained nursing assistants. In some facilities, those rates were below 20%. Ohio's in-home care providers also report workforce challenges. The LTSS worker shortage is one of the most critical challenges now facing long-term service providers. Wages and benefits, staffing patterns, organizational structure, market conditions, and a host of other factors have been shown to impact workforce quality and rates of turnover. For example, a recent study reported higher nursing assistant retention was a significant predictor of fewer

NH deficiency citations (Castle et al., 2020). Our data show that even in similar labor markets, variation in retention rates is significant, suggesting that technical assistance and administrative and policy changes can have a considerable impact in this area. As a result, researchers continue to investigate the effects of managerial practices, including empowerment and consistent assignment, organizational culture, financial benefits, and the working environment on NH workforce stability.

### *Impacts of the Under Sixty-Five Age Group of Nursing Home Residents*

Nearly one in four Ohio NH residents are under the age of sixty. About 45% of this group stay three months or less, suggesting that Medicaid has become a short-term rehabilitation funding source for many younger participants. However, three in ten of the under-sixty age group are NH residents for one year or more. This age group generally has lower overall rates of disability, which raises questions about the appropriateness of the NH setting for these individuals. As Ohio has expanded HCBS options, considerable efforts have been made to ensure individuals of all ages reside in the most appropriate setting. A recent evaluation of the Money Follows the Person program found that Ohio had the largest number of transitions from NHs to the community in the nation in 2015 and 43% of those leaving the facilities were individuals with mental illness (Irvin et al., 2017). A comprehensive study of the factors contributing to younger residents' longer stays in NHs is warranted.

### *Shifting from the Medicaid Paradigm*

More than half of all older people in Ohio with severe disabilities use long-term services funded through the Medicaid program. If the disability rate remains constant between now and 2040, the economic pressures to the state could overshadow other areas of need. Today, 90% of older people living in the community do not use Medicaid, but two-thirds of NH residents rely on the program. Moderate- and middle-income elders typically do not turn to Medicaid until they require NH care or their disability becomes so severe that they need substantial assistance at home or in assisted living. A proactive question to consider is how to reduce the proportion of older people that will need Medicaid assistance.

Several recent studies have identified the importance of supportive services, such as home-delivered meals, homemaker assistance, and transportation for groceries and medical appointments on the use of NHs by individuals with low-care needs (Thomas & Mor, 2013). As an example, the AARP Long-Term Services and Supports Score Card reported that 11.2% of Ohio's NH residents are considered low care, giving Ohio a ranking of 25th. With services and support, those low-care residents can often reside in the community. The best state in the nation had a rate of 4.1% (Reinhard et al., 2017). Today supportive services available through

the federal Older Americans Act are inadequate. Therefore, it will be critical to provide resources to target supportive and preventive services to those with moderate levels of disability and moderate-income levels to prevent premature reliance on Medicaid.

## Conclusion

This paper has documented the tremendous changes that have occurred in the long-term services and support system, using Ohio as an example of a state that has made dramatic changes based on dedicated policy efforts. The shifts that have occurred in Ohio were unexpected and in fact were deemed politically unimaginable two decades ago. The changes have been dramatic and are the result of an array of public and private decisions. Despite this progress, the challenges of tomorrow are more daunting than the hurdles we have already faced. As the population of older people with disabilities continues to increase, it will be critical to adapt our approach to delivering, financing, regulating, and staffing our system of long-term services and supports. Future policy decisions will indeed matter.

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# Life in a world for all ages: From a utopic idea to reality

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Abstract

Ageism is defined as stereotypes, prejudice, and discrimination toward people because of their age. Although ageism can be directed toward both young and old and can be both positive and negative, this paper reviews the negative manifestations and consequences of ageism toward older adults in policy, politics, the urban environment, the healthcare system, and the individual-intra-psychic level. Obstacles to and opportunities for reducing and potentially eliminating ageism are discussed. This review is intended to instigate interest and motivation in researchers, policy stakeholders, and the general public to change the way we think, feel, and act in order to live in a world for all ages, in which old age is no longer seen as a burden or a barrier.

***Keywords:*** ageism, age discrimination, age stereotypes, age segregation

# La vida en un mundo para todas las edades: de una idea utópica a la realidad

Resumen

La discriminación por edad se define como estereotipos, prejuicios y discriminación hacia las personas debido a su edad. Aunque el envejecimiento está dirigido tanto a jóvenes como a viejos y puede ser tanto positivo como negativo, este artículo revisa las manifestaciones negativas y las consecuencias del envejecimiento hacia los adultos mayores en política, política, entorno urbano, sistema de salud y el individuo-intra- nivel psíquico Se discuten los obstácu-

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los y las oportunidades para reducir y potencialmente eliminar la discriminación por edad. El objetivo de esta revisión es estimular el interés y la motivación de los investigadores, los interesados en las políticas y el público en general para cambiar la forma en que pensamos, sentimos y actuamos para vivir en un mundo para todas las edades, en el que la vejez ya no se considera una carga o una barrera.

***Palabras clave:*** *ageism*, discriminación por edad, estereotipos de edad, segregación por edad

# 在一个善待所有年龄的世界中生活：从一个乌托邦观念到现实

## 摘要

年龄主义被定义为因年龄而对人产生的刻板印象、偏见和歧视。尽管年龄主义能指向年青人和老年人，也可以是积极或消极的，但本文审视了在政策、政治、城市环境、医疗体系、以及个人内心层面年龄主义对中老年人造成的负面表现和结果。探讨了减少或潜在消除年龄主义遭遇的困难与挑战。这篇评论旨在引起研究者、政策利益攸关方和一般大众的兴趣和动机，以改变我们思考、感受和行动的方式，以期生活在一个面向一切年龄、年老不会被视为一种负担或阻碍的世界中。

关键词：年龄主义，年龄歧视，年龄刻板印象，年龄隔离

Ageism is defined as stereotypes, prejudice, and discrimination toward people because of their age. Ageism can be both positive and negative (Ayalon & Tesch-Römer, 2018a; Officer & de la Fuente-Núñez, 2018). According to the Stereotype Content Model, people often are classified along the dimensions of warmth and competence (Fiske, Cuddy, Glick, & Xu, 2002). As such, older adults tend to be seen as high on warmth, e.g., presenting with good intentions, but low on competence, and thus, as having limited abilities to actually materialize their intentions (Cuddy, Norton, & Fiske, 2005). This classification suggests that our perceptions of older adults include both positive and negative aspects. This in return, may generate positive

or negative behaviors and emotions. For instance, one can give one's seat to a woman, whom one sees as old and fragile, simply because the woman has white hair and white hair is associated with frailty, which inspires compassion. A negative example of ageism might be laying a person off work because this person is already sixty-five and is seen as unable to learn new skills due to age.

This paper is focused on ageism toward older adults with a primary focus on the negative consequences of ageism, which can be manifested at the macro-institutional level in policies or politics, at the meso level of interpersonal relations, or at the micro, intrapersonal level (Ayalon & Tesch-Römer, 2018a). In this paper, I rely on several contexts to demonstrate how ageism is manifested in policy and politics, the healthcare system, the workforce, interpersonal relations, and our own ageist attitudes, sentiments, and behaviors toward our aging selves. Capitalizing on existing theories in the field of ageism, I then outline various attempts to explain the occurrence of ageism. I conclude with suggestions to tackle ageism both at the individual and societal levels, focusing on bottom-up processes, such as increasing awareness or knowledge, and top-down processes, which legally ban age discrimination. Challenges faced by policy stakeholders and researchers who wish to reduce or prevent ageism are discussed, as are ways of overcoming these challenges. This comprehensive review aims to provide researchers, policy stakeholders, and the general public with important information not only about the nature of ageism, but also about future steps that should be taken in order to live in a world for all ages.

## The Prevalence, Manifestation, and Consequences of Ageism

According to the European Social Survey (a large cross-national survey of twenty-nine countries and almost 60,000 people), ageism is the most prevalent "ism" in society —more prevalent than the other two major isms, namely sexism and racism. Whereas only 17 percent of the sample reported exposure to racism and 25 percent reported exposure to sexism, a little over 34 percent reported exposure to ageism (Ayalon, 2013). A similar pattern was also found in the Health and Retirement Survey, a large representative study of American citizens over the age of fifty (Ayalon & Gum, 2011). Moreover, in the World Value Survey, which gathered data from fifty-seven countries and almost 80,000 people, 60 percent of the interviewees stated that older adults are not respected in society (Officer et al., 2016). Ageism affects all of us, as we all move along the age continuum if we live long enough. This is contrasted with sexism and racism, which are more likely to affect women and ethnic minority groups, respectively (Radke, Hornsey, & Barlow, 2016; St Jean & Feagin, 2015).

When considering the manifestations, consequences, and etiology of ageism, it is important to recognize intersectionality (Krekula, Nikander, & Wilińska, 2018). It is usually not age alone, but age in interaction with other characteristics, such as gender, ethnici-

ty, or socioeconomic status, that makes a difference. Specifically, research shows that aging affects men and women differently (McGann et al., 2016). Women are more likely to experience ageism due to physical changes in their appearance that are associated with loss of attractiveness (Clarke, 2018). Men, on the other hand, are thought to maintain their power and influence in old age. Yet, they too hold negative age stereotypes about their own aging process (Clarke & Korotchenko, 2016). Moreover, the hegemonic masculinity model further suggests that older men are likely to be lower in the hierarchy compared to young, fit men (Spector-Mersel, 2006).

Another intersection concerns the distinction between ableism and ageism, which is not always clear. As older adults are expected to age successfully without showing any signs of decline or impairment (Gibbons, 2016), negative attitudes directed toward older adults may reflect ableism rather than ageism (Overall, 2006). Age and socioeconomic status also intersect; thus, wealthy older adults not only enjoy better health and wellbeing, but are also less likely to be exposed to ageism (Cohen, 2001).

## Ageism in Policies and Politics

At the macro, institutional level, ageism is manifested in the language we use to talk about older adults (Gendron, Inker, & Welleford, 2017). For instance, discussing the "silver tsunami" in an attempt to raise awareness of the importance of aging policies may fail to make its intended effect as this term negatively portrays older adults (Perry, 2009). Similarly, the term "dependency ratio," which is used to reflect the percentage of older adults, immediately associates old age with dependency and disability (Thornton, 2002). Other terms, such as premature death, which defines death prior to the age of seventy as premature, also result in ageist perceptions, which portray the death of older adults as expected and unrelated to their health or medical condition. This may impact the allocation of health resources and the denial of necessary resources from older adults (Lloyd-Sherlock, Ebrahim, McKee, & Prince, 2016).

The United Nations (UN) human rights conventions specifically prohibit discrimination on multiple grounds; yet, age is not among the various categories mentioned. To date, there is no UN treaty specifically dedicated to the rights of older adults (Doron, Numhauser-Henning, Spanier, Georgantzi, & Mantovani, 2018). Explicitly addressing ageism in a UN treaty is important, as this would send a clear message of disapproval and allow for the development of tools to ban age discrimination.

Politically, we see ageism in the framing of major political issues. In the case of climate change discourse, age and generation serve as sources of power differential (Sachs, 2014). Children are often thought to be those most affected by climate change. This is because of their increased vulnerability to injury, disease, and extreme weather conditions (Alderson, 2016) and be-

cause they are expected to suffer the effects of climate change for a substantially longer period of time, with these effects becoming more severe over time (Gibbons, 2014). However, research has shown that it is older adults who have been most affected by climate change because they are more vulnerable to the impact of extreme heat waves, severe weather disruptions, and polluted air (Yu et al., 2011).

Currently, a sixteen-year-old girl from Sweden has become a symbol of the fight against global warming (Stott, et al.,2019). This teenager is attempting to persuade us of the real effects of climate change, explicitly blaming adults for stealing her future, while the president of the United States, a seventy-three-year-old man, denies the effects of global warming (De Pryck & Gemenne, 2017). The movement inspired by her actions, Fridays for Future (FFF), calls children all over the world to protest in an attempt to persuade adults who she thinks have neglected their duty to mitigate the negative effects of climate change: "Since our leaders are behaving like children, we will have to take the responsibility they should have taken long ago" (Thunberg, 2018). "You are not mature enough to tell it like it is. Even that burden you leave to us, children" (Thunberg, 2018). Other activists, such as Bill Nye, an American science communicator, explicitly states that climate science will advance only when older adults finally "age out" and die (Mayfield, 2019).

Brexit is yet another example of intergenerational tension, presented in terms of young versus old. Post-analysis of the votes shows that older, less educated Brits were more likely to favor Brexit. In contrast, young and educated Brits favored the United Kingdom (UK) remaining in the European Union (EU). Older adults were more likely to vote in the Brexit referendum; thus, they had a greater impact on the results (Dorling, Stuart, & Stubbs, 2016). After the vote, older adults were portrayed as having made a life-changing decision for future generations, some of which were not even allowed to vote and express their opinion on a matter that was going to affect the rest of their lives (Future, Pottinger, & Hall, 2017). An analysis of the UK media suggests that Brexit was portrayed as an intergenerational clash between Baby Boomers and Millennials. According to this analysis, the Baby Boomer generation was constructed as a social problem (Bristow, 2020). The meme "OK Boomer," which originated in the United States, reflects a similar sentiment towards the Baby Boomer generation as being irrelevant to current affairs.

An explicit message of the intergenerational divide can be found in a recent video produced by "Die Partei," also known as "The Party," a German political party that started as a satire but now has two seats in the European parliament. In this video, an older man is shown lying in a hospital bad, connected to a vent machine. With this man lying in the background, the following message is conveyed: "This old white man is already considered dead, but still retains the right to vote. Like five million other German last-time voters,

he is determining a future in which he will have no part." Following a few electrical shocks, the old man finally votes for Merkel. The video concludes with the following message: "Therefore we are demanding a maximum voting age. Just as people don't vote during the first eighteen years of their life, they should not vote in the last eighteen years of their life, either." This political party explicitly states that people's right to vote should be taken away because of their advanced age.

In contrast, in Israel, which has a substantially lower proportion of older adults in the population (~12 percent in Israel, compared with ~22 percent in Germany or ~18 percent in the United Kingdom), the portrayal of older adults has been that of a vulnerable population (Lowenstein, Eisikovits, Band-Winterstein, & Enosh, 2009) that requires legal and social protection. When older adults are discussed within the political arena, they are portrayed as a disadvantaged and disenfranchised social group whose rights should be protected. This has led the Israeli party, Gil—"age" in Hebrew—to obtain an unprecedented number of seats in the 2006 election. The party gathered forces from large retiree organizations in the country to protect the rights of older adults. However, a large number of votes also came from young people, who were fed up with the political system in Israel, which has compromised the welfare of disempowered populations, including that of older adults. Possibly, the achievement of this political party can be attributed to high levels of intergenerational solidarity in Israeli society (Lowenstein, Katz, & Daatland, 2004), as many young people who voted for this party stated that they voted to maintain the rights of their parents or grandparents. This can also be attributed to a general sentiment of respect and compassion toward older Holocaust survivors (who represented a substantial portion of older Israelis at that time), as the importance of the Holocaust in shaping intergenerational relations cannot be underestimated (Chaitin, 2002; Halik, Rosenthal, & Pattison, 1990).

Both European examples and the Israeli example reflect ageism, as they automatically associate certain qualities with people simply due to age. The European examples portray older adults as powerful and self-centered, whereas the Israeli example portrays older adults as disempowered and vulnerable. Both portrayals are quite negative, but they result in different reactions. We tend to react with aggression or anger toward the powerful and egocentric, but with empathy and compassion toward the weak (Cuddy & Fiske, 2002).

## *Ageism and the built environment*

At the meso, interpersonal level, ageism is manifested, among other things, in the built environment. In the built environment, older and younger adults rarely interact. This is thought to be both a sign of ageism and a means to perpetuate the separation between generations (Hagestad & Uhlenberg, 2005). A research study shows that when young people attend urban open spaces, they usually end up being "on the go," moving from one place to another (Noon & Ayalon, 2017). Older adults, in con-

trast, usually come to these open spaces to stay. Nonetheless, only a few of them engage in interpersonal social interactions (Noon & Ayalon, 2017). The one instance in which older and younger adults were documented together in the built environment was when younger adults served as carers of older adults. This possibly results in high levels of loneliness, isolation, and social exclusion of older adults (Noon & Ayalon, 2017). In support of this claim, a different study shows that neighborhoods characterized by higher levels of ageism among young people resulted in the lower social integration of older adults (Vitman, Iecovich, & Alfasi, 2013).

Others argue that neighborhoods socially exclude older adults through gentrification processes that leave older adults behind as the sole reminders of previous generations. Obstacles in the physical environment further impair older adults' opportunity to participate socially (Dahlberg 2019). Approaching older adults as a vulnerable population intensifies their sense of insecurity and lack of safety in the environment (Pain, 1997). Consistently, a qualitative study conducted in the United States shows that fears of being socially rejected or exploited and threats to one's identity inhibit older adults' social participation Goll et al., 2015).

The design of housing for older adults may also have ageist features. Analysis conducted in Australia suggested that the physical space of older adults is designed either with the image of older adults as ageless or with the view of older adults as dependent, allowing for limited variability along these poles. Others have noted an active attempt to separate older adults from younger people in the built environment by designing separate housing for older adults (Petersen & Warburton, 2012). Indeed, research has shown that ageism is prevalent in long-term care settings for older adults and that the structure of the setting, which separates younger adults from older adults and older adults with sickness and disability from independent older adults, instigate stigma (Ayalon, 2015; Dobbs et al., 2008).

### *Ageism in the Healthcare System*

One of the most prominent areas in which ageism occurs is the healthcare sector (Wyman, Shiovitz-Ezra, & Bengel, 2018). Ageism in healthcare is manifested at the macro institutional level, the meso interpersonal level, and the micro level (Ayalon & Tesch-Römer, 2018b). The last year of life is usually the most expensive in terms of healthcare costs (Hogan, Lunney, Gabel, & Lynn, 2001). As people age, they are more likely to eventually die. This is why older adults consume more healthcare services than younger people. Although these facts are not ageist per se, their interpretation often is ageist. This is because older adults are seen as using services disproportionally, leading some to question whether older adults have a duty to die, simply to save money and decrease healthcare costs (Denier, Gastmans, Vandevelde, & Hardwig, 2013). This belief is prevalent in the healthcare sector.

At the macro policy level, the National Institute for Health and Clinical Excellence (NICE) uses Quality Adjusted Life Years (QUALYs) to determine the benefits of different healthcare services. Using QUALYs, a healthy year of life expectancy is worth more than an unhealthy year of life expectancy. This may result in those who have a shorter life expectancy or unhealthy life expectancy receiving a lower priority in the healthcare system (Harris & Regmi, 2012). Consistently, the services provided to older Americans with disabilities are deemed less expensive than those provided to younger people with disabilities. Moreover, older adults with disabilities often receive services that are rejected as undesirable by younger adults with disabilities (Kane, Priester, & Neumann, 2007).

Older adults also are less likely to be included in clinical trials even for conditions that are more common in old age, such as diabetes type 2, heart conditions, or dementia (Cruz-Jentoft, Carpena-Ruiz, Montero-Errasquín, Sánchez-Castellano, & Sánchez-García, 2013; Herrera et al., 2010). This is because older adults often suffer from multiple medical conditions and take a large number of medications (Clague, Mercer, McLean, Reynish, & Guthrie, 2017). As such, there is a preference to recruit into clinical trials less complicated participants for whom the effects of new medication can be determined easily (Herrera et al. 2010). However, this may result in treatment being inappropriately tested on non-representative populations (Cherubini, Signore, Ouslander, Semla, & Michel, 2010).

At the meso level, research consistently shows that physicians and other healthcare and social care professionals tend to treat young and older adults differently, even when a differential treatment is not warranted (Gewirtz-Meydan & Ayalon, 2017; Yechezkel & Ayalon, 2013). In a study conducted in Israel, physicians were randomly shown one of two possible vignettes. The only difference between the vignettes was the age of the patient. In both vignettes, the patient had sexual problems, which were largely attributed to psychosocial origins, as the patient was able to function sexually with one partner, but not with the other. Yet, the older patient was more likely to be seen as suffering from erectile dysfunction, while the younger patient was seen as suffering from psychosocial issues. Consistently, the older patient was more likely to be prescribed Viagra, whereas the younger patient was more likely to be referred to a sexual counselor (Gewirtz-Meydan & Ayalon, 2017).

In a different study, social workers were randomly presented with one of two case vignettes that differed based on age. Both vignettes described a woman who was being abused by her husband. Compared with the older woman, social workers were more likely to view the younger woman as experiencing abuse. They also were more likely to offer social care to the younger woman and referral to law enforcement for the older woman. Even though the older woman was less likely to be viewed as experiencing abuse, social workers were more likely to refer the woman to a law enforcement agency, assuming the case required a le-

gal intervention (Yechezkel & Ayalon, 2013). Using a similar methodology, a study conducted in France found that physicians and medical students are more likely to use elder speak, which is characterized by short sentences and the use of simple vocabulary, when speaking with older adults compared to when they spoke with younger adults (Schroyen et al., 2018).

Not only is the treatment of younger and older adults in society different simply due to age, but ageism also results in the reduced interest of healthcare and social care professionals to work with older adults (Ball, 2018; King, Roberts, & Bowers, 2013). This could potentially account for the shortage of geriatricians (Lester, Dharmarajan, & Weinstein, 2019) or direct care workers (Hussein & Manthorpe, 2005) who wish to work with older adults. A recent systematic review of the impact of ageism on the health of older adults has concluded that ageism has led to significantly worse health outcomes in the vast majority of the studies reviewed. Ageism was found in forty-five countries across eleven domains of health over a period of twenty-five years (Chang et al., 2020). The impact of ageism in the healthcare system also can be quantified financially. The one-year cost of age discrimination toward older adults, negative age stereotypes, and negative self-perceptions of aging is as high as $63 billion USD (Levy, Slade, Chang, Kannoth, & Wang, 2018).

## *Ageism in the Workforce*

A different setting in which ageism is prevalent is the workforce (Naegele, De Tavernier, & Hess, 2018; Solem, 2016; Stypińska & Nikander, 2018). Like the healthcare system, ageism in the workforce can manifest at all three levels (e.g., macro, meso, and micro) (Ayalon & Tesch-Römer, 2018b). An indication of explicit institutional ageism can be seen in the fact that in many countries, older adults are forced to retire, simply because they have reached a certain age (Santos, Justin, Joshi, & Jacob, 2019). Thus, older adults are expected to give their education, skills, and training for free, as volunteers, simply because they have reached a certain age.

Given demographic changes, many countries are now actively attempting to extend working life by delaying or completely abolishing a fixed retirement age (Barslund, 2015; Flynn, Schröder, Higo, & Yamada, 2014). Nonetheless, there is a gap between policies and practice (Loretto et al., 2013). One potential reason for this could be the exposure of older employees to ageism. Research conducted among 3,122 Danish employees fifty years and older shows that perceived ageism is associated with male workers' retirement plans (Thorsen et al., 2012). In contrast, a longitudinal study shows that perceived ageism in the workforce has an impact on job satisfaction and withdrawal, but not on actual retirement (Griffin, Bayl-Smith, & Hesketh, 2016).

A recent scoping review categorizes the literature on ageism in the workplace into thematic categories (Harris, Krygsman, Waschenko, & Laliberte Rudman, 2018). One thematic category consists of stereotypes concerning older workers. In total, twen-

ty-six of the studies reviewed addressed this thematic category. The majority of the studies explored negative perceptions of older workers as less competent, less willing to participate in training, and less technologically apt. Other stereotypes were quite positive, however, including the view of older workers as more committed and reliable (Harris et al., 2018).

Another thematic category addressed ageism in relation to behavioral intentions and actual behaviors (Harris et al., 2018). Ageism is highly prevalent in hiring intentions and practices, with research showing over and over again that employers have a preference toward younger workers. Even when younger and older workers present with similar skills, employers are more likely to prefer younger workers (Dörfler, 2018; Fasbender & Wang, 2017). Consistently, research has shown that people as young as forty or fifty years old already have a harder time finding a job (Solem, 2016). Moreover, older adults are less likely to be offered a promotion or extra training. Older adults also are the first to be laid off due to their age (Cheung, Kam, & Man-hung Ngan, 2011). In addition, compared with younger workers, older workers are more likely to be judged harshly for poor performance (Rupp, Vodanovich, & Crede, 2006).

## *Self-Ageism*

At the micro, intrapersonal level (Ayalon & Tesch-Römer, 2017), ageism plays a role in the life of each and every one of us, as we all internalize age stereotypes throughout our life (Levy, 2009). We might look in the mirror and become alarmed, viewing ourselves as grey and wrinkled and therefore old and "ugly." Similarly, older adults might interpret their physical ailments as signs of aging and thus refrain from seeking help. The way we think, feel, and act toward age and aging makes a difference in our lives, as it may imprison us in our own minds by predetermining what we can and cannot do simply based on our chronological age (Ayalon & Tesch-Römer, 2018a; Levy, 2001). As such, much of the literature on self-perceptions of aging is concerned with how people view their own aging process and as a result, how these views affect their health behaviors, wellbeing, health, and even mortality (Levy & Myers, 2004; Levy, Slade, & Kasl, 2002; Levy, Slade, Kunkel, & Kasl, 2002).

Stereotypes associated with our own aging become more prominent as we age. Older adults who hold more positive self-perceptions of aging are more likely to engage in preventive health behaviors compared to those who hold negative self-perceptions of aging (Levy & Myers, 2004). Self-perceptions of aging become a self-fulfilling prophecy. This is why when physical losses occur, those individuals who hold negative self-perceptions of aging are less likely to engage in health-related strategies to maintain a healthy lifestyle (Wurm, Warner, Ziegelmann, Wolff, & Schüz, 2013). Negative self-perceptions of aging are associated with worse functional health (Levy, Slade, & Kasl, 2002), an increased risk for falls (Ayalon, 2016b), a decline in walking speed (Robertson, Savva, King-Kallimanis, & Ken-

ny, 2015), and lower levels of quality of life (Ingrand, Paccalin, Liuu, Gil, & Ingrand, 2018). Moreover, individuals who hold negative age stereotypes die 7.5 years before those who hold positive age stereotypes (Levy, Slade, Kunkel, et al., 2002).

## Why is Ageism so Prevalent in Society?

Several theories have attempted to explain the occurrence of ageism at the institutional macro level, the relational meso level, and the individual micro level (Ayalon and Tesch-Römer 2018a). These various theories clearly attest to the multi-faceted nature of ageism and to the fact that its effects are widespread. The fact that each theory may be relevant to certain life periods or certain contexts, but not to others, suggests that ageism is not a uniform construct, but is rather highly contextual (Kornadt, Hess, & Rothermund, 2020).

A well-known theory at the macro level is modernization theory, which states that in today's modern society, the status of older adults has declined (Cowgill & Holmes, 1972). This is because as technology advances, older adults' knowledge and skills become less relevant. Moreover, with increasing urbanization and the transition of young people into the cities, older adults' status and support decline. This theory closely corresponds with an Italian social movement that flourished in the early twentieth century: "Futurism." Mesmerized by modernity and the machine, members of this movement invited the public to toss away old values and traditions, stating that modernity, velocity, and youth represent the bright future and that anything old is obsolete.

At the meso level, our entire social lives are organized by chronological age (Hagestad & Uhlenberg, 2005). When we are young, we are expected to study and develop academically with people who are of our own age. In middle age, we are expected to raise a family and work. Finally, in old age, we are expected to retire. Throughout our entire life, we associate with people who are of similar chronological age. This results in the construction of an in-group vs. an out-group, with older adults being seen as an "out-group" by other age groups in society. Limited interaction among generations induces ageist attitudes and the view of us versus them, which prevents the development of empathy and friendship between generations (Vanderbeck, 2007).

A complex explanation at the micro level relies on the integration of several theoretical explanations to account for the occurrence of ageism across the life course (Lev, Wurm, & Ayalon, 2018). This model suggests that different theories, e.g., stereotype embodiment theory (Levy, 2009), terror management theory (Martens, Goldenberg, & Greenberg, 2005) and social identity theory (Tajfel, 1974), play a differential role across the life course. The stereotype embodiment theory suggests that ageism first develops at a very young age, but influences our own perceptions of our aging process throughout our lives (Levy, 2009). While negative stereotypes of old age are internalized (Levy, 2009), people may hold these

negative stereotypes not only toward other older adults, who are seen as "aged," but also towards their own aging selves (Bodner, 2009). As old age is associated with death and disability, younger and middle-aged adults who are concerned with their own mortality, become anxious around older adults, as seeing older adults makes them realize that their own time in this world is limited (e.g., terror management theory) (Martens et al., 2005). Social identity theory suggests that in old age, to maintain their self-image as belonging to a worthy group, older adults may attempt to disassociate from other older adults as they have learned to devalue old age (Bodner, 2009). Hence, attempts to conceal or delay aging are often made to disassociate from the devalued group of older adults (Lev et al., 2018). These strategies of successful or active aging might be helpful in the short run, but not in the long run, as older adults are expected to eventually come to terms with the gains and losses associated with aging (Lev et al., 2018).

## Why is it so Challenging to Fight Ageism?

Relative to the other two big "isms" (sexism and racism), ageism has received substantially less research attention. A recent query resulted in 8,491 studies on racism and 2,836 studies on sexism, but only 750 studies on ageism )North & Fiske, 2012). Moreover, compared to the other two big "isms" (e.g., racism and sexism), ageism is regarded more leniently. Nelson (2011) argues that the reason that people explicitly express ageist attitudes is we believe that these ageist attitudes reflect true facts. Birthday cards, for instance, portray terms such as "over the hill," or "sorry to hear you are getting older." These terms would never be used with regard to other categories, such as sex or ethnicity. Consistently, commercial companies actively attempt to advertise anti-aging products, explicitly stating that aging is something to avoid and conceal (Nelson, 2011). The overall societal acceptance of ageist attitudes and behaviors makes efforts to address ageism more challenging.

A major barrier to address ageism concerns the fact that the term ageism is not much acknowledged in society at large. Although the term ageism was coined 51 years ago (Butler, 1969), many countries still do not have a common term for ageism in their national language. Moreover, even if there is a term in a certain language, it might be used only by experts or by those who have a vested interest in the topic (e.g., the term for ageism in Hebrew or Spanish). This makes any attempt to address ageism at the global level, beyond English-speaking countries, quite challenging. If laypeople do not even have the term ageism in their lexicon, the concept is not well grounded and its understanding is impaired. Past research shows that knowledge of ageism is one of the most important components in combating ageism (Burnes et al., 2019). However, such knowledge cannot be gained in the absence of language to describe the phenomenon.

Another major obstacle concerns the assessment of ageism at the

micro and/or meso levels. A recent systematic review reveals that out of eleven possible scales that meet the rigorous criteria put forth by the reviewers, only one scale met minimum psychometric qualities. However, that scale was limited as it evaluated only explicit stereotypes toward older adults (Ayalon et al., 2019). This is problematic because ageism is multi-dimensional: it consists of stereotypes, prejudice, and discrimination. If available scales address only stereotypes and neglect the other two domains, our understanding of ageism is impaired (Ayalon et al., 2019). Moreover, the explicit nature of the measure makes it quite easy for well-educated people who are aware of the fact that ageism is an undesired quality to respond desirably and deny their ageist attitudes so that they present as less ageist than they actually are (Cherry, Allen, Denver, & Holland, 2015). A more appropriate measure of ageism should cover all three dimensions: stereotypes, prejudice, and discrimination and consist of both explicit and implicit measures (Ayalon et al. 2019). The new measure should also take into account context effects, given the fact that the nature of ageism changes based on the context in which it occurs (Voss, Wolff, & Rothermund, 2017).

A related challenge concerns the assessment of exposure to ageism. This is because exposure to ageism is usually assessed subjectively. Most of the time, we cannot observe exposure to ageism, but instead have to infer it by querying respondents. However, research shows that the way we phrase the question about ageism or its location in the questionnaire will result in a different responses (Ayalon, 2018). When the question about ageism was placed as part of an overall module on ageism, more than one third of respondents reported exposure to ageism. However, when a question about exposure to ageism was placed out of context, less than 2 percent of the same sample reported exposure to ageism (Ayalon, 2018). A different study shows that it is not perceived ageism that precedes depressive symptoms, but rather depressive symptoms precede perceived ageism (Ayalon, 2016a). Potentially, those individuals who see the world in a more negative light also tend to report higher levels of perceived ageism. Thus, reports concerning the exposure of ageism are highly affected by one's mental state (Ayalon, 2016a). These studies further allude to the subjective nature of ageism and to the challenges researchers face when evaluating it, given that the way we currently assess ageism is based on subjective rather than objective indicators.

At the macro level, there are also no clear indicators of ageism or age discrimination. The AgeWatch Index (Taipale, 2014) or the Active Ageing Index (Zaidi et al., 2013) attempt to quantify how well older adults are doing or how active older adults are in different countries. Although important, these indices do not provide direct information about older adults' exposure to ageism at the country level. An attempt to quantify age-based inequalities at the country level has concluded that more efforts should be put into such an endeavor (Ayalon & Rothermund, 2018). This is because the classification of young vs.

old people in society is unclear. Moreover, it is unclear what should constitute grounds for age-based inequality at the macro level. For instance, age differences in access to healthcare or workforce participation might be due to multiple factors other than chronological age (Ayalon & Rothermund, 2018). Hence, a clear indicator of ageism at the macro-level is not available at present. This is unfortunate, as such a tool could direct stakeholders' attention to changes that should be made to reach greater age-equality at the country level. It is important to note that measures of gender inequality at the country level have been used extensively to direct policies and public attention toward gender discrimination (Gaye et al., 2010).

Having adequate measures of ageism is a first step in tackling ageism. This is because measures of ageism can provide important information about the prevalence of ageism and its consequences. This is needed in order to generate action at the country and individual levels. Moreover, any intervention developed to address ageism must use some measure in order to assess its progress. If current measures are inadequate for capturing the phenomenon of ageism, the phenomenon is more elusive and our ability to target all three domains of ageism in different contexts is impaired.

## What can we do to Live in a World for all Ages?

To live in a world for all ages, in which old age is no longer seen as a burden to society or oneself, we need to change the way we think, feel, and act towards age and aging (Officer & de la Fuente-Núñez, 2018). This is not an easy task, as we live in a world in which age is used to categorize individuals arbitrarily and to differentially allocate opportunities, resources, services, and rights. A first step to combat ageism should be to acknowledge the fact that there is a great variability in old age, which is greater than in any other period of life (Burns et al., 2019; MacAulay et al., 2018). Once that variability is recognized, old age will not serve as the sole criterion and its arbitrary nature will be acknowledged. Under these circumstances, physicians will treat patients based on their medical conditions and physical needs, rather than their chronological age (Rollandi et al., 2019). Similarly, employment opportunities will not be restricted based on chronological age, but rather on people's skills and abilities (Sargeant, 2016).

There is a need to explicitly ban age discrimination. To date, age has been a major basis for legitimate and even desired forms of discrimination. In many countries around the world, people are expected to retire from work and give their skills, abilities, talents, and experience for free simply because they have reached old age )Solem, 2016). In some countries in Europe, people over a certain age are not allowed to rent a car, unrelated to their health, abilities, or skills. In certain countries, older adults are banned from rehabilitation services or implant services simply because of their age (Wyman et al., 2018). Practices that employ a rigid and arbitrary age criterion should be prohibited so that

age is no longer used as the sole criterion for the allocation of rights, goods, or services (Binstock, 2005; Deley et al., 2019).

To change behaviors, a very useful mechanism can be rules and regulations that prohibit age-based discrimination. Because ageism constitutes three dimensions, however, it is important to also target stereotypes and prejudices toward people due to their age. A recent systematic review and meta-analysis concludes that the two most effective strategies to reduce ageist attitudes are intergenerational contact and the provision of education about ageism (Burnes et al., 2019). Such efforts are already underway. For instance, there is a popular TV show that documents social interactions between older adults and four-year-olds in retirement communities (e.g., old people's home for four year-olds). Other intergenerational activities, such as college students who live in retirement communities or intergenerational home-sharing, also are available in many countries (Lee & Suh, 2016; Sánchez et al., 2011).

Educational efforts to inform the public about ageism and its detrimental effects might also prove useful. For instance, the AGE-Platform Europe Ageing Equal campaign includes testimonies and research from around the world to raise awareness of the topic of ageism.[1] Old School, the anti-ageism clearinghouse, is another platform, which provides research and educational information on ageism.[2] In support of these efforts, a recent study demonstrates the effectiveness of a brief online educational program to reduce ageism (Lytle & Levy, 2017).

Nonetheless, there is still a need to develop a strong body of evidence on effective interventions to reduce ageism (Burnes et al., 2019). Specifically, there is limited information about the type of messages that are most effective in changing people's views regarding older adults at the public level. In addition, the majority of research to date comes from North America (Burnes et al., 2019). Given the socio-cultural nature of ageism (Wilińska, de Hontheim, & Anbäcken, 2018), it is important to develop interventions that are culturally appropriate to different settings and can be used at the public level, rather than in a small group format.

Acknowledging old age as a possible opportunity, rather than as a mere obstacle, is yet another important step we should all take to move away from a one-sided negative view of old age. Obviously, old age has its share of losses. Older adults are more likely to suffer from physical disability and medical illness and more likely to lose their spouse, family members, and friends (Baltes, 1995; Covinsky et al., 2003). At the same time, there also are advantages and opportunities that come with age. Older adults have a second, third, or even fourth opportunity to start a new career or a relationship (Koren, 2015; Merriam & Kee, 2014). Moreover, older adults have an opportunity to de-

1 https://www.age-platform.eu/press-releases/ageing-equal-human-rights-do-not-diminish-age

2 https://oldschool.info/

velop relationships with grandchildren and to possibly overcome sore relationships with children or parents (Di Gessa, Glaser, & Tinker, 2016). We are used to fearing old age and examining the passage of time with apprehension and despair (Nelson, 2016). However, we may benefit from readjusting our thinking about our aging experiences and the opportunities that aging could bring with it.

Old age also has a tremendous potential for society at large, not only for the individual (Gonzales, Matz-Costa, & Morrow-Howell, 2015). Specifically, some people can continue to have productive roles in the workforce until very late age. Older adults often are experienced workers who have time on their hands and are known to be highly reliable and devoted to their work. Moreover, society at large can capitalize on older adults' wisdom and experience and benefit from a lifelong perspective that allows for the dissemination and continuation of tradition and customs delivered from older to younger generations (Schniter, 2009). Older adults provide a comprehensive perspective, incorporating lifelong experiences and knowledge. Older adults also are known to exchange both material and non-material commodities with younger generations (Gurven & Schniter, 2010). Specifically, research has shown that the transfer of financial commodities is more likely to go from old to young, as the former often support their adult children for many years after adolescence and early adulthood (Attias-Donfut, Ogg, & Wolff, 2005). Moreover, older adults also provide assistance in various tasks, such as grandparenting or housing, that are not necessarily financially quantified and yet have a tremendous value to society at large (Albertini, Kohli, & Vogel, 2007; Silverstein, 2007). Opportunities for intergenerational solidarity, however, do not go one-way. Older adults also allow for intergenerational exchange from young to old (Albertini, 2016). Such exchanges have the potential to create a more inclusive and compassionate society that encourages empathy and understanding towards others, even if they do not contribute in active and productive ways, as not all older adults (just like not all younger adults) can or wish to contribute.

Although some of the proposed steps seem like utopic unobtainable ideas at present, these are necessary first steps to a life in a world for all ages. In 2016, the World Health Organization received a mandate from 194 countries to combat ageism via global campaign to combat ageism (Officer & de la Fuente-Núñez, 2018). The global campaign is expected to last until 2031, with the understanding that it takes time to change the way we think, feel, and act toward age and aging. We are at the beginning of a new era. This will result in moving away from viewing one's chronological age as a barrier or burden so that people of all ages will be able to fulfill their full potential.

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# Is There no Place for Us? The Psychosocial Challenges and Rewards of Aging with HIV

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## Abstract

According to the Centers for Disease Control and Prevention (CDC), nearly half a million people aged fifty years and older have human immunodeficiency virus (HIV) in the US. This population will continue to grow and some estimates suggest that approximately 70% of all persons with HIV (PWH) in the US will be 50 and over by 2030. This pattern is found globally, as access to antiretroviral therapy becomes widespread. This population includes newly infected older adults and long-term survivors aging with HIV. This article reviews the challenges and opportunities for older PWH, focusing primarily on psychosocial issues. While the growth of this population testifies to the success of HIV treatments, older PWH encounter numerous difficulties in later life, including high rates of multi-morbidity, behavioral health issues, HIV stigma, and social isolation. Many older PWH face difficulties finding care in fragmented systems poorly aligned for the dual challenges of aging and having HIV. We address these structural problems and misalignment with eight policy recommendations to improve access to care and support healthy aging. These recommendations fall into three main categories: 1) increased recognition of this population in planning and the National HIV/AIDS Strategy, 2) improved access to programs through the Ryan White and Older American's Act programs, and 3) better surveillance data on this population globally. Short of a cure, the dramatic increase in the population of older PWH will continue for the foreseeable future. It is the duty of advocates, gerontologists, health and social service providers, and policymakers to meet the needs of those growing older with HIV.

***Keywords:*** HIV/AIDS, older adults, systems of care, Older Americans Act, Ryan White HIV/AIDS program, aging policy

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# ¿No hay lugar para nosotros? Los desafíos y recompensas psicosociales del envejecimiento con VIH


## Resumen

Según los Centros para el Control y la Prevención de Enfermedades (CDC), casi medio millón de personas mayores de cincuenta años tienen el virus de la inmunodeficiencia humana (VIH) en los Estados Unidos. Esta población continuará creciendo y algunas estimaciones sugieren que aproximadamente el 70 por ciento de todas las personas con VIH (PWH) en los EE. UU. Tendrán 50 años o más para 2030. Este patrón se encuentra en todo el mundo, a medida que el acceso a la terapia antirretroviral se generaliza. Esta población incluye adultos mayores recién infectados y sobrevivientes a largo plazo que envejecen con VIH. Este artículo revisa los desafíos y las oportunidades para las personas con discapacidad mayores, centrándose principalmente en cuestiones psicosociales. Si bien el crecimiento de esta población atestigua el éxito de los tratamientos contra el VIH, los PWH mayores se enfrentan a numerosas dificultades en la edad adulta, incluidas las altas tasas de morbilidad múltiple, problemas de salud conductual, estigma del VIH y aislamiento social. Muchos PWH mayores enfrentan dificultades para encontrar atención en sistemas fragmentados mal alineados para los desafíos duales del envejecimiento y el VIH. Abordamos estos problemas estructurales y la desalineación con ocho recomendaciones de políticas para mejorar el acceso a la atención y apoyar el envejecimiento saludable. Estas recomendaciones se dividen en tres categorías principales: 1) un mayor reconocimiento de esta población en la planificación y la Estrategia Nacional contra el VIH / SIDA, 2) un mejor acceso a los programas a través de los programas de la Ley Ryan White y Older American's Act, y 3) mejores datos de vigilancia sobre esta población globalmente A falta de una cura, el aumento dramático en la población de personas mayores con PWH continuará en el futuro previsible. Es deber de los defensores, gerontólogos, proveedores de servicios sociales y de salud y formuladores de políticas satisfacer las necesidades de las personas mayores con VIH.


***Palabras clave:*** VIH / SIDA, adultos mayores, sistemas de atención, Ley de Estadounidenses Mayores, programa Ryan White sobre VIH / SIDA, política de envejecimiento

# 我们没有立足之地吗？携带艾滋病毒衰老的心理社会挑战与回馈


## 摘要

根据疾病预防控制中心（CDC），美国近50万50岁及以上的成人患有人类免疫缺陷病毒（HIV）。这一人口将继续增加，并且一些预测暗示美国HIV携带者（PWH）总数中近70%将在2030年达到50岁及以上。随着抗逆转录病毒疗法的可及性得以扩散，该模式在全球都是如此。这一人口包括新感染的中老年人和长期伴随HIV衰老的生存者。本文审视了中老年PWH的挑战与机遇，主要聚焦于心理社会问题。尽管这一人口的增长证实了HIV治疗的成功，但中老年PWH在之后的生活中面临诸多困难，包括多种疾病的高发病率、行为健康问题、HIV耻辱、以及社会隔离。许多中老年PWH在分散的医疗卫生体系中寻求护理时面临困难，这些体系无法良好应对老龄化与HIV的双重挑战。我们提出八项政策建议应对这些结构性问题和不一致，以期提高护理可及性并支持健康老龄化。这些建议分为三个主要类型：1） 在规划国家艾滋病毒/艾滋病战略时提高对这一人口的重视；2） 通过瑞安·怀特项目和《美国老年人法案》项目提高相关项目的可及性；3）提升全球在这一人口上的监测数据。鉴于无法痊愈，中老年PWH人口的显著增加情况将在可预见的未来中继续存在。满足那些携带HIV衰老的人口的需求，是倡导者、老年学家、卫生与社会服务提供者、以及决策者的职责。


关键词：艾滋病毒/艾滋病，中老年人，护理体系，《美国老年人法案》，瑞安·怀特艾滋病毒/艾滋病项目，老龄化政策

## Introduction

Advances in the management of the human immunodeficiency virus (HIV) have altered the care and treatment for people with HIV (PWH) globally (Emlet, O'Brien, & Fredriksen-Goldsen, 2019). Due to new HIV infections among older adults and increased longevity among PWH, the number of adults fifty years and over with HIV is growing rapidly wherever access to anti-retroviral therapy (ART) is widely available (Heckman & Halkitis, 2014; Mahy et al., 2014). Historically, older PWH are defined as being fifty years and older in surveillance data and by specific clinical markers, including

immunological response to medication and poorer survival rates (CDC, 2018; Blanco et al., 2012; High et al., 2012). In the US, 17% of all new HIV diagnoses annually are among older adults (CDC, 2019a). While new diagnoses of HIV have decreased over the past five years (CDC, 2019b), the rate of new infections among older adults has remained stable.

At the end of 2017, there were approximately 495,569 PWH age 50 and older in the US (CDC, 2019b), representing 49% of PWH. Some estimates suggest that by 2030, 70% of PWH will be fifty or over (Gilead, 2019). Globally, in 2016 there were 5.7 million PWH age fifty and older [range=4.7 to 6.6 million] representing 16% of this population; a proportion expected to rise to 21% by 2020 (Autenrieth et al., 2018).

## Health Inequalities

Health disparities or inequalities have been a hallmark of HIV since early in the epidemic. HIV impacts various communities disproportionately, fostering health disparities in comparison to community members without HIV. Since the beginning of the epidemic, gay and bisexual men and transgender women (also included in the term men who have sex with men or MSM) have been disproportionally impacted by HIV (CDC, 2019b). Recent CDC data (2019b) indicates that 69.7% of all new diagnoses of HIV in the US are among MSM and MSM who inject drugs, and 49.5% of PWH over the age of fifty have MSM as their transmission category (CDC, 2018). Classifying transgender women as MSM has led to a lack of specific information about this population (Porter & Brennan-Ing, 2019), but available data indicate they are at a high risk for HIV (Dragon et al., 2017; Operario, Soma, & Underhill, 2008). Women comprise 23% of older PWH in the US, with most infections due to heterosexual contact (70%), followed by injection drug use (29%) (CDC, 2018). Overall, 16% of US infections were due to injection drug use and 12% were due to heterosexual contact in older adults (CDC, 2018).

Globally, most HIV infections are the result of heterosexual transmission and injection drug use. In sub-Saharan Africa, heterosexual transmission is the most common vector for HIV (Piot et al., 2001). However, in China and Eastern Europe, HIV started among injection drug users and then spread to their heterosexual partners (Piot et al., 2001). Regional differences also exist. Injection drug use is the primary mode of HIV infection in Pakistan, Iran, Libya, Afghanistan, and Egypt. In the Eastern Mediterranean, female sex workers, gay and bisexual men, and injection drug users are the primary groups affected by HIV (Sprague & Brown, 2016).

HIV disparately affects older adults of color. At the end of 2015, Blacks/African Americans made up the largest percentage of older PWH (39%) in the US, compared with Whites (37%), or Latinxs (18%) (CDC, 2018). Older adults of color are disproportionally impacted by late HIV diagnosis; the highest percentage of older adults with a Stage 3 (AIDS) classification at the

time of HIV diagnosis was among persons of multiple races (47.3%) (CDC, 2018).

HIV long-term survivors are another important subpopulation of older PWH. There is no single definition for long-term survivors, but many define these individuals as PWH who acquired the virus before ART became widely available in 1996. This was a time when HIV diagnosis meant early death (The Well Project, 2018). These older PWH lived through significant trauma that had lasting effect on their physical and mental wellbeing.

It is important to consider the impact of intersectionality on older PWH. For example, Emlet et al. (2019) analyzed data from the National Health, Aging, Sexuality/Gender Study (NHAS) in order to better understand health disparities among older gay and bisexual men. They found that compared to their HIV negative counterparts, those living with HIV were more likely to be men of color and to have lower levels of resilience and social support, a past diagnosis of anxiety or drug addiction, poorer general health, and increased levels of depressive symptoms. Data from the Health Resources and Services Administration (HRSA) found that older Black/African American and Latinx PWH were more likely to live below the federal poverty level and to experience greater housing instability (Cohen et al., 2019), which in turn impacted viral suppression. Older transgender adults with HIV also experience health disparities, including unstable housing, higher rates of poverty, and lower levels of viral suppression (Cohen et al., 2019). The impacts of gender/gender identity, race/ethnicity, sexual orientation, and length of time with HIV are complex and a detailed analysis is beyond the scope of this article.

## Burden of Disease

Older PWH not only face the challenges of aging with the virus, but also must contend with other comorbid conditions, some HIV-related and others experienced by the general population. Multi-morbidity is related to how ongoing HIV infection impacts health. Fülöp et al. (2017) proposed that ART transforms HIV into a chronic inflammatory disease, and that changes to the immune system resulting from HIV infection render it less able to protect the body from a host of threats.

Older adults with HIV average three or more comorbid conditions in addition to HIV (Balderson et al., 2013; Havlik, Brennan, & Karpiak, 2011). Common comorbid conditions include cardiovascular disease, certain cancers, hepatitis C, fractures, and depression (Karpiak & Havlik, 2017). It is unclear if this higher burden of disease is due to accelerated aging with HIV (i.e., increased disease incidence at earlier ages), or accentuated aging (i.e., disease incidence at similar ages as non-HIV infected persons, but a greater number of comorbidities) (Karpiak & Havlik, 2017). Globally, tuberculosis (TB) is a prevalent comorbidity and progresses more rapidly among PWH compared with HIV-negative peers; in 2016, there were an estimated 1 million new

cases of HIV-TB co-infections among PWH, with 374,000 deaths (Dolai, Roy, & Roy, 2020). As the population PWH grows older, they are increasingly likely to experience geriatric syndromes associated with vulnerabilities in physical, psychological, and environmental domains (Greene et al., 2015). Geriatric syndromes include falls, urinary incontinence, functional impairment, sensory loss, depression, cognitive impairment, and frailty, and are associated with HIV disease severity, greater multi-morbidity, and minority race/ethnicity (Brothers et al., 2014; Greene et al., 2015). The high level of disease burden among older adults with HIV requires new policy and programmatic approaches to meet the social care needs of this aging population.

## Prevention Challenges

An important element of creating a system of HIV care for older adults must include relevant, sensitive, and evidence-based prevention strategies. Seventeen percent of all new HIV diagnoses in the US are among people fifty and over (CDC, 2019a). It is estimated that only 69% of those over fifty-five living with HIV receive some HIV care (CDC, 2019b), creating opportunities for older PWH to transmit HIV. A recent analysis of HIV transmission in the US estimates that over 50% of HIV infections in 2016 originated from people age forty-five and older (Li et al., 2019). In the Research on Older Adults with HIV (ROAH) using a diverse sample of older PWH (83% people of color, 29% women, 67% heterosexual), 50% had been sexually active in the past three months, and 80% of those who were sexually active engaged in penetrative anal or vaginal sex (Golub, Grov, & Tomassilli, 2009). Among the sexually active, many had unprotected sex: 21% with HIV-positive partners and 20% with serodiscordant partners (HIV- or HIV status unknown). In ROAH, safer sex practices and HIV risk management behaviors were associated with better psychological wellbeing, with unprotected sex linked to recent substance use and loneliness (Golub et al., 2010; Golub et al., 2013).

Among older PWH in the US, 30 to 40% are classified as having a "dual diagnosis" of HIV and AIDS (CDC, 2019a). A dual diagnosis is a "late" diagnosis, as HIV has been present long enough to progress to AIDS. In addition, because these individuals did not know they were HIV-positive, they may have placed others at risk (CDC, 2018, Cohen et al., 2011; Li et al., 2019). A dual diagnosis of HIV/AIDS is associated with greater morbidity and mortality given the damage caused to the immune system by untreated HIV (Chadborn et al., 2005; Egger et al., 2002). Ageist beliefs that older adults are not sexually active or engage in other HIV risk behaviors are likely factors in late HIV testing, as providers may believe HIV symptoms in older patients arise from other health conditions (DeMarco, Brennan-Ing, Brown, & Sprague, 2017).

Recent local, national, and global policy initiatives to end the epidemic (ETE) have the potential to reduce HIV infections, late testing, and dual HIV/AIDS diagnoses among older adults (Bain, Nkoke, & Noubiap, 2017; Facen-

te, 2016; HHS, 2019; New York State Department of Health, 2015). ETE policies share a common framework of universal testing and getting people who test positive engaged in care, on ART, and virally suppressed. Prompt HIV testing and initiation of ART to achieve viral suppression result in better clinical outcomes for older PWH. Further, PWH who sustain undetectable viral loads cannot infect others through sexual contact and are referred to as Undetectable = Untransmittable (U=U) (Cook, Davidson, & Martin, 2019; Eisinger, Dieffenbach, & Fauci, 2019). Successful implementation of ETE policies has the potential to greatly improve the health of older adults with HIV and reduce HIV incidence. Yet among older PWH, rates of viral suppression are approximately 60% (Crepaz et al., 2017; Muthulingam et al., 2013; Yehia et al., 2015), well below public health targets of 73 to 85% (Bain et al., 2017; Facente, 2016; New York State Department of Health, 2015).

## *Psychosocial Issues: Social Isolation, Stigma and Mental Health Issues*

Older PWH face multiple psychosocial challenges that can be exacerbated by aging, such as social isolation, stigma, and mental health concerns. These issues are both intrapersonal and interpersonal, and we have chosen to focus on issues that are of major concern.

### Social Isolation

Social isolation is common among older PWH. The Caring and Aging with Pride project (Fredriksen-Goldsen et al., 2011) found that 64% of older LGBT adults with HIV lived alone. In the ROAH 2.0 study (53% people of color, 15% female, 22% heterosexual), 67% of participants lived alone and 43% were lonely (Erenrich et al., 2018). Social isolation arises from a variety of sources, including the death of partners/spouses (Emlet et al., 2019), stigma (Brennan-Ing, Seidel, & Karpiak, 2017), and disconnection from family (Brennan-Ing et al., 2017a; Brennan-Ing, Seidel, Larson, & Karpiak, 2017). Many older PWH find it difficult to locate and identify their community (Johnson Shen et al., 2018). A recent study of social isolation among older adults living with HIV found that increased social isolation is associated with increased hospitalizations and mortality (Greysen et al., 2013), reinforcing the tie between social wellbeing and physical health.

### Stigma

HIV stigma is a serious social problem among older PWH (Emlet, 2017; Foster & Gaskins, 2009; Haile, Padilla, & Parker, 2011). HIV stigma involves a complex array of intrapersonal and interpersonal experiences, including enacted stigma (prejudice/discrimination), internalized stigma (internalization negative attributes and beliefs), and anticipated stigma (the expectation of enacted stigma and resulting anxiety and fear) (Earnshaw & Chaudoir, 2009). HIV stigma among older adults is associated with depression, poorer quality of life, lack of disclosure, and loneliness (Grov et al., 2010; Haile et al., 2011). Older PWH may

face the intersectionality of HIV stigma with other forms of discrimination, including ageism (Emlet, 2006), racism, sexism, homophobia, ableism, and/or transphobia (Johnson Shen, Freeman, Karpiak, Brennan-Ing, Seidel, & Siegler, 2019; Porter & Brennan-Ing, 2019). Ageism, namely discrimination toward older people on the basis of age, has deleterious effects on older PWH, rendering them invisible in HIV education, testing, and treatment settings, and when internalized, leads to poorer health outcomes (DeMarco et al., 2017).

Healthcare and HIV providers working with older PWH must assess stigma and carefully consider the intersection of HIV and other stigma and how these forms of discrimination are mitigated. In a recent study of older adults, Emlet and colleagues (2013) note the importance of social support and mastery as a means of counteracting HIV stigma.

**Mental Health**

Mental health concerns, particularly depression, anxiety, and substance misuse, are common among older PWH. Rates of depression greater than 50% have been identified in numerous studies, including ROAH (Brennan, Karpiak, & Cantor, 2009; Frontini et al., 2012; Justice et al., 2004). In ROAH 2.0, 62% reported feeling depressed during the past year (Erenrich et al. 2018). Rates of substance use and misuse among older PWH are higher than among older HIV-negative individuals (Justice et al., 2004). Emlet et al. (2019) found that older sexual minority men with HIV more likely to have a history of substance use disorders, alcoholism, and depression compared with HIV-negative peers. Commonly used illicit substances among older PWH include marijuana, cocaine, and methamphetamines (Erenrich et al., 2018; Frontini et al., 2012). Anxiety is a serious and prevalent mental health issue among older PWH; in ROAH 2.0, 65% of participants experienced anxiety in the past year (Erenrich et al., 2018). The NHAS found anxiety to be twice as common among older PWH compared to HIV-negative counterparts (Emlet, et al., 2019).

Behavioral health problems can be risk factors for HIV infection or result from the crisis of an HIV diagnosis. Substance use complicates HIV care. Using alcohol or other substances is a barrier to ART adherence in younger and older PWH alike (Azar et al., 2010; Reda & Biadgilign, 2012; Spaan et al., 2018). Parsons et al. (2014) found that older PWH who used alcohol and other substances were significantly more likely to be non-adherent to ART and have detectable viral loads. In a sample of middle-aged and older PWH, Sinha and colleagues (2017) found that marijuana, alcohol, and heroin use were significantly related to poor ART adherence. Further, there is evidence that the use of alcohol and other substances decreases the efficacy of ART, potentially impacting clinical outcomes (Michel et al., 2010).

### *Exploring the Deficit in Social Resources*

The issues of social isolation and fragile social networks have been well documented in the HIV and aging literature. Moving forward with a useful and thoughtful approach is also necessary. Using the original ROAH study data, Brennan-Ing and colleagues (2017a) developed a typology of social networks of older PWH. Three network types emerged, with each type accounting for approximately one-third of the sample. The first group, the "Isolated," reported no friends or community involvement, but had intermittent contact with a few family members. This group was predominantly composed of heterosexual women and men. The "Friend-centered" group had frequent contact with friends, but little contact with family or community involvement. This group was dominated by gay and bisexual men who tend to have so-called families of choice, regardless of their HIV status (Brennan-Ing et al., 2017b). The "Integrated" group had a large proportion of heterosexual women and the broadest spectrum of support from family and friends and was involved with their communities. Older PWH in the Isolated group reported the lowest levels of perceived instrumental and emotional social support, and did more poorly with regard to psychosocial functioning (HIV stigma, depression, loneliness) compared to their peers. Those in the Friend-centered group had similar psychosocial functioning compared to the Integrated group. While social support from friends can be vital when family support is not available, support from friends does not fully compensate for a lack of assistance from family (Brennan-Ing et al., 2017b).

Given the lack of informal social resources among older PWH, it is questionable whether their needs for caregiving and other forms of support can be met as they age. Nearly half of the ROAH 2.0 sample (45%) indicated they either had needed caregiving help in the past (24%) or currently needed such help (21%) (Erenrich et al., 2018). Of those needing caregiving, 31% said they received help from a partner/spouse, 25% indicated a family member, 67% said a friend, and 21% received help from neighbors (participants could select more than one category). However, 23% said they had no one to turn to for caregiving assistance. Thus, a sizeable proportion of older PWH appears to lack critical caregiving resources. A fragile informal support system can be mitigated through the use of formal services, such as home care or case management (Cantor & Brennan, 2000). For older PWH however, turning to formal services may be difficult. Experiences of fear, discrimination, marginalization, invisibility, and distrust may serve as a barrier in accessing needed services (Cox & Brennan-Ing, 2017; Johnson Shen et al., 2019).

Not only must older PWH access treatment for HIV and common health conditions of old age, but they also must access dual systems of care. Unfortunately, that coordination across systems is often difficult. DeMarco and colleagues (2017) suggest that "ageism perpetuates the invisibility of older adults which renders current medical

and social service systems unprepared to respond to the needs of aging people with HIV infection" (235). For example, in a statewide survey of area agencies on aging (AAA) in Washington state, more than 80% of AAAs felt they had limited or no experience in working with older PWH and agreed they needed more training (Emlet, Gerkin, & Orel, 2009).

Similarly, when older adults access AIDS service organizations, they often find that the programming is not framed to fit their needs (Johnson Shen et al., 2018). Even though older adults living with HIV may be more likely to seek services from the network of care designed for those with HIV, as opposed to services for older adults (Emlet, 2004), services in that arena may not be a good fit. As an example, one seventy-year-old Black heterosexual male participant in a study of service needs among older PWH stated "Yah, and I went to the thing called ... I forget the name of it, but when I met the group of young, young people, 21 years old, you know, 24, 25 years old, I was like ... as soon as I got there it's 'Oh, we got a grandpa.' When they called me grandpa, I said that's it, done" (Johnson Shen et al., 2019).

## *Social and Interpersonal Resources*

Strengths and resilience can aid in adjustment and serve as protective factors against the deleterious impacts of HIV among older adults. Interpersonal and intrapersonal factors have been associated with decreased psychological distress and improved quality of life in this population. Social support has been repeatedly found to benefit older PWH. Emlet et al. (2013) found emotional and informational social support to be associated with decreased HIV stigma among 378 older male and female PWH. These results parallel Logie and Gadalla (2009), who found a negative relationship between HIV stigma and social support. Recently Emlet and colleagues (2017) found social support to be associated with both mastery and resilience in 335 older gay and bisexual men living with HIV. Both mastery and resilience were associated with increased psychological health-related quality of life.

Increasingly, researchers are examining successful or optimal aging among PWH. Successful aging among older PWH requires us to rethink classic models of this concept (Rowe and Kahn 1998), and acknowledge that diverse older adults, particularly those with late-life disability, will require a redefinition of what it means to age successfully (Romo et al., 2013). Kahana and Kahana (2010) developed the "preventative and corrective model of successful aging" specific to HIV. Unlike earlier models, this model presented HIV more positively, with a focus on prevention and on "corrective" activities that would realize meaning and success in the aging process.

Vance and colleagues (2019) adapted Baltes and Baltes' (1998) model of successful aging to older adults with HIV by proposing that a more productive approach would be to examine how people manage challenges and losses while maintaining well-being as they age (Vance et al. 2019). Vance and colleagues (2019) concluded that to enable

successful aging, older PWH require information and support to manage their HIV and other comorbid conditions. Further, health and social service providers should be mindful of both deficits and strengths that characterize this population, and utilize the latter to help these individuals age successfully.

Research has noted the importance of intrapersonal characteristics, including mastery, optimism, and spirituality, in aging successfully with HIV. Moore et al. (2013) utilized self-ratings of successful aging in 166 HIV-positive and HIV-negative older adults. They found that optimism and mastery were associated with improved self-rated successful aging and other indicators of physical and psychological functioning. Mastery has also been associated with reduced stigma in HIV-positive older Canadians (Emlet et al., 2013). Other researchers have taken a more naturalistic approach, allowing older PWH to self-define successful aging (Solomon et al., 2018; Emlet et al., 2017).

A recent inquiry has identified the importance of resilience in coping and managing HIV disease. Porter et al. examined the mediating effects of spirituality and complimentary and integrative health practices (CIH) on the relationship between HIV stigma and psychological wellbeing in the original ROAH study (Porter et al., 2015). Greater HIV stigma was related to poorer psychological wellbeing. However, results found that both spirituality and CIH buffered the impact between stigma and wellbeing. In a follow-up study, Porter et al. compared the relationships of these factors between older gay/bisexual men and older heterosexual men with HIV (Porter et al., 2017). They found that spirituality was a stronger mediator of stigma relative to wellbeing in sexual minority men compared to heterosexuals. Social workers and other health and social service providers need to ensure that their assessment processes identify and capitalize on strengths and resilience in this population.

## Policy Recommendations

Older PWH are not typical of the general aging population (Cox & Brennan-Ing, 2017), and thus it is not surprising that Brennan-Ing et al. (2014) found that older PWH used three times as many non-HIV services as their community-dwelling HIV-negative counterparts. Despite the complex needs of this population, there are problems associated with the coordination of services across systems. What follows are recommendations for policy changes in eight domains, ranging from worldwide HIV reporting structures to the provision of more localized services in the United States.

### Recommendation #1. Explicitly address the support and care needs of older HIV-positive adults in the US National HIV/AIDS strategy.

The National HIV/AIDS Strategy for the United States (White House Office of National AIDS Policy, 2017) clearly identifies older adults as an important group of people regarding HIV prevention and treatment. While it is laudable that older adults are specifically mentioned in the updated strat-

egy, older adults are identified as part of a long list of at-risk groups. Despite this important recognition, of the ten indicators identified in the National HIV/AIDS Strategy, none address the specific needs of older PWH. Thus, the impact that HIV has on older adults is not proportionately represented in the current strategy. For example, the strategy continues to recommend that all individuals between fifteen and sixty-five years be tested for HIV. CDC data indicate that in 2017, more people age sixty-five and over were living with HIV (approximately 90,000) than those up to twenty-four years of age. With some estimates that upward of 70% of PWH in the US will be fifty years old and older by 2030, specific approaches for this population are needed. HIV advocates and older consumers should work more closely to identify the prevention and care needs of this population before the next strategy update occurs.

Given the extent of health challenges among older PWH, the National HIV/AIDS Strategy should also address universal healthcare coverage. Engagement in care is a key component of HIV treatment and addressing age-related multi-morbidity, yet this is not possible without access to healthcare. The Affordable Care Act (ACA) increased health insurance participation among PWH through Medicaid expansion, reducing uninsured rates from 19% to 5% (Dawson & Kates, 2019). However, Medicaid expansion has occurred on a state-by-state basis, and many states in the southern US, where HIV infection rates are growing, chose not to expand Medicaid (Reif et al., 2017). Approximately nine out of ten PWH who fall into the Medicaid coverage gap, i.e., have an income that is too high to qualify for Medicaid, but too low for an ACA subsidy, live in the Deep South (Reif et al., 2017). Without addressing these gaps and without working to guarantee universal health insurance coverage for younger and older PWH, the National HIV/AIDS Strategy falls short.

**Recommendation #2. Reconvene the National Institute of Health Office of AIDS Research (NIH OAR) workgroup on HIV & Aging.**

In April 2011, the NIH OAR convened a working group to address the aging of the HIV epidemic in anticipation of adults fifty and older making up a majority of PWH. The working group developed four priorities for NIH to address in HIV and aging research: 1) mechanisms and triggering of functional decline/aging in HIV-infected persons; 2) biomarkers and clinical indices as predictors/surrogate outcome markers; 3) aging with HIV infection; multi-morbidity and the clinical research agenda; and 4) societal infrastructure, mental health/substance abuse, and caregiving issues (High et al., 2012). Reflecting the scientific disciplines of the working group, three of the four priority areas were focused on biomedical and clinical research, and NIH support for HIV and aging research has reflected this predisposition since the working group report was issued. As we have highlighted in this paper, the psychosocial issues around HIV and aging are key policy considerations in meeting the needs of this growing population, and this policy

needs a robust evidence base to ensure that recommendations will be relevant and efficacious. Given the growth of older PWH in the last decade, the NIH OAR should reconvene this working group to update research priorities on HIV and aging, with a greater focus on psychosocial challenges.

**Recommendation #3. Insure that ETE initiatives address the special needs of older adults.**

The federal government, along with state and local jurisdictions have adopted ETE plans that involve universal HIV testing and having PWH be engaged in care, on ART, and virally suppressed. ETE plans promote HIV prevention by providing greater access to pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (nPEP). At the time this manuscript was being prepared, twelve states and the District of Columbia had ETE plans available, eleven states had plans in development, and twenty-three county or city jurisdictions had ETE plans in existence or in process (NASTAD, 2019). However, few of these plans explicitly address the HIV prevention and care needs of older adults. An example of how this can be achieved is provided by New York State, which convened advisory groups to develop ETE implementation strategies (New York State Department of Health, 2019). The New York State Older Adults Advisory Group noted various barriers and strategies to achieving ETE goals, including low rates of HIV testing, condom use, and PrEP uptake in adults fifty and older. Other challenges to meeting ETE goals were the recognition of high levels of multi-morbidity and concomitant polypharmacy in this population, along with high rates of unmanaged depression; factors with the potential to interfere with ART adherence and efficacy in the older population. Considering the proportion of older adults who comprise the current HIV population and substantial incident HIV in this group, it is imperative that ETE plans consider the special needs of older adults to ensure the success of these initiatives.

**Recommendation #4. Increase CDC funding for primary and secondary HIV prevention.**

The CDC published its first surveillance report on HIV among people fifty and older in 2013 (CDC, 2013), and the latest update was released in 2018 (CDC, 2018a). While the CDC is paying greater attention to older PWH, greater efforts should be made to address the prevention challenges faced by older adults. Older adults experience a delay between HIV infection and diagnosis, resulting in high rates of late dual HIV/AIDS diagnoses (CDC, 2018; Cohen et al., 2011). People 50 and older represent 17% of new HIV infections in the US (CDC, 2019a), and may be responsible for nearly half of all new HIV infections (Li et al., 2019). While the CDC supports the use of high-impact prevention approaches to reducing HIV infections in older adults (CDC, 2019a), these programs were developed for people under the age of fifty, and there has been little CDC-specific funding or prevention efforts targeting older individuals. The problem with this ap-

proach is illustrated in the case of PrEP. While PrEP could be an important prevention tool for older adults, given the prevalence of erectile dysfunction in older men, which can render condom use problematic, the active ingredient in PrEP—tenofovir—is associated with kidney toxicity, and such toxicity is more likely in people over fifty (Franconi & Guaraldi, 2018). Thus, general guidelines around PrEP uptake ignore enhanced screening and the consideration of other mitigating factors like the comorbid conditions that physicians should be aware of when prescribing this medication to older patients (Franconi & Guaraldi, 2018). To better meet the prevention needs around HIV and aging, the CDC should work to develop tailored strategies to address low rates of HIV testing and the prevention challenges facing older adults, rather than relying on a one-size-fits-all strategy. Other prevention efforts, such as the "Age is Not a Condom," campaign could be expanded as well.

**Recommendation #5. Increase targeting of older adults in Ryan White-funded programs, with incentives to develop new programming for an older population.**

The Ryan White HIV/AIDS program is administered through HRSA and serves over 500,000 PWH who are uninsured and underserved (HRSA, 2020a). Ryan White provides grants to entities that provide medical and supportive services to PWH. In 2018, 44% of Ryan White program participants were age fifty and older, most were people of color, and a majority had incomes at or below the federal poverty level (HRSA, 2018). A number of Ryan White grantees run programs targeting older PWH (HRSA, 2018); however, supportive services targeting psychosocial needs are not as common as those focused on medical care. As this population grows, their needs for these types of services will increase as they face the dual challenges of HIV and aging, and Ryan White funding for older adults programing needs to reflect this growing need (Cahill, Mayer, & Boswell, 2015). Unfortunately, Ryan White funding decreased between 2011 and 2019 (HRSA, 2020b). While HRSA provides limited online resources to train Ryan White providers to work with older adults (AETEC National Coordinating Resource Center, 2015), a greater commitment to cultural competency training for PWH over fifty is warranted (Cahill et al., 2015). The Ryan White program should also fund Special Projects of National Significance (SPNS) grants specifically geared toward programs for older adults, which could spur programmatic innovations.

**Recommendation #6. Within the Older Americans Act (OAA), define older PWH and LGBTQ individuals as populations of greatest social need and relax age eligibility requirements for OAA program access**

The OAA is an example of age-based public policy and has, since the beginning of the act in 1965, made services available to older people based on age (Greenfield & Giunta, 2016). The OAA also focuses resources on those older

adults with greatest social and economic needs, including those with (a) physical and mental disabilities; (b) language barriers; and (c) cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that (i) restricts the ability of an individual to perform normal daily tasks or (ii) threatens the capacity of the individual to live independently (42 USC §3002(23)-(24) (2016)). Older adults living with HIV have been defined as those fifty and over since very early in the epidemic (Poindexter & Keigher, 2004), with similar age criteria for older LGBT individuals based on health inequities and comorbidities (APA, 2020). Because many older PWH are under sixty years of age, but otherwise meet criteria for greatest social needs, it is recommended that individuals age fifty and over be included in eligibility for OAA programs. Title V of the act currently allows employment services to be made available to individuals who are fifty-five years of age and older. This recommendation is consistent with the purpose of developing the Administration for Community Living to assist those with disabilities younger than age sixty.

**Recommendation #7. Relax Medicaid and public assistance income requirement to help older PWH return to the workforce without the loss of health and social benefits.**

Before the advent of ART, an HIV diagnosis resulted in increasing levels of disability and eventual death. With effective treatments and near-normal life expectancies, many older adults with HIV are capable of returning to the workforce, but fear doing so would result in a loss of eligibility for Medicaid, Social Security Disability Insurance, and other forms of public assistance (Maestas, Mullen, & Strand, 2013). Workforce participation among older adults with HIV is low, with one study finding less than 10% being employed, 21% unemployed, and 56% on disability income (Karpiak & Brennan, 2009). Many older PWH would like to contribute to society in a meaningful way, yet lack the opportunity to do so (Emlet & Harris, 2019; Johnson Shen et al., 2019). Older PWH would like to return to the workforce, which would be psychologically beneficial and help restore a sense of purpose and meaning to their lives (Brennan, 2008; Porter et al., 2015). This situation was described to one of the authors as wearing *golden handcuffs*, namely, they wanted to rejoin the workforce, but were unable to do so for fear of losing critical sources of public assistance. To provide older PWH with a better quality of life and allow them to contribute to society, we should redefine income requirements for this population and those with other types of disabilities to encourage workforce participation without the loss of benefits that sustain health and wellbeing.

**Recommendation #8. UNAIDS and the World Health Organization (WHO) should pay increased attention to addressing the global aging HIV epidemic.**

Evidence suggests that while the population of older PWH is growing globally (Emlet, O'Brien, & Fredriksen-Goldsen, 2019; Sprague & Brown, 2017), a

unified examination of older adults and the impact of HIV on them is sporadic. Historically, and in the most recent report from UNAIDS (2019), adults living with HIV are defined as those fifteen to forty-nine years of age. While some reports from UNAIDS focus specifically on the older adult population (UNAIDS, 2013), overall reporting mechanisms of prevalence, incidence, and treatment targets do little to shed light on those age fifty and over. As an example, the UNAIDS most recent report from 2019 examines stigma and discrimination by country (when available), but gathers information from women and men aged fifteen to forty-nine who report discriminatory attitudes towards PWH (UNAIDS, 2019). Similarly, WHO places little focus or emphasis on older adults with HIV in their web-based material and does not list older adults as a key or vulnerable population.[1] This is not to say that WHO has not made important contributions through their SAGE Well-being of Older People Study (WOPS), which examined older people infected with or affected by HIV in Uganda and South Africa. While there have been many valuable scientific contributions from WOPS, other older PWH populations across the globe remain understudied. Thus, without consistent acknowledgement or hard data from global organizations, such as UNAIDS or WHO, our understanding of the impact of HIV on older people, and how county, culture, and social belief impact identification, care, and treatment will continue to be hampered.

## Conclusion

The purpose of this paper was to shed light on the complex physical and psychosocial issues that impact older PWH and to craft policy recommendations to improve the lives of this population. These issues are complex and could not be fully addressed and explored within the length of this manuscript. For example, while an extensive examination of vulnerable and at-risk populations of older adults in warranted, it could not be fully explicated here.

Older PWH are a rapidly growing population comprised of several subpopulations, each with their own needs. Short of a cure, this population will continue to grow over the next several decades, regardless of the effectiveness of HIV prevention strategies. These individuals face multiple and complicated intersectional stigma and discrimination around age, HIV status, gender, race/ethnicity, sexual orientation, and gender identity. They also share in complex issues of comorbidity and unanswered questions concerning the interaction of HIV and aging in terms of both natural aging processes and age-associated diseases and treatments. The title of this paper came from comments made by multiple older adults living with HIV infection. Their experience is often one of "not fitting in anywhere." Programs developed and delivered under the OAA may not be sensitive to the needs of this population, and OAA service providers may not be knowledgeable and prepared to serve

1 https://www.who.int/news-room/fact-sheets/detail/hiv-aids.

these individuals. HIV related services often have gaps, whereby older adults do not fit well into social support and support group structures. Thus, older adults often voice frustration about not having a suitable place to obtain help and assistance.

Despite these complications, older PWH are positive, resilient, and interested in healthy and successful aging. If that goal is to be accomplished, however, policy changes at local, national, and global levels will need to take place. These changes range from the acknowledgement of older PWH worldwide down to the eligibility criteria for local OAA program need, with the participation of HIV consumers and advocates in this process. In service of this goal, we have presented eight policy recommendations that attempt to move toward more friendly and inclusive systems of education, care, treatment, and service delivery for this growing, vulnerable, and resilient population.

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42 U.S.C. §3002(23)-(24)

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# Policy Challenges for Grandparents Caring for Grandchildren with Disabilities

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Abstract

Childhood disability rates in the US are increasing, but supports for families are not. As a result, US grandparents provide a great deal of care for grandchildren with disabilities. When they do, they face a myriad of social policy challenges. Here we explore three such challenges: (1) how access to employment benefits such as paid vacation, paid sick leave, paid parental leave, or affordable, high quality childcare shapes grandparent care work; (2) how access to poverty-based, social assistance programs, such as SNAP, SSI, and Medicaid, shapes grandparent care work; and (3) how access to disability policies and programs, such as those pertaining to accessible classrooms, parks, or apartments, shapes grandparent care work. We augment this assessment of policies with quotes from fifty interviews we conducted with grandparents caring for grandchildren with disabilities. We found that grandparents were providing childcare, bathing, feeding, transportation, and therapy; helping with homework; accompanying grandchildren for medical care; paying for everything from groceries to surgeries; and assisting with technical medical care. Several were also advocating for their grandchildren with administrators at SNAP, SSI, Medicaid, public schools, park districts, and landlords. Caring for grandchildren with disabilities gives many grandparents a great deal of joy, satisfaction, and purpose. Although most are eager and happy to help, doing so may adversely impact their financial, social, emotional, and physical wellbeing. Those with sufficient resources may be more readily able to absorb the impact, but those who provide the most care with the fewest resources are more likely to deplete their savings, incur new debts, reduce or end employment, restrict social lives, and forego travel plans. They are also more likely to experience anxiety and emotional distress, have disabilities of their own, and neglect their physical wellbeing through a lack of exercise, improper diets, and delayed medical and dental care.

***Keywords:*** grandparenting, childhood disabilities, care work

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# Desafíos de política para los abuelos que cuidan a nietos con discapacidades


## Resumen

Las tasas de discapacidad infantil en los EE. UU. Están aumentando, pero los apoyos para las familias no. Como resultado, los abuelos de los Estados Unidos brindan una gran atención a los nietos con discapacidades. Cuando lo hacen, se enfrentan a una miríada de desafíos de política social. Aquí exploramos tres de estos desafíos: (1) cómo el acceso a beneficios laborales como vacaciones pagadas, licencia por enfermedad remunerada, licencia parental remunerada o cuidado infantil asequible y de alta calidad configura el trabajo de cuidado de los abuelos; (2) cómo el acceso a programas de asistencia social basados en la pobreza, como SNAP, SSI y Medicaid, configura el trabajo de cuidado de los abuelos; y (3) cómo el acceso a las políticas y programas de discapacidad, como los relacionados con aulas, parques o apartamentos accesibles, configura el trabajo de cuidado de los abuelos. Aumentamos esta evaluación de políticas con citas de cincuenta entrevistas que realizamos con abuelos que cuidan a nietos con discapacidades. Descubrimos que los abuelos brindaban cuidado de niños, baño, alimentación, transporte y terapia; ayudando con la tarea; nietos acompañantes para atención médica; pagar por todo, desde comestibles hasta cirugías; y asistencia con asistencia médica técnica. Varios también abogaban por sus nietos con administradores de SNAP, SSI, Medicaid, escuelas públicas, distritos de parques y propietarios. Cuidar a los nietos con discapacidades les da a muchos abuelos una gran alegría, satisfacción y propósito. Aunque la mayoría está ansiosa y feliz de ayudar, hacerlo puede afectar negativamente su bienestar financiero, social, emocional y físico. Aquellos con recursos suficientes pueden ser más capaces de absorber el impacto, pero aquellos que brindan la mayor atención con la menor cantidad de recursos tienen más probabilidades de agotar sus ahorros, incurrir en nuevas deudas, reducir o terminar el empleo, restringir la vida social y renunciar a los planes de viaje. También son más propensos a experimentar ansiedad y angustia emocional, tener sus propias discapacidades y descuidar su bienestar físico por falta de ejercicio, dietas inadecuadas y atención médica y dental tardía.


***Palabras clave:*** abuelos, discapacidades infantiles, trabajo de cuidado

# 祖父母养育残疾孙辈所面临的政策挑战


## 摘要

美国儿童残疾率正在上升，但对家庭提供的支持却没有增加。结果，美国祖父母为身患残疾的孙辈提供了极大的照顾。当他们这么做时面临着许多社会政策挑战。我们在此探究三种这类挑战：(1) 对例如带薪假期、带薪病假、带薪产假、或可负担的高质量儿童护理等员工福利的获取如何影响祖父母对孙辈的护理工作；(2) 对基于贫困的社会协助项目，例如补充营养援助计划（SNAP）、 补充保障收入（SSI）、医疗补助（Medicaid）的获取如何影响祖父母对孙辈的护理工作；(3) 对残疾政策及相关项目，例如那些与残疾人教室、公园或公寓有关的获取如何影响祖父母对孙辈的护理工作。通过与那些养育残疾孙辈的祖父母们进行的50次面谈得出的引述，我们对该政策评估进行了阐述。我们发现，祖父母曾提供儿童护理、洗澡、喂食、交通和治疗；帮助完成家庭作业；陪同孙辈进行医疗；支付从杂货到手术等一切费用；协助技术医疗。几位祖父母还曾在SNAP、SSI、Medicaid、公立学校、公园区域和房东管理员面前公开支持孙辈。教养残疾孙辈为许多祖父母带来了极大的快乐、满足和目的。尽管大多数祖父母都乐意帮助，但这样做可能会对其经济、社会、情感和身体健康造成消极影响。那些拥有充足资源的祖父母可能更能准备好承受这些影响，但那些用最少资源提供最多护理的祖父母更可能耗尽其储蓄、引起新债务、较少或终止就业、限制社交生活、放弃旅行计划。他们也更可能经历焦虑和情感痛苦，并由于缺少锻炼、不协调饮食、医疗及口腔护理拖延而忽视其个人的身体健康。


关键词：祖父母教养，童年残疾，护理工作

When one of her twin grandsons was diagnosed with Down syndrome and the other was diagnosed with autism, Marsha and her husband moved to a new city and changed jobs so that they would be nearby to help. Now sixty-four, Marsha has become a real estate agent making her job flexible and allowing her to care for her grandsons. She rearranges her schedule constantly to care for them days, evenings, and weekends. She and her husband take them to doctor and therapy appointments and look after them during sick or snow days (Harrington Meyer 2014).

> When the second was diagnosed, it became imperative that we live close. They needed family .... I needed something very flexible, so I could help at various times of the day and week. I just can't do a Monday through Friday job. I gave up paid vacation and paid sick leave when I went into real estate. I needed to be available to help with the kids, especially because they have special needs.

In addition to giving up benefits such as paid vacation and sick leave, employer-based health insurance, and private pensions, Marsha paid for training to become a licensed real estate agent. Moreover, she and her husband help with some of the boys' expenses and plan to continue to do so. As a result, their incomes and retirement nest eggs are much smaller than they had expected they would be. Thus, they both plan to work for another ten years, until Marsha is seventy-four (Harrington Meyer, 2014).

> I would have retired if I could have, but financially we could not. We needed more money, and we wanted to be able to help the kids with financial strain. It was a big financial strain on the kids to have two sons with special needs.

Marsha and her husband have learned what many other grandparents have learned: childhood disability rates in the US are increasing, but supports for families are not (Hogan, 2012; Zablotsky et al., 2019). Roughly 17 percent of US children have developmental disabilities (Center for Disease Control, 2019; Hogan, 2012; Kraus, 2017; Zablotsky et al., 2017). As a result, US grandparents provide a great deal of care for grandchildren with disabilities. When they do so, they face a myriad of social policy challenges. Here we explore three such challenges: (1) how access to employment benefits such as paid vacation, paid sick leave, paid parental leave, or affordable, high quality childcare shapes grandparent care work; (2) how access to poverty-based, social assistance programs, such as SNAP, SSI, and Medicaid, shapes grandparent care work; and (3) how access to disability policies and programs, such as those pertaining to accessible classrooms, parks, or apartments, shapes grandparent care work.

Grandparents are often highly coveted sources of grandchild care because they tend to be more flexible, lower cost, and reliable (Silverstein & Lee, 2016). Grandparents are generally much more nimble than organized daycare in that they are able and willing to rearrange their schedules to care for grandchildren before school, after school, evenings, weekends, holidays, snow days, and sick days (Cherlin & Furstenberg, 1992; Harrington Meyer, 2012, 2014; Loe, 2011; NACCRRA, 2008). They often provide care for free or at a very low cost. Moreover, they often share parenting styles and family values with their adult children (Barnett et al., 2012; Bengtson, 2001; Bengtson & Oyama, 2010; Hoang & Kirby, 2019; May et al., 2012; Musil et al., 2013; Silverstein & Giarrusso, 2010).

Grandparenting varies by socio-demographic factor, including gender, race, socioeconomic standing, and family composition. Grandmothers are more likely to provide care than grandfathers, Hispanic grandparents are more likely to live in multigenerational households and to stay in those households longer, and grandparents are more likely to provide care when their adult children are single parents (Harrington Meyer, 2014; Hayslip et al., 2019; Lou et al., 2012; Silverstein & Lee, 2016). African Americans are more likely to be custodial grandparents, and custodial grandparents are more likely to have lower incomes and to live in poorer housing in poorer neighborhoods (Baker et al., 2008; Livingston & Parker, 2010). Grandparenting is not for everyone; each year, about half of grandparents provide grandchild care, and the remainder does not (Harrington Meyer, 2014; Livingston & Parker, 2010).

To illuminate how social supports shape grandparent care work, we integrate excerpts from our forthcoming manuscript, *Grandparenting Children with Disabilities*.[1] We interviewed fifty grandparents who care for grandchildren diagnosed with disabilities. Interviews were transcribed verbatim; however, names have been changed to protect confidentiality. Like other studies, we found that the amount of support grandparents provide varies considerably (Hayslip et al., 2019; Livingston & Parker, 2010; Lou et al., 2012). Some live far away and help one weekend a month, some live nearby and help several times a week, some live in the same house and help every day, and some have become custodial grandparents and provide around-the-clock care and supervision. The types of care they provide also vary considerably and often include assisting with feeding, bathing, dressing, medicating, and transportation. Many help with homework, therapies, lessons, and doctor visits. Some assist with medical procedures, oxygen and feeding tubes, specialized wheelchairs, and other medical equipment. They often pay for expenses, including groceries, rent, utilities, nurse's aides, private school tuition, therapies, and legal fees. Several also advocate for their grandchildren, taking on programs like Medicaid, public schools, and landlords to garner the services their grandchildren need.

During our interviews, we found a great deal of joy about their special relationships. For example, Colleen, a sixty-two-year-old married mother of four and grandmother of nine, cares for seven-year-old Sam and two-year-old Kit, who both are diagnosed with Down syndrome. She avowed, "We love each other immensely .... I love all my grandkids. But these two, I just love everything about them." We also found frustration that US social policies did not provide more supports for families. Lizzy is a fifty-year-old divorced mother of one and grandmother of three. Her oldest grandson, Mark, who is twelve and has ADHD, has lived in her custody since he was two months old because his mother was addicted to drugs and his father died of a heroin overdose. Like several grandparents we interviewed, she found that there were

far too few resources and programs for grandparents of grandchildren with disabilities. She explained, "There are not many programs around here for anything like special needs .... So there is not support."

## Lack of Federal Policies for Working Families

Studies suggest that grandparents in the US provide more care than grandparents in many other countries because the US does not provide federal policies that help families juggle work and childcare (Baker et al., 2008; Igel & Szydlik, 2011). Igel and Szydlik (2011) find that in countries where policies help young families juggle employment and parenting, grandparents provide less intensive childcare. In countries with few such policies, grandparents provide more childcare. The US does not guarantee paid vacation, paid sick time, paid parental leave, or high quality affordable daycare (Harrington Meyer, 2014; Igel & Szydlik, 2011). Some US employees have access to these benefits through their jobs, but employers are more likely to offer these benefits to their higher paid and full-time employees (Glynn, 2012). The lack of federal guarantees makes it hard for both parents and grandparents to juggle work and childcare.

### *Paid Vacation*

Although 127 countries guarantee paid vacation to workers, the US does not (Glynn, 2012; Maye, 2019). Instead, 77 percent of US workers receive paid vacation benefits through their employer, but access varies markedly by hours and pay (Maye, 2019). Just 40 percent of part-time workers, compared to 90 percent of full-time workers, have paid vacation days (Maye, 2019). Roughly 52 percent of workers in the bottom quartile, compared to 91 percent in the top quartile, have paid vacation (Maye, 2019). Women, blacks, and Hispanics, because they are more likely to be in part-time or lower-waged work, tend to be less likely to have paid vacation time (Glynn, 2012). Employed parents who do not have paid vacation may have little choice but to call on grandparents for childcare.

### *Paid Sick Leave*

The US is the only developed country that does not guarantee workers paid sick leave (Boesch, 2018; Glynn, 2012). Instead, workers receive paid sick leave as an employee benefit, but access varies markedly. While most public sector employees receive paid sick leave, in 2018, 29 percent of private sector workers did not (Boesch, 2018). Currently, 61 percent of part-time workers, 69 percent of very low-wage workers, and 48 percent of service workers do not have paid sick days (Boesch, 2018). Hispanic workers are 27 percent less likely to have paid sick leave compared to white workers, and only 49 percent of Hispanic women have access to paid sick leave (Boesch, 2018). The lack of federal guarantees for paid sick leave makes it more likely that families will turn to grandparents for care.

### *Paid Parental Leave*

Although 180 countries offer paid maternity leave and eighty-one offer paid

paternity leave, the US offers neither (Heymann, 2013). According to Bureau of Labor Statistics (BLS, 2018), only 17 percent of the civilian labor force had access to paid family leave, which includes maternity and paternity leave. Workers are more likely to be offered paid family leave if they are full-time, higher paid, and in larger firms (Glynn, 2012). The US guarantees unpaid leave through the Family and Medical Leave Act, and the BLS (2018) reports that in 2018, 89 percent of civilian workers had access to unpaid family leave. However, to be able to take unpaid leave, employees must have worked with the company for twelve months, worked at least 1,250 hours during the preceding twelve months, and worked for an employer with at least fifty employees within a seventy-five-mile radius (BLS, 2018; Heymann, 2013). Nearly 74 percent of workers earning over $100,000 qualify, compared to 39 percent of earners making $20,000 (Heymann, 2013). Even when workers qualify for the program, many cannot afford to take advantage because they cannot afford to go without pay (Glynn, 2012). In the absence of paid parental leave, families may turn to grandparents to help them balance work and family (Harrington Meyer, 2014).

### *Affordable High Quality Child Care*

The lack of affordable quality daycare options puts tremendous stress on young families, particularly when children have disabilities. Among parents with a child under five, 83 percent reported that finding quality affordable childcare was a serious problem in their area (Malik et al., 2018). The US offers childcare support via tax subsidies, tax credits, and subsidized childcare (Malik et al., 2018). However, of the low-income families eligible for subsidized childcare, only 15 percent receive it due to long waiting lists and insufficient funding (Malik et al., 2018). Many childcare facilities do not accommodate children with disabilities; many are inaccessible and relatively few provide needed therapies or assistants, facilitate integrated learning and play, or work cooperatively with parents on solving problems that may arise at daycare (Booth-LaForce & Kelly, 2004; Boyle et al., 2011; DeVore & Bowers, 2006; Gaines & Curry, 2011; Hogan, 2012). Who cares for children with disabilities is particularly important because studies show that they are more likely to suffer physical, sexual, and emotional abuse and neglect, which adversely affects wellbeing across the life course (Cicchetti & Valentino, 2015; Maclean et al., 2017; McDonnell et al., 2019; Spencer et al., 2005; Sullivan & Knutson, 2000). Adult children often regard grandparents as the most capable and trustworthy source of childcare for children with disabilities (Barnett et al., 2012; Bengtson, 2001; Bengtson & Oyama, 2010; Hoang & Kirby, 2019; May et al., 2012; Musil et al., 2013; Silverstein & Giarrusso, 2010; Silverstein & Lee, 2016). Given the dearth of affordable high-quality options for children with disabilities, working parents may have few options other than relying on grandparents for childcare.

High quality daycare is not only an issue for youngsters. When growing

children have disabilities, families often struggle to find after school and summer programs. Chris says they always expected to move closer to the grandchildren when they retired, but they never expected to provide this much grandchild care (Harrington Meyer & Abdul-Malak, forthcoming). Chris is a sixty-seven-year-old married mother of two. She and her husband, who is on the heart transplant list, moved across the country to provide care for their two grandchildren, Wendy, who is ten and diagnosed with anxiety disorder and has autism-like symptoms, and Mark, who is seven and diagnosed with ADHD and Oppositional Defiant Disorder. Mark is prone to violent outbursts, and as he grows stronger, Chris and her husband face growing difficulties containing the violence.

> I was a bit surprised, once we moved here, that we have the kids so much .... I thought Mark would be in a structured after-school program; we thought he needed that, that it would be best for him. But he is not. I thought we would just have Wendy; she is much easier to watch. But we have them both. It's much more childcare than we expected.

Because of his violent outbursts, Mark has been expelled from several programs. Chris feels there should be many more programs for Mark that can accommodate his violence, provide him with the structure he needs, and provide his parents and grandparents with respite.

## Reliance on Poverty-Based Social Welfare Programs

Grandparents in the US also tend to be called upon for help more often than in other countries because social welfare programs in the US are primarily poverty-based rather than universal (Igel & Szydlik, 2011). As such, benefits tend to be small and emphasize gatekeeping. Key poverty-based social welfare programs include Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI), and Medicaid.

SNAP is a poverty-based program that provides food benefits to low income people. Although the eligibility rules and benefit levels for SNAP are set federally, state variation is substantial (Center on Budget and Policy Priorities, 2019b). Generally, households of three qualify if gross monthly income is below 130 percent of the poverty line, although households with people who are older or have disabilities do not have to meet this qualification (Center on Budget and Policy Priorities, 2019b). SNAP limits assets to $2,250 for households without and $3,500 for households with people who are older or have disabilities (Center on Budget and Policy Priorities, 2019b). To obtain benefits, individuals must overcome substantial red tape, including attending interviews and providing required documents, such as pay stubs, house payments, birth certificates, immigration records, and deductible expenses (Center on Budget and Policy Priorities, 2019b; Herd & Moynihan, 2019). Beneficiaries may have to reapply as of-

ten as every six to twelve months (Center on Budget and Policy Priorities, 2019b). Nonetheless, SNAP take-up rates are high; 85 percent of individuals who qualify for SNAP receive it (Center on Budget and Policy Priorities, 2019b). Benefits are so meager that an estimated 50 percent of households on SNAP remain food insecure (Coleman-Jensen et al., 2018). When families struggle to put enough food on the table they may turn to grandparents to provide financial assistance, cohabitate to combine resources or take custody of the grandchildren (Baker et al., 2008; Harrington Meyer, 2014; Luo et al., 2012; Silverstein & Lee, 2016).

Like many custodial grandparents, Elsie pays for absolutely everything but does not receive sufficient support from poverty-based welfare programs (Harrington Meyer & Abdul-Malak, forthcoming). Initially, Elsie, age sixty-two, had her daughter and grandson, Curt, both of whom have disabilities, living with her. When her daughter stole money to buy drugs, Elsie told her to leave and she became Curt's sole legal guardian. Curt, now age eleven, has ADHD and learning disabilities. Elsie is unemployed due to her own disabilities and is struggling to support them both on just $23,000 a year. She has Social Security and Medicare, and Curt has SSI and Medicaid. They are in dire straits, but have not been able to qualify for SNAP.

> I pay for everything, his clothes, school supplies, everything. As long as we are together and get both of our benefits, we will make it .... I make $100 a year too much to qualify for SNAP.

SSI provides cash benefits to people who are older or have disabilities if they are sufficiently poor enough to qualify (Center on Budget and Policy Priorities, 2019a). Generally, incomes must be below 75 percent of the federal poverty line, and assets must be below $2,000 for an individual and $3,000 for a couple (Center on Budget and Policy Priorities, 2019a). Applicants must overcome administrative burdens, including attending interviews, proving immigration status, or providing financial records, such as pay stubs, lease agreements, or diagnostic records (Herd & Moynihan, 2019). The program has been shrinking for the elderly but growing for those with disabilities (Center on Budget and Policy Priorities, 2019a). The combination of strict asset limits, meager benefits, and administrative burdens means SSI raises relatively few above the federal poverty line. Family members must often turn to each other for income stability as they raise the next generation.

As a grandparent, Connie, age fifty-seven, has expended a lot of time and energy fighting with SSI about benefits (Harrington Meyer & Abdul-Malak, forthcoming). Connie cares for Andy, who is two-and-a-half-years old and diagnosed with cerebral palsy. Andy and his mother live with Connie, and she cares for him about fifty hours a week. Andy receives $125 a month from SSI. Connie is paid a small stipend for caring for Andy, and her daughter has a full time job. In total they have

less than $60,000 a year to cover all of their expenses, which Connie says is not enough. Connie and her daughter have worked to obtain more SSI benefits, but in fact, their benefits have been reduced. She wishes SSI benefits were larger and more readily obtained. She becomes alarmed whenever she hears politicians propose reductions.

> I don't want to see any cuts at all. It's just, people are barely getting by now and for them to cut even more for people that depend on that, my daughter being one. Then what are they going to do? They're going to have all these people needing this stuff and not being able to get it and no place to get it from. So, it's kind of scary .... I fought with them, and I'm not fighting any more. If they cut it out, they cut it off, fine. What can you do with $25 a week? You can't even pay diapers.

Medicaid has expanded in recent decades and now covers more people with disabilities than ever (Musumeci & Foutz, 2017; Shea, 2016). Private insurance is often less desirable for people with disabilities because they may need specialized care such as attendant care, medical equipment or supplies, ongoing physical or speech therapy, assistance with feeding tubes, or IV medications, which are often excluded under private health insurance (Musumeci & Foutz, 2017; Shea, 2016). Medicaid coverage of those services is more robust; thus, it is often the preferred source of health insurance for people with disabilities. Medicaid expanded under Children's Health Insurance Program (CHIP) and the Affordable Care Act (ACA). Currently 20 percent of the US population, and one-fifth of all healthcare expenses, are covered by Medicaid. The expansion for children has been pronounced. Currently, 43 percent of Medicaid enrollees are children, and Medicaid covers 83 percent of children in poverty (Rudowitz et al., 2019). However, eligibility and benefits vary widely by state. In Louisiana, newborns on Medicaid funded programs are eligible with incomes up to 142 percent of the federal poverty line. By comparison, in Iowa, they may have income up to 380 percent of the federal poverty line.

Currently, Medicaid/CHIP covers 48 percent of children with special healthcare needs—only some of whom are diagnosed with disabilities. Medicaid covers a wide range of health services, including doctor's visits, hospital visits, prescription drugs, prenatal care, home and community-based services, assistive technologies, and mental health services. Medicaid also provides healthcare services that are particularly important for children with disabilities. Early Periodic Screening Diagnosis and Treatment (EPSDT) provides medical, vision, dental, and hearing screenings and interventions; physical, occupational, and speech therapies; and other health-related services to over 13 million children who have special needs (Bruder, 2010; Musumeci and Chidambaram, 2019a 2019b). EPSDT also covers private nursing, medical transportation, personal attendants, and some assistive technologies. Long-Term Services and Supports (LTSS),

through Home and Community-Based Waivers, provide services to keep people with disabilities in the community rather than in long-term care facilities. Generally, LTSS covers services including attendant care, medical equipment, and assistive technologies, but services vary tremendously by state and in some states, waiting lists for services are long (Eiken et al., 2018; Kaiser Family Foundation, 2017; Lewis et al., 2018; Reaves & Musumeci, 2015; Thach & Wiener, 2018).[2]

Although coverage is often comprehensive, Medicaid beneficiaries must overcome considerable administrative burdens (Herd and Moynihan 2019). Families who pursue care through Medicaid often face difficulties obtaining prompt appointments, garnering Medicaid approval of procedures or prescriptions, securing transportation to healthcare facilities, and coordinating care services (Chien et al., 2017; Kaye, 2019; Medicaid.gov, 2017; Musumeci & Chidambaram, 2019a; Musumeci & Foutz, 2017; Okoro et al., 2018; Rudowitz et al., 2019). Currently, 32 percent of US physicians will not accept Medicaid patients (Herd & Moynihan, 2019; Holgash & Heberlein, 2019; Rudowitz et al., 2019). In addition to completing financial paperwork to prove that they are sufficiently poor, those with disabilities must undergo physical examinations and additional paperwork reviews to prove that they are sufficiently disabled. As a result, some applicants endure delays in eligibility and services (Candisky, 2019; Harrington Meyer & Stevens, 2020; Hirschi et al., 2019; Whittle et al., 2017). In part due to these administrative burdens, only 75 percent of those who are eligible receive benefits (Moynihan & Herd, 2010; Rudowitz et al., 2016)

Hanna feels that Medicaid and other disability benefits should be more readily available, easier to obtain, and focused on early intervention (Harrington Meyer & Abdul-Malak, forthcoming). At seventy-one, Hanna is a Middle Eastern retired married grandmother who cares for her grandson Danny, now nineteen and diagnosed with autism. Danny missed out on most early intervention programs because he was not able to qualify for Medicaid benefits in time.

> I think the government should have made sure that teachers and doctors ... help much earlier. My daughter went to hell navigating the system to get him Medicaid. He didn't get Medicaid until, I think, a couple of years ago.

Whatever headaches are created by Medicaid's administrative burden, not being eligible for benefits can create nightmares (Harrington Meyer & Abdul-Malak, forthcoming). Since the birth of her granddaughter, Jill and her family are drowning in debt. Jill is a forty-eight year-old married mother of three and grandmother of three. She cares for her youngest granddaughter, Minnie, age three months, who is diagnosed with Down syndrome, a heart defect, and an intestinal disorder. Jill works full time from home and also cares for Minnie around the clock several days a week when Minnie's mother is at work. Jill says her daughter and

son-in-law earn $30 a month too much to qualify for Medicaid in their state, and they now have a $580,000 medical bill for Minnie's care, a bill that is growing almost daily. None of them have the resources to cover such an enormous bill; Jill is dismayed they are not receiving Medicaid assistance for her granddaughter's considerable medical needs.

> Because my son in law makes $30 too much a month, she will not qualify for supportive Medicaid or anything really as far as the state goes. So their medical bills, they've got a $580,000 medical bill that's now going to be the responsibility of us, both of us, to try and figure out how to pay ... even though it's a disability, it's not enough a disability for his income to allow her the extra medical coverage to make up the difference for what insurance doesn't cover. $580,000, right now, and growing. Yeah, we don't even have the latest hospital visit bill back yet ... and, that was only one hospital. She was in two when she was born, so.

## Limited Disability Policies and Programs

In addition to employer-based benefits and poverty-based benefits that are available to all, the US provides numerous pieces of legislation and programs designed specifically for people with disabilities. Although such policies aim to increase access and inclusion for people with disabilities, critics point out that disability policies are often difficult to use and poorly enforced. For example, the Individuals with Disabilities Education Act (IDEA) provides early intervention for infants and toddlers with disabilities until age three and special education for children over three (NECTAC, 2011; Stuart, 2018; US Department of Education, 2018). Legislation allows parents a role in creating annual Individual Education Plans (IEPs) with schools for students with disabilities, but many families struggle to get the services they need. These procedures are complicated and time-consuming and can be expensive. They are underused, particularly by those with less education and experience navigating paperwork (Araujo, 2009; NECTAC, 2011). At twenty-four months, only 12 percent of eligible children receive early intervention services, and eligible white children receive benefits at five times the rate of eligible black children. Those who are older than three, have families with lower socioeconomic status, and for whom English is not the first language often have more difficulties participating in, and maximizing the usefulness of, IEPs (Araujo, 2009; NECTAC, 2011).

During our interview, Mary noted how poorly this legislation functions for some families (Harrington Meyer & Abdul-Malak, forthcoming). Mary is a sixty-three-year-old mother of two and grandmother of three who attended some college and works part time. Four days a week, she provides childcare for her youngest, Alice, who is four and has been diagnosed with Williams syndrome, autism, and ADHD. At age three, Alice enrolled in public school

for early intervention. Although federal law requires them to do so, and although the family worked with specialists to develop programs that would be beneficial for Alice, the public school did not implement the supports that would encourage Alice's verbalization.

> At the time, Alice could only speak five words ... not a good situation. The school had no concept. We brought in pictures of her, lists of her strengths and needs, but they paid no attention. We might as well have burned them. We had taken her to specialists telling them how to create a program for her, saying you are going to have to hire a person to develop a program for her, but it was a nightmare in the school.

Mary says that Alice stayed at public school for four months, and then they moved her to a small private school that emphasizes teaching children to talk. In an ongoing effort to make sure that Alice's needs are met, Mary and her husband have paid for private school. They also hired a lawyer.

> Initially, my husband and I paid for part of it. Then we hired an attorney so the public school would have to help pay. We had to demonstrate that the public school was not giving her what she needed. They did an evaluation, but we wanted an independent evaluation. But they said no and tried to take us to due process. They declined an independent evaluation. We were challenging the evaluation the school had done. We hired an attorney to settle in mediation, and the school gave us a financial settlement so that we could pay for her schooling for two years, plus to pay for the co-pays for the PT and OT in addition to the speech therapy from the school.

For now, Alice's progress is good, but next spring, the two years will end, and the family will have to go back to the public schools for new evaluations and a new education plan. Paying for lawyers to help arrange educational services is challenging for Mary and her family, and utterly impossible for families with fewer resources.

Since 1990, the Americans with Disabilities Act (ADA) guaranteed equal treatment in, and equal access to, employment and public accommodations. Although all businesses and service providers are required to provide reasonable accommodations to employees and consumers with disabilities, many do not. Many of the grandparents we interviewed have no accessible parks in their areas or find that the accessible parks are minimalistic and not well developed. Several grandparents we interviewed talked about travelling long distances to playgrounds that are appropriate for their grandchildren with disabilities (Harrington Meyer & Abdul-Malak, forthcoming). Doris is advocating for more convenient and accessible parks. A fifty-five-year-old retired mother of two, Doris cares for her only biological grandchild. John, age eleven, has been diagnosed with atrophy of the brain, Lennox-Gastaut sei-

zures, and visual and hearing impairments. Doris lives just a few minutes away, and despite her multiple sclerosis, assists with John's feeding tube, ventilator, tracheotomy, and catheter. She wishes that there were more and better equipped accessible parks.

> There's all kinds of playgrounds and city parks. And one of them should be, one of them. We shouldn't have to travel out of state to go to a park that is handicap accessible .... We have some that have handicap accessible swings, but there might be one, one swing. There needs to be more activities for disabled children.

Even when they expend a great deal of time and resources to achieve equitable access, people with disabilities often find their needs are unmet or denied (Dunn & Andrews, 2015; Harlan & Robert, 1998; Priestley, 2003). Andy and his mother live with Connie, and she cares for him about ten hours a day Monday through Friday and then also sits for him occasionally on evenings and weekends (Harrington Meyer & Abdul-Malak, forthcoming). Because he is not mobile, Andy travels in a special wheelchair; additionally, his care requires several heavy pieces of medical equipment. To leave the apartment, Andy and the equipment must all be carried down flights of steps. Connie is not strong enough to do it all. While federal law requires public spaces to be made accessible, the owners of their apartment building have refused to put in ramps on the grounds that the building is private space. Connie and Andy are typically housebound unless Andy's mom is also there to help get him out of and back into the building.

> We don't go out as much because we live in an apartment building and we have stairs ... there's no ramps and that apartment complex doesn't want to put in ramps. We are pretty much stuck in the house so we go out on our deck and get some sun and air and stuff like that. Pretty much stay in all day. During the weekends when his mama's here, we go out. She carries him outside, and we'll either go to this grocery store or we'll go out to the mall or just, we've gone out to dinner with him. But, it's, his equipment is really heavy, and I have to be the one to carry his equipment down the steps to her car, and she carries him. And, I just can't do that by myself.

Thus, in addition to all of her other duties, Connie also spends a great deal of time and energy fighting for a much-needed ramp. So far her efforts have been unsuccessful.

> I've looked, and we want to get out of this apartment because it's been fighting tooth and nail with them to trying to approve ramps, and they go, "Oh, no, we're not going to pay for that. You have to."

Connie says that the entire family would readily move to an accessible apartment if they could find one they could afford. She dreams of winning the lottery.

## Discussion

The US welfare state provides very little support for children with disabilities or their families. As a result, grandparents provide a great deal of support. The US does not provide federally guaranteed paid vacation, paid sick leave, paid parental leave, or affordable high-quality childcare. When providing assistance for working families, the US relies almost entirely on poverty-based social welfare programs, including SNAP, SSI, and Medicaid. Due to the dearth of federal supports for families, unmet need is substantial, and families turn to grandparents for much needed assistance. In our interviews with fifty grandparents caring for grandchildren with disabilities, grandparents were providing childcare, bathing, feeding, transportation, and therapy; helping with homework; accompanying grandchildren to medical care; paying for everything from groceries to surgeries; and assisting with technical medical care. Several were also advocates for their grandchildren, fighting with administrators at SNAP, SSI, Medicaid, public schools, park districts, and landlords to garner the services their grandchildren need.

Caring for grandchildren with disabilities gives many grandparents a great deal of joy, satisfaction, and purpose. Although most are eager and happy to help, doing so may adversely impact their financial, social, emotional, and physical wellbeing (Harrington Meyer, 2014; Harrington Meyer & Abdul-Malak, forthcoming). Those with sufficient resources may be more readily able to absorb the impact, while those with fewer resources may not. Grandparents who provide the most care for grandchildren with disabilities and have the fewest resources are more likely to deplete their savings, incur new debts, reduce or end employment, restrict social lives, and forego travel plans. They are also more likely to experience anxiety and emotional distress, have disabilities of their own, and neglect their physical wellbeing through a lack of exercise, improper diets, and delayed medical and dental care.

Nearly all of the grandparents we interviewed need more social, medical, and financial support than they are receiving (Harrington Meyer & Abdul-Malak, forthcoming). They need policies and programs that will assist them as they care for their grandchildren with disabilities.

Federally guaranteed paid vacation days, sick days, and parental leaves would give all US families much needed support. If parents were more readily able to juggle work and family responsibilities, less would fall upon grandparents. Better access to high-quality affordable childcare that was much more responsive to the needs of children with disabilities would also provide much needed care for children and respite for families. Streamlining the application processes for poverty-based programs, such as SNAP, SSI, and Medicaid, and expanding the benefits would reduce challenges for families caring for grandchildren with disabilities. Finally, disability policies never seem to go far enough; a lack of responsiveness and accessibility often confounds grand-

parents. Better implementation and enforcement of a wide array of disability policies would enable children with disabilities to be more fully engaged. Because they have less income, education, and experience from which to draw, such policy reforms would make the biggest difference for families with relatively fewer resources.

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## Notes

1 Our sampling and methods are described in detail in Harington Meyer and Abdul-Malak (forthcoming).

2 States provide a wide variety of policies and programs for children with disabilities and space limitations prevent us from addressing these variations. One example, however, is Ohio where the Department of Health (2020) provides a *Family Handbook* that describes programs for children with special healthcare needs, including programs for children with medical handicaps and programs designed to help families integrate services.

# Restructuring Public Policy for Large Numbers of Elders Living with Disabilities

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## Abstract

With nearly twice as many elderly Americans living with disabilities expected within a dozen years, public policy must update and revise the social arrangements that support caregiving, disability, and old age. Needs that already often go unmet will mount, growing from quietly suffered indignities to broadly felt breakdowns. Inequities faced by young and old will compound this shared strain.

Creating long-term care financing arrangements, accessible housing stock, and resilient macroeconomics for an aging population will require long lead times and therefore prompt convergence and enactment of policies and programs to address these needs. For example, while academic and independent policy institutions have recommended public catastrophic long-term care social insurance and private insurance market reforms, delay in enacting these modest policies keep the US on a default course to underfunded but cripplingly expensive safety net obligations, any gaps in which will impoverish elders and their families. The US has not even developed a serious dialogue on disability adapted and affordable housing or on the macroeconomics facts that demand investment in highly productive young adults.

Equity, efficiency, and capacity of social services, caregiving, and medical care also require redesign over the next few years. Community arrangements shape much of the experience of declining health in old age. The US urgently needs to enable a number of communities (counties, cities, and rural regions) to move ahead aggressively to redefine excellence and affordability in eldercare, making exemplars that the rest of the nation could emulate.

Some critical issues do not yet have the language for public discourse, being treated as taboo subjects. We outline four of these and call for data and reflection.

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We all deserve to come to old age confident that we have the needed supports, so that we can enjoy the last of life with comfort and meaningfulness, without impoverishing the next generations.

***Keywords:*** homecare, health care delivery policy, aging network, Older Americans Act, social insurance, long term care insurance

## Reestructuración de la política pública para un gran número de ancianos que viven con discapacidades

Resumen

Con casi el doble de estadounidenses de edad avanzada que viven con discapacidades dentro de una docena de años, las políticas públicas deben actualizar y revisar los arreglos sociales que apoyan el cuidado, la discapacidad y la vejez. Las necesidades que ya a menudo quedan insatisfechas aumentarán, pasando de indignidades sufridas en silencio a crisis generalizadas. Las desigualdades que enfrentan los jóvenes y los mayores agravarán esta tensión compartida.

La creación de acuerdos de financiación de la atención a largo plazo, el inventario de viviendas accesibles y la macroeconomía resistente para una población que envejece requerirá largos plazos de entrega y, por lo tanto, una pronta convergencia y promulgación de políticas y programas para abordar estas necesidades. Por ejemplo, si bien las instituciones de política académicas e independientes han recomendado reformas catastróficas públicas del seguro social y del mercado de seguros privados a largo plazo, la demora en la promulgación de estas políticas modestas mantiene a los EE. UU. En un curso predeterminado con obligaciones de red de seguridad insuficientemente costosas pero agobiantes, cualquier brecha en lo que empobrecerá a los ancianos y sus familias. Estados Unidos ni siquiera ha desarrollado un diálogo serio sobre viviendas adaptadas para discapacitados y asequibles o sobre los hechos macroeconómicos que exigen inversiones en adultos jóvenes altamente productivos.

La equidad, la eficiencia y la capacidad de los servicios sociales, el cuidado y la atención médica también requieren un nuevo diseño en los próximos años. Los acuerdos comunitarios configuran gran parte de la experiencia de deterioro de la salud en la vejez. Estados Unidos necesita con urgencia permitir que varias comunida-

des (condados, ciudades y regiones rurales) avancen agresivamente para redefinir la excelencia y la asequibilidad en el cuidado de los ancianos, convirtiéndose en ejemplos que el resto de la nación podría emular.

Algunos temas críticos aún no tienen el lenguaje para el discurso público, siendo tratados como temas tabú. Esbozamos cuatro de estos y solicitamos datos y reflexión.

Todos merecemos llegar a la vejez confiando en contar con los apoyos necesarios, para que podamos disfrutar lo último de la vida con comodidad y sentido, sin empobrecer a las próximas generaciones.

***Palabras clave:*** atención domiciliaria, póliza de atención médica, red de envejecimiento, Ley de estadounidenses de edad avanzada, seguro social, seguro de atención a largo plazo

# 为大量残疾中老年人重组公共政策

## 摘要

鉴于未来十二年里年老的残疾美国人数量将是现在的两倍，公共政策必须更新且修订那些支持看护、残疾、和老龄的社会安排。那些经常未被满足的需求将会上涨，从不出声地忍受侮辱发展为大范围的崩溃。年青人与老年人面对的不平等将加重这样的压力。

为老龄化人口打造长期护理资助安排、可获取的住房存量、以及有韧性的宏观经济将需要长时间的准备阶段并因此推动政策及相关项目的融合与采纳，以应对这些需求。例如，尽管学术机构与独立政策机构已经建议对糟糕的公共长期护理社会保险和私人保险市场进行改革，但在通过这些适当政策时的拖延一直让美国处于一种默认资金不足但极为昂贵的安全网义务的过程，这种义务出现任何形式的不履行都将让中老年人及其家庭一贫如洗。就针对残疾人士的可负担住房或针对要求对高生产力的年青成人进行投资的宏观经济事实，美国甚至还未提出相关严肃对话。

公平、效率、以及社会服务、看护及医疗方面的能力也需要在未来几年里进行重新设计。社区安排对老龄人口健康情况下降的经历具有相当的影响力。美国急需让一些社区（县、城市和农村地区）快速取得进步性发展，以重新定义老年护理方面的卓越性和可负担性，为全国其他地区创造能够效仿的模范。

一些关键问题目前还不能在公共话语中出现，被视为禁忌主题。我们列出了四个禁忌主题并呼吁取得相关数据及反思。

我们都值得在老年时对我们所需的支持感到自信，进而能以舒适和有意义的方式享受生命的最后时光，同时不让后代贫穷。

关键词：家庭护理，医疗交付政策，老龄化网络，《美国老年人法案》，社会保险，长期护理保险

## Introduction

Most Americans will grow old; for that, we are thankful. Most of us will have a substantial period of illness and disability in the last years of life; for that, we are unprepared. Indeed, left to drift without deliberate change, current societal arrangements will leave many elderly people without housing and food during their last years, many families bankrupted, and ensuing generations in despair. Known and proven strategies to avert these outcomes abound; what is missing is the will to undertake substantial changes.

At the start of the 1900s, the average age at death was just forty-six years old. The dominant causes of death in adulthood included childbirth for women and occupational hazards for men; most Americans still lived on farms (Noymer & Garenne, 2000). The few people who lived into advanced old age usually had many descendants available to take them in, if needed. While old age has grown more common, fewer elderly have adult children capable of providing support and residing nearby (Ryan, Smith, Antonucci, & Jackson, 2012). We forget that supporting large numbers of disabled elderly people is new and that our society's practices were established in a very different era. Updating poses a set of public policy challenges.

Most of us will live past the traditional retirement age of sixty-five; and, while we will likely have some chronic conditions, we will mostly be quite functional at that age. But death is rarely entirely sudden. Modern living conditions and medical care have made it commonplace to live for many months with advancing illness and disabilities. Sudden death, or even dying over a few days, has become rare. Instead, elders now mostly gradually lose resilience due to illness (including frailty), so that staying alive becomes more and more precarious, and some unpredictable small disruption can create a cascade of inadequate responses that end in death (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). The average duration of disability in old age, sufficient to require daily help from another person, is now around two years, with an average price

of $266,000, and fully 14 percent of us will need this level of help for more than five years (Favreault & Dey, 2016).

We are woefully unprepared. The median household at retirement (ages sixty-five through seventy-four) has no savings at all, and the households with some savings average only $148,000 saved (U.S. Government Accountability Office, 2015, pp. 14-15), requiring elders to hope that other sources will meet their needs. Fewer own their homes than in the past, and banks hold more of the value of homes owned by retirees than ever before (U.S. Census Bureau, 2019; Rosnick & Baker, 2016, p. 23). About 10 percent have any insurance to help cover supportive care. Families are small, dispersed, and older. Nearly all housing stock has barriers to living with disabilities: entry steps, narrow bathroom doors, a flight of stairs to bathrooms and bedrooms, inaccessible tubs and showers, and so on. Personal care aides are scarce, poorly trained, paid below a living wage without benefits, and culturally distant from the elders they help. Many elderly people are isolated and lonely with no human contact for weeks at a time. Discriminatory practices in housing, jobs, and access to capital and savings make the situation even worse for African-Americans, Latinos, and women.

## The Situation

This is not the future we desire, and it is not the future we are doomed to endure. We can do so much better, but creating a worthy last phase of life will require mobilizing attention and practical improvements, some of which require a lead-time of a decade or more. The large rise in disabled elders will come in the 2030s, as the population over age eighty-five is set to double between 2015 and 2032 and to triple by 2050. In America in 2015, one person in fifty was older than eighty-five; by 2050, one in every twenty people will be (Houser, Fox-Grage, & Ujvari, 2018). The US has put off serious consideration of how to support elders who are living with serious disabilities , but we have run out of time. We must act soon or we will have to learn to abandon a very large number of elders who have no means of support.

As one would expect, social change as dramatic as the new prevalence of disabled elderly people will have ramifications throughout the broad society. The major issues that this essay will develop are in these domains: financing, housing, the macroeconomy, the direct-care workforce, medical care, food provision, transportation, and inclusion in human relationships. The urgency of reforms is driven by the quite predictable rise in the number of disabled elders, with issues like financing, housing, and the economy having priority because they require long lead-times.

## Reforms that Require a Decade or More

Many Americans remember a time when people in their last years of regular work often threw a party to tear up the paid-off mortgage. A few years later, they re-

tired, with a pension, Social Security, and a secure home. And then they died, mostly within a decade, living frugally but having enough, especially when Medicare started picking up the medical bills. Most elements of this picture have become rare. Few have pensions, many lost their home equity in the recession in 2008, many cannot fully retire because they need additional earnings from the gig economy, and more and more are losing their housing.

How dire is the financing of retirement and the period of ill health and disability? Within a decade, most Americans who lived in the middle class during their working years will be unable to afford housing and supportive services (Pearson et al., 2019). More than two-thirds of Americans in the decade leading up to age sixty-five have less saved for retirement than a year of current income—a sum sure to be inadequate for the typical twenty years of retirement (Brown, Saad-Lessler, & Oakley, 2018, p. 11). One-half of those in the first decade after age sixty-five have no savings at all (U.S. Government Accountability Office, 2015, p. 14). Likewise, long-term care insurance provides a variable level of protection for only one-tenth of the retiree population, and premiums increase and coverage declines for most policies every year (Johnson, 2016).

In short, we face a future in which most elderly persons will not have financial resources to cover their needs in retirement and eventual disability. Some will qualify for Medicaid, but Medicaid's threshold for long-term care support will have to become ever more draconian since states must balance their budgets. Elders with income or assets above Medicaid limits will have to rely upon family and community supports. When those are not enough, disabled elders will have to go without food, heat in winter, cooling in summer, medical care, personal care, and housing. Relying upon family to support a destitute elder generates financial depletion for successor generations, an approach that epitomizes imprudent social arrangements when done on the broad scale that is anticipated.

The costs of living in retirement and eventually with disabilities pose a classic situation ripe for an insurance solution. No one can know what he or she will need—whether no long-term supports at all or two decades of around-the-clock personal care. Every American family with members in or approaching old age will be forced into a pernicious gamble, held accountable for the unpredictable amounts of care for disabilities that elders will experience in old age. A thoughtful middle-aged person could scrimp and save to cover as much as two years of nursing home care, around $250,000, and still have the misfortune of needing four years, or twenty years. That thoughtful person cannot buy long-term care insurance to cover these extreme risks since no company now offers this sort of policy. Much like fire insurance or liability insurance, it makes sense to pool funds to cover the most threatening of the risks when the costs are unpredictable. No insurance company can enroll enough people to take on the extreme

risks – the persons who live in nursing homes for twenty years or more. These risks are very expensive and require a very large enrolled population to build a useful insurance product (Convergence Center for Policy Resolution, 2016, pp. 8–10). This is the sort of situation that should lead to government involvement, where funds can be automatically collected from large numbers of people to provide a pooled resource.

However, elderly people living with disabilities have an astonishing variety of personal preferences and family resources, including financial assets and personal relationships. Getting governments involved in making an unending array of fine distinctions as to family obligations and fair allocation of government support would be detrimental to good order, trust in government, and the value of family. Having individuals make decisions that reflect their situation, preferences, and acceptance of risks is much better public policy, which is what this proposal encourages. Furthermore, this proposal adds only a modest part of the overall costs of long-term care to government control, making it more acceptable. Thus, an optimal policy is to have the government pick up the exceedingly long needs for long-term care and leave the typical shorter-term needs to individuals and their communities and organizations (Cohen, Feder, & Favreault, 2018; Convergence Center for Policy Resolution, 2016, p. 12).

The fact that elderly persons needing supportive services will mostly have had the opportunity to work, usually for many years, makes it appealing to derive the funding for governmental long-term care coverage from collections from income during those working years, thus paying for catastrophic protections in a palatable manner over many years. Automatic participation lowers administrative costs and mitigates the effects of outliers because of the broad risk pool. For the same reason, working persons with existing health risks for disability would not be excluded from the insurance pool, unlike their frequent exclusion from private markets (Johnson, 2016, p. 5). A high-wage earner would be expected to self-fund more long-term care, based on their ability to have saved or bought insurance for a longer initial period of long-term care needs. Lower wage earners would have a shorter delay for which they must plan for their own long-term supports and services, since they would have had less opportunity to save for disability in retirement.

This approach has been modeled with a ten-year minimum contribution period before allowing pay-outs from the insurance, with individuals covering their needs for one to four years depending upon their earnings (Cohen, Feder, & Favreault, 2018). An elder's self-coverage period would begin once documented to be dependent in two activities of daily living (ADLs), such as moving about, getting dressed, and feeding oneself. After the first one to four years, the public insurance would provide $110 per day (in 2010 dollars) for as long as needed. This particular structuring would cost about 0.85 percentage points added to the earnings

tax for Medicare after workers reach age forty. The surcharge would sustain this long-term-care backstop for at least the next seventy-five years (p. 22). For workers, the catastrophic insurance mechanism costs them less than half of what they have been found to be willing to pay out of each paycheck for long-term care premiums (p. 9). Note, however, that this approach would require a ten-year introductory phase before any benefits were paid, so it would be helpful for financing of long-term care by the early 2030s if implemented now. This approach would greatly reduce the number of elderly who spend-down to Medicaid, thus reducing the pressure on Medicaid. Liberal and conservative think tanks alike have suggested frameworks similar to the proposed structure (Calmus, 2013; Veghte, Bradley, Cohen, & Hartmann, 2019).

How would elders pay for the first years of needing supportive care? We could save through our working years, we could have large and well-financed families willing and able to be of help, our communities and organizations could pitch in (as Washington state has done with $36,500 of first-dollar coverage for workers in that state (Veghte, Bradley, Cohen, & Hartmann, 2019, p. 190), and we could buy long-term care insurance privately that reflects our situation and willingness to take risks. Insurance companies, freed of the risks of very long durations of long-term care, would offer a variety of coverage packages to individuals, companies, and organizations to precede and wrap around the government's catastrophic coverage. The insurers might offer a mix of long-term care coverage with annuities, for example. Minnesota is investigating adding first-year coverage of long-term care costs to Medigap policies. Very likely, a wide variety of vehicles for covering the first year(s) will arise.

A second element that requires substantial lead-time is housing, because only a small proportion of a community's housing is built in any one year. Most existing housing poses challenges for disabled elderly people on three counts: inaccessibility, risk of harm, and unaffordability (Smith, Rayer, & Smith, 2008). Some existing housing can be modified to accommodate a disabled person at a reasonable cost: for example, with entry ramps, hand bars in the shower, and handrails on the steps. Under federal law, 7 percent of new housing built with public funds must be disability-accessible, but that housing need not be sold or rented to a person who needs it. In 1985, Singapore started requiring all new housing and major renovations to include elements enabling disabled persons to function well, making most housing accessible now to a person using a walker or wheelchair (Graham & Bilger, 2017). Communities in the US could follow that example. The federal government could require more disability-adapted housing when rebuilding after disasters or providing insured loans, and local zoning laws could facilitate the housing additions seniors need to age in place (Scharlach, 2012; Smith, Rayer, & Smith, 2008). When planning and subsidizing housing for seniors who downsize in late middle-life, communities can low-

er barriers to mobility, thus reducing the costs of frailty (Prosper, 2004). This country would still have challenges in the supply and costs of housing, but at least the challenges would not disproportionately afflict persons living with disabilities.

A third element that requires substantial lead-time is deliberately investing in a stronger economy (National Research Council, 2012). Some developed countries, such as Japan, have realized that having a large population that is no longer conventionally productive in old age will require having a robust economy that can bear some added taxation. They invest in ensuring that children arrive at young adulthood with marketable skills and jobs. The US is still willing to have most children be born in poverty and to sustain high rates of incarceration and low-wage jobs, which suppress the economy. Being concerned about low wages for service jobs and marginalization of children, immigrants, and people of color may seem far afield of eldercare policy, but the connections are quite strong and obvious. The wellbeing of elders depends on keeping the US economy growing.

## Reforms to Services in Local Communities

Much of the experience of living with disabilities in old age depends upon the arrangements that have developed, usually without much planning, in the local community. How difficult is it to get food delivered to a homebound elder? Is the food appealing and appropriate to the person's medical conditions and culture? Are homecare aides available and are they skilled in handling behavioral problems arising from dementia or the personality of the elder being served? Is there transportation from door to door oronly curb to curb, or does public transportation leave the frail to navigate the first and last miles? Are services affordable? Does the elder have a medical team that participates in developing comprehensive care plans that reflect the priorities and preferences of the elderly person and their family? Do local employers support family caregiving?

Communities vary greatly in their readiness to support disabled elderly people. Many cities now have more than six-month waiting lists to get home-delivered food, and most do not offer door-to-door transportation. Some have active "Villages" that help with neighborly services, like getting groceries, making minor repairs and upkeep, and providing companionship, while other communities have no such services.

The federal support for these services comes through the Area Agencies on Aging (AAAs), which are established under the Older Americans Act (OAA). Every part of the country has an AAA, which is required to develop a directory of services, provide nutrition services, assess community needs, and advocate for eldercare in their locality. The OAA has had nearly flat funding for the past twenty years, while the population needing services keeps growing. Some agencies and

communities supplement the resources available; however, this strategy is less effective for areas with few resources. OAA funding needs substantial escalation. Once it approaches an adequate funding level, automatic adjustments to funding to match inflation and the number of elderly people in need will be essential. Medicare spending more than doubled between 2004 and 2015, while OAA funding grew by less than 5 percent, and the population older than age sixty-five rose by more than a third (Parikh, Montgomery, & Lynn, 2015, p. 401). For example, a diabetic senior, waiting with an empty pantry and empty stomach, dials up Meals on Wheels and is placed on a many-months-long waitlist. However , calling for an ambulance gets that diabetic senior treated by high-paid specialists, "rescuing" that elder from harms that could have been avoided by having food at home.

The workforce for personal eldercare includes family (and sometimes other volunteers) and paid direct-care workers. Severe shortages of these workers limit supports for disabled elders. Both kinds of caregivers suffer from limited training and support. Family caregivers often must provide services that would require professional licenses if performed in hospitals or nursing homes, and they often must be on standby twenty-four hours per day. A family member caregiving full-time loses an average of $303,880 of income and retirement security, often guaranteeing inadequate funding for the caregiver's retirement and long-term care (Met Life Mature Market Institute, 2011). The psychological burden, lost career advancement, and lost leisure time cost the caregiver much more (Coe, Skira, & Larson, 2018; Mudrazija, 2019).

Paid caregivers still work, on average, for less than $12 per hour, mostly without benefits, making this one of the most difficult and injury-prone occupations at one of the lowest wage scales in the nation (Scales, 2019, p. 43). Workers have no career ladders to justify long-term commitment. One-third of these workers are immigrants (p. 27). These paid workers usually have incomes at or below the federal poverty line, never have the opportunity to save for retirement, endure cultural and personality differences with the person served, and experience a high rate of job-related injuries. The fact that caregiving to elders has a severe supply shortage is hardly surprising, and the corrective policies are evident (pp. 67–101).

Paying adequately for caregiving would challenge private resources and Medicaid, but doing so seems to be required, both to encourage economic growth and to appropriately value this difficult work. The US should professionalize paid caregiving, with adequate compensation and benefits, ongoing education, and career ladders. For family caregivers, the US should provide targeted financial support, training, respite, back-up, employer flexibility, credit for caregiving work in Social Security and long-term care catastrophic insurance, and neighborly support for a range of tasks appropriately done by a volunteer.

Indeed, the advent of substantial numbers of elders needing help to live

in the community calls for a revival of neighborliness. Neither Medicaid nor elderly people should generally pay for the kinds of help that nearby residents could readily offer: minor repairs, minor upkeep of the outdoor area, changing light bulbs, delivering groceries, taking out the trash, and just being a friendly companion. Widespread and coordinated volunteers would reduce the per capita costs of disabilities and add meaningfulness and socialization to our later years. The Villages movement has started reforms in this arena, but coverage needs to grow rapidly and probably needs a variety of arrangements. Widespread volunteer services pose a public-management opportunity requiring new policy guidance, free-of-charge management software, and other inducements. Governments at all levels could provide these encouragements.

Communities also need to attend to their transportation arrangements. Some disabled elders can readily use public transportation, where available. But many can only get to the curb and some need help getting that far. Internet-enabled transportation services (like Uber and Lyft) might inspire a new generation of targeted mass transit that address not only the "last mile" but also the last few feet. Self-driving cars, some with attendants, might open substantial possibilities. All too often, an elderly person with mobility challenges is effectively imprisoned due to a lack of adequate help in getting around.

The most far-reaching reforms involve moving services to the disabled elder's home efficiently. The US has an unexamined belief in competition as the heart of reducing costs and securing quality, one that ignores key complexities in eldercare. Many areas have competing homecare services that incur the costs of servicing a small percentage of the elders in need in a large area, and then impose minimum visit durations to reduce travel time. Between travel time and minimum stays, homecare services can waste half of the payment dollar. Most countries arrange homecare dominantly by geographic area, so a nurse, an aide, or any other service provider can move from one home to the next efficiently and thereby get to know the resources and challenges of that neighborhood. In France, for example, mail carriers—who already visit every home—check in with local elders on behalf of family, who subscribe to the service for a nominal fee (Poll, 2019).

The US would be in a much better position to undertake serious transformation to improve eldercare if we enabled a small number of quite diverse communities (counties, cities, and regions) to put all the community-anchored reforms in place, monitored by population-based metrics (Lynn, 2016). We do not now have any exemplar communities, and we do not trust that we could follow good practices demonstrated by communities in other countries.

## Reforms in Medical Care

If we had convened a dozen ninety-year-olds and their caregivers to design Medicare, they almost certainly would have included dental care,

hearing aids, vision care, podiatry, and rehabilitation. But we did not do that. Medicare was designed to cover the expensive medical procedures needed by persons near retirement age—mostly surgical operations. Revisions since have covered dialysis and drugs but not the elements needed to live with declining hearing, vision, and mobility. Indeed, medical care for elderly persons living with progressive illnesses and disabilities is all too often marked by overuse of medical interventions, as well as some discriminatory underuse. Very few physicians are trained in geriatric syndromes, and even fewer engage in comprehensive care planning that reflects what matters most to elderly persons and their families. Home visits are rare, concern for the caregiver(s) is uncommon and not generally documented in the patient or caregiver record, and continuity across settings and time is nearly nonexistent. Efficient care for patients in their later years requires a high-functioning continuity team with substantial engagement with their community and skills in behavioral management, spiritual support, rehabilitation, prevention, treatment, and care planning—all in an environment where critical supportive services are readily available. This is out of reach for nearly all Americans.

Medicare could start covering more of the elements that are important—either for everyone or by beneficiary choice. Continuity and care planning should be key to the "care redesigns" encouraged by the Center for Medicare and Medicaid Innovation. Medicare pays for most graduate medical education—physician trainees could be required to learn how to serve ill or disabled elders. Medicare could generate community-level data as to how well eldercare arrangements are working. This relatively small change could generate a culture of learning among the many systems serving elders. For personal planning and in the community interest, the public should know elements that are not now available: e.g., the risks and causes of impoverishment in old age, the likelihood of care at home rather than in the Emergency Room, and the risks of and protections against neglect or abuse. The public should demand honest prognoses, comprehensive care planning, and reasonable availability of supportive services, and local governments should help manage eldercare arrangements in their area.

## Four Challenging Considerations for Reformers

Eldercare in the US is boxed in by a lack of direction with regard to four issues that have rarely been discussed as matters affecting public policy:

1. How shall we serve those among us who lose memory and cognition?

2. What shall we do about the remarkable disparities in resources and lifespan that afflict persons arriving at old age with the life-long effects of discrimination?

3. How shall we begin to work with the obvious interaction of the timing of death and the resources used?

4. What burdens will we expect family members to bear?

These difficult challenges have mostly gone unexamined. When people lose their sense of self and recognition of others, some courts have found them to be disabled within the meaning of the protections for disabled persons and have ordered life-extending treatments (even those that incur substantial pain and distress), while many people see this situation as one of living with a fatal illness that calls for palliative care and little life-extension. Bearing the effects of life-long discrimination and limited opportunities, African-Americans at retirement average only one-seventh of the savings that white households have (Bricker, 2017; Carr, 2019). Our evaluations of treatment strategies often evaluate mortality or cost, but seldom explicitly consider that most costs of living with disability arise from living with disability, and an earlier or later death often has more impact on costs than any treatment effect or effort to achieve savings. Finally, our habits in planning for and delivering eldercare assume that families will take care of their own, but family members now often do not exist, or they cannot or will not take on the burdens of caregiving for indefinite time periods with limited support; these situations are not explicitly incorporated in decisions about public support.

The lack of public discussion of these issues arises from the lack of established language to address the issues, the newness of the situations, and a lack of leadership. However, these are important issues, and we will eventually have to find ways to acknowledge them and find morally acceptable responses.

## Conclusion

Whenever public figures talk about eldercare and caregiving, they most often tell their own family story, usually about how an older parent is faring or fared before death. Remarkably, just like most other Americans, these policymakers relate positive or negative aspects of their experience with the family member's situation and the responses of the family and the elder; they do not usually take note of how policies shaped what happened and what can happen now. Yet, how this society has structured itself profoundly shapes the possibilities for how one can live with disabilities in old age. Our structures are overly generous about medical care, making all of it an entitlement. The situation warrants substantial reinvestment in supportive services. We could bring dental care, hearing and vision supports, and home delivery of medical care and food into the scope of medical insurance coverage. We could support family caregiving and pay direct care workers a fair wage. Because of the long timeline, we must quickly work on the financing issues, aiming to make self-funded long-term care the norm by supplementing the Medicaid-based public safety net with a combination of public catastrophic insurance and private savings. For the same reason, we need to invest now in disability-adapted housing and in facilitating young adults' contributions to a highly productive economy. Along the

way to these good ends, many additional reforms should be enacted. We all deserve to age with confidence that we will have the support we need and that we will be able to enjoy the last phase of life with comfort and meaningfulness, without impoverishing the next generations.

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# Developing Age-friendly Cities: Policy Opportunities and Challenges

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Abstract

Since the mid-2000s, the need to create age-friendly cities and communities, meaning places where older people are actively involved, valued, and supported, has emerged as a major concern for urban policy. The World Health Organization (WHO) has driven this age-friendly agenda through its Global Network for Age-friendly Cities and Communities (GNAFCC). This paper reviews some of the challenges associated with the development of this policy, given the variety of economic and social pressures facing urban communities. The discussion provides background to the development of the age-friendly model and a summary of some of the factors necessary for its successful implementation. The paper then reviews a range of key areas where age-friendly policies might be developed, with a particular focus on issues relating to the various inequalities affecting older populations. The paper also emphasises the importance of future age-friendly work being grounded in collaboration with the range of movements seeking to improve the quality of life of people living in cities. The paper concludes with a call for a more inclusive age-friendly movement, one that acknowledges the full diversity of aging experiences.

***Keywords:*** age-friendly, urban policy, inequality, co-production

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# Desarrollando ciudades amigables con los mayores: oportunidades y desafíos políticos


## Resumen

Desde mediados de la década de 2000, la necesidad de crear ciudades y comunidades amigables con los mayores, lo que significa lugares donde las personas mayores están activamente involucradas, valoradas y apoyadas, se ha convertido en una preocupación importante para la política urbana. La Organización Mundial de la Salud (OMS) ha impulsado esta agenda amigable para las personas mayores a través de su Red Global para Ciudades y Comunidades Amigables para las Personas Mayores (GNAFCC). Este artículo revisa algunos de los desafíos asociados con el desarrollo de esta política, dada la variedad de presiones económicas y sociales que enfrentan las comunidades urbanas. La discusión proporciona antecedentes para el desarrollo del modelo amigable con la edad y un resumen de algunos de los factores necesarios para su implementación exitosa. Luego, el documento revisa una variedad de áreas clave donde se pueden desarrollar políticas amigables con la edad, con un enfoque particular en los problemas relacionados con las diversas desigualdades que afectan a las poblaciones de mayor edad. El documento también enfatiza la importancia de que el trabajo futuro favorable a la edad se base en colaboración con la gama de movimientos que buscan mejorar la calidad de vida de las personas que viven en las ciudades. El documento concluye con un llamado a un movimiento más inclusivo y amigable con la edad, uno que reconozca la diversidad completa de las experiencias de envejecimiento.


***Palabras clave:*** amigable con todas las edades, política urbana, desigualdad, coproducción

# 发展老年友好型城市：政策机遇与挑战


## 摘要

自2005年前后开始，创造老年友好型城市和社区（即老年人获得积极参与、价值和支持的地方）的需求已成为城市政策的一个主要关切。世界卫生组织（WHO）已通过其全球关爱老年城市和社区网络（GNAFCC）来推动该老年友好型议程。鉴于城市社区面临的不同经济压力和社会压力，本文审视了

与该政策发展相关的一些挑战。讨论部分为老年友好型模式的发展提供了背景，并为其成功执行的部分必需因素提供了总结。本文随后审视了一系列老年友好型政策可能得以发展的关键领域，尤其聚焦于与影响中老年人口的各种不平等相关的议题。本文还强调了未来老年友好型工作的重要性，这项工作基于与试图提升城市人口生活的不同运动进行协作。本文结论呼吁进行一项更具包容性的、承认老龄化经历多样性的老年友好型运动。

关键词：老年友好，城市政策，不平等，合作提供

## Introduction

Population aging is taking place across all countries of the world, raising major issues for the direction of public policy. By 2050, one in six people in the world will be sixty-five and over (16 percent), up from one in eleven in 2019 (9 percent). In Europe and North America, one in four persons is expected to be aged sixty-five or over by 2050 (United Nations, 2019). Of equal importance is the continuing spread of urbanization, with 55 percent of the world's population now living in urban environments (UN, 2018). The relationship between these two major trends—aging and urbanization—is now the subject of increased academic and policy analysis. The Organisation of Economic Cooperation and Development (OECD) (2015, p. 18) argues that:

> Designing policies that address ageing issues requires a deep understanding of local circumstances, including communities' economic assets, history and culture. The spatially heterogeneous nature of ageing trends makes it important to approach ageing from an urban perspective. Cities need to pay more attention to local circumstances to understand ageing and its impact. They are especially well-equipped to address the issue, given their long experience of working with local communities and profound understanding of local problems.

Cities are regarded as central to economic development, attracting migrants, professional workers, and knowledge-based industries (Burdett & Sudjic, 2016). Urban environments create many advantages for older people, for example through providing access to cultural activities, leisure facilities, and specialist medical care (Phillipson, 2010). At the same time, they may also produce feelings of insecurity, arising from the impact of urban regeneration, population turnover, and environmental problems associated with climate change, together with high levels of pollution[1] (Burns, Lavoie, & Rose, 2011; Rolnik, 2019; Wallace-Wells, 2019).

The pressures associated with city living indicate challenges for policies seeking to reconcile population aging with urban development (Buffel & Phillipson, 2016). An emerging theme has concerned the need to create age-friendly cities and communities. Alley et al. (2007, p. 4) define an age-friendly community as a "place where older people are actively involved, valued, and supported with infrastructure and services that effectively accommodate their needs" (see, also, van Hoof, 2018). The period from the mid-2000s saw a substantial growth of interest in age-friendly issues. This initial period of development recorded a variety of achievements, linking aging populations to the need for changes to the built environment, transportation, housing, and neighborhood design (Moulaert & Garon, 2016; Stafford, 2019). However, a combination of widening inequalities within and between urban environments, and the impact of austerity on local government and city budgets, has raised questions about future progress in age-friendly and related activities. Age-friendly programs encompass interventions across a range of environments, from large metropolitan areas to isolated rural communities. In this paper, and reflecting the bulk of research to date, the discussion focuses on issues faced by older people living in urban neighborhoods. This article contributes to the debate on developing age-friendly programs, with particular attention to factors that might assist in extending their influence across different groups and communities. The paper does this by, first, reviewing their origins; second, outlining success factors behind their development; and third, examining new approaches to advancing age-friendly interventions.

## The Development of Age-Friendly Cities and Communities

The relationship between population aging and urban change has become the focus of various initiatives, for example, through the American Association of Retired Persons (AARP), the International Federation on Ageing (IFA), and AGE Platform Europe. The age-friendly perspective was first developed by the World Health Organization (WHO) (2007; 2015; 2018) through a project examining the experiences of older people living in urban environments. The result of this work was a guide identifying the key characteristics of an age-friendly community in terms of *service provision* (e.g., health services, transportation), the *built environment* (e.g., housing, outdoor spaces, and buildings), and *social aspects* (e.g., civic and social participation) (WHO, 2007). This guide has since become one of the most frequently used tools to assess the age-friendliness of cities and communities (Plouffe, Kalache, & Voelcker, 2016). To encourage dissemination of its work, the WHO launched in 2010 the Global Network for Age-friendly Cities and Communities (GNAFCC), which by 2020 had reached a membership of around 1000 cities and communities in forty-one countries.[2]

The growth in popularity of the age-friendly movement has led to the development of various age-friendly frameworks and initiatives. These can be found under headings such as "age-friendly," "elder-friendly," "aging-friendly," "livable," and "lifetime neighborhoods" (see, further, Buffel, Handler, & Phillipson, 2018). The difference in terminologies reflects the variety of approaches to, and organizations involved in, creating age-friendly environments. Lui and colleagues (2009) developed a typology for categorizing these, with models ranging from an emphasis on the *physical* versus *social* environment on the one hand, and from *top-down* to *bottom-up* governance on the other. Some models focus on adapting the *physical infrastructure,* for example through providing access to green spaces, promoting home adaptations, and enabling mobility and walkability,[3] while others pay more attention to *social aspects* of the environment by emphasizing inclusion, participation, and social support.

Scharlach (2016, p. 313) emphasizes the importance of combining both physical and social infrastructure in building age-friendly communities, highlighting the following elements:

1. Adequate general physical and social infrastructures that promote health and wellbeing for the entire community;

2. Minimal age-related barriers faced by older community members in trying to access that infrastructure;

3. Compensatory and enabling features that respond to the particular age-related needs and sensibilities of older community members;

4. Mechanisms for engaging older adults as valued members of community life.

What are the success factors identified in the research literature that can assist in the development of age-friendly policies? Fitzgerald and Caro (2016) identify the main ones as a large and growing concentration of older people, a strong network of social and civic organizations, the availability of health and social services, an extensive transportation network, a variety of housing options, and access to green and open spaces. Another factor cited as important in the research literature is the extent to which cities and communities can mobilize a range of stakeholders, built around partnerships with public, private, and third sector organizations (Garon et al., 2014). Linked with this is the need for strong political leadership in gaining support for age-friendly policies at local and regional levels of government (Moulaert & Garon, 2015). McGarry (2018, p. 247) illustrates this from developments in Manchester, UK (an early member of the GNAFCC), commenting on the extent to which the work has "been able to secure much needed political support [by] harnessing leadership around the ageing agenda within the local authority, and embedding age-friendliness increasingly firmly into local authority thinking." Drawing on the example of Portland

,Oregon, in the US, Neal et al. (2014, p. 96) cite "existing relationships between the university and local city planning and other government agencies" as a strength of the age-friendly program developed in the city.

Second, the ability of cities and communities to develop their own interpretation of the age-friendly model has often been described as a feature of the WHO approach. Various researchers have advocated the need for the movement to remain flexible in adapting to the needs of each local context (Liddle et al., 2014; Menec et al., 2011).

The notion of flexibility has been interpreted in various ways in the age-friendly literature. Liddle and colleagues (2014), for example, stress the importance for the age-friendly movement to extend its focus beyond cities. They question the ability of the WHO's age-friendly definition to be applied to non-city settings (e.g., rural areas and retirement communities). Flexibility will also be important in the context of new challenges facing cities, not least with the effects of climate change, the impact of pandemics (such as COVID-19), and the movement of populations arising from civil and military wars (Gatrell, 2019; Mehta, 2020).

Third, the extent to which policies for older people are integrated with the management and planning of cities, will be an important element in developing successful age-friendly policies. Social policies can promote older people's participation in urban change in a variety of ways: for example, by ensuring greater use of the resources associated with living in cities. Urban regeneration can benefit from the skills and experience of older people and the attachments they bring to their neighborhoods (Lewis et al., 2020). However, as a group, older residents often tend to be "invisible" in the implementation of policies. Kelley, Dannefer, and Masarweh (2018, p. 56) refer to this as a process of "erasure," whereby "certain groups are 'unseen' in policy, research, or institutional practice." Making cities more age-friendly will therefore require radical interventions in terms of involving both older people and the generation approaching old age as key actors setting the agenda for future urban development (see further below).

## New Directions for the Age-Friendly Movement

Despite the many achievements arising from age-friendly activities, a variety of problems may frustrate the growth of high-quality programs. The initial development of age-friendly work came at a time of economic growth, with an expansion in public sector programs of different kinds. However, support for these was thrown into reverse with the financial crash of 2008 and the application of neoliberal policies, which led to a scaling back of social protection for vulnerable groups (McBride & Evans, 2017; Walsh, 2015). Thus, the implementation of age-friendly programs has come during a period when cities are experiencing substantial reductions in physical infrastructure and services, including the closure of libraries, cuts to

community center provisions, and the tightening of eligibility for support for home and residential care (Klinenberg, 2019; Toynbee & Walker, 2020).

Changes in the economic and social environment facing cities are raising important issues for the way that the age-friendly movement might progress over the next decade. To consider these, the next section of the paper identifies a number of areas for development, grouped under the following headings: linking age-friendly work with urban policies and movements, focusing on social inequality, acknowledging diversity around health issues, securing innovation in work within neighborhoods, and strengthening research programs on age-friendly issues.

## *Linking Age-Friendly Work with Urban Policies and Movements*

A starting point for extending the scope of age-friendly activity would be to strengthen collaboration with movements that are campaigning to improve urban environments. The growth of age-friendly work has been led in Europe mainly by departments within local government; in other countries (e.g., the US), non-governmental organizations (e.g., AARP) play a more influential role. Although this has led to a significant expansion in projects, the range of partnerships with non-age-related organizations, such as property developers and the business sector more generally, has been limited. This was less an issue when economic conditions were favorable for developing age-friendly programs; however, financial pressures on cities have created a need for forging a broader range of partnerships as a means of protecting existing resources and accessing additional resources.

One response would be to establish links with groups working on initiatives such as smart cities, healthy cities, resilient, and sustainable cities (Ramaswami et al., 2016; UN-Habitat, 2016). The age-friendly movement has been weakened, it might be argued, by operating separately from other urban projects, with the division between healthy and age-friendly cities programs—both WHO-sponsored—as an example. Moreover, encouraging links between different urban programs might help expand the range of age-friendly interventions. For example, ideas from the smart and sustainable cities movement around supporting alternatives to cars, increasing energy efficiency, and reducing pollution, should also be a central part of making cities age-friendly. Engagement with this type of work has the potential to produce further resources for the movement and add to the sustainability of existing projects.

In addition, the concept of age-friendliness needs to be developed in a way that recognizes the complexity of the urban environment and its influence across different phases of the life course. While the trend toward urban living is worldwide, the pattern of urban growth demonstrates considerable variation: a mix of expanding and declining cities (in terms of population size) in the Global North and accelerating urbanization in Africa and Asia. Securing

age-friendliness in the context of the rise of mega-cities and hyper-cities provides another variation (UN, 2018). At the same time, processes for developing age-friendliness will need radical adaptation given the type of urban expansion prevalent in parts of Southern Asia and sub-Saharan Africa (UN-Habitat, 2012). Population growth in these continents has taken place largely through the rise of so-called slums, many of which are located on the periphery of capital cities (Davis, 2006; Mayne, 2017). The problem of reaching older people and migrants who are aging in place, albeit housed in temporary accommodation bereft of basic facilities, underlines the need for new models of intervention that can respond to the highly unequal contexts experienced by urban elders across the work.

## *Challenging Social Inequality*

A second area for development concerns grounding age-friendly work in policies that challenge social inequality. A key task for future activity must be to ensure equal access to basic necessities for daily living and the decision-making processes underpinning urban life, explicitly addressing gender, social class, ethnic and other inequalities affecting the older population (see, further, Kelly, Dannefer & Masarweh 2018). In the Global North, the age-friendly brand has been adopted in various guises in (mainly) white communities, but is much less evident among black and minority ethnic groups (Lehning et al., 2017). However, it is precisely the latter that experience the most disadvantaged and least age-friendly communities. It will be difficult to take age-friendly policies seriously unless there is closer engagement with those neighborhoods and groups of older people that are abandoned in the face of urban change (Scharf & Phillipson, 2005). Acknowledging social and ethnic diversity is thus an important issue for the age-friendly movement to address (Gonyea & Hudson, 2015). The implications are wide-ranging, including responding to different cultural interpretations of what age-friendliness might mean; shaping policies around the needs of particular groups with contrasting migration histories and life course experiences; recognizing distinctive forms of inequality experienced by particular ethnic groups, notably in areas such as health, income, and housing; and understanding the impact of racism on communities and the challenge this presents for the achievement of successful age-friendly work.

As well as identifying and analyzing inequities between different groups of older people and neighborhoods, there is also a need to identify viable and effective strategies, interventions, and actions to tackle such disparities. The potential of age-friendly cities to reduce health and social inequalities at the local level is highlighted by Kendig and Phillipson (2014). However, systematic monitoring and evaluation are necessary to determine which strategies are most appropriate and the type of resources required that can support such work.

Developing effective responses to inequality will almost certainly require

stronger linkages between different levels of age-friendly work: macro (e.g., government), meso (e.g., corporations, municipal authorities), and micro (e.g., neighborhood). Case studies of cities in the WHO global network (WHO, 2018) confirm that, to date, there has been considerable success in securing support at the meso and macro levels—financial and administrative—for age-friendly initiatives (notably around areas such as social isolation and loneliness). However, age-friendly work has been much less successful in attracting the interest of key government departments, e.g., in areas such as economic development, transport, and urban planning. Such attention will clearly be necessary if the movement is to avoid the danger of economic and social inequalities limiting the range and effectiveness of initiatives.

### *Acknowledging Diversity in Health Issues*

The diversity of health issues experienced by older people also raises important issues for age-friendly work. A relevant question here is *do age-friendly initiatives reach out to people with all types of health conditions or are they focused predominantly on the "healthy,"* i.e., those involved in different forms of "active aging" (Golant, 2014)? To date, it is the latter who have dominated the development of the movement. But this raises questions about whether the goal is to create *inclusive* rather than *exclusive* communities (Gonyea & Hudson, 2015). If the former, then age-friendly initiatives must have the capacity to support people diagnosed as frail or with dementia and associated conditions (Grenier, 2007). This would argue against the trend of developing separate dementia-friendly communities or similar. Rather, the approach should acknowledge the variety of groups for whom age-friendly issues are relevant, and the need to build environments that support and reflect the diversity of conditions in middle and later life.

### *Widening Participation*

Consideration is also needed when reaching out to groups that may be disengaged from age-friendly issues. To date, the movement has—in many urban areas—drawn upon organizations already involved in campaigns on issues affecting older people, such as voluntary bodies working on behalf of older people, pensioner action groups, and carer organizations (Steels, 2015). But these may have limited connections to organizations representing black and minority ethnic groups, the LGBTQ community, women's groups, and faith-based organizations. Each of these will be affected by age-related issues in different ways: Their involvement could make a substantial contribution to creating a more inclusive and representative age-friendly movement.

The variety of groups within the older population is likely to mean that the process of developing age-friendly communities will involve reconciling conflicting interests and concerns (Moulaert & Garon, 2015). This suggests the need for methods of community engagement that will work with the range of concerns affecting different age groups. An example of such an ap-

proach is that of coproduction (Buffel, Skyrme, & Phillipson, 2017). Coproduction builds on a partnership among older people, their families, communities, and statutory and non-statutory organizations that work together to develop research and a shared understanding and to design, develop, and deliver opportunities, projects, and solutions promoting social and political change (Sanz et al., 2015). The ultimate goal is to facilitate different forms of community empowerment and to allow individuals and groups to organize and mobilize themselves toward social action.

### *Encouraging Innovations within Neighborhoods*

Attention must also be given to devising new ways of delivering age-friendly interventions at a neighborhood level. The age-friendly domains put forward by the WHO provide a valuable framework for developing ideas and initiatives. The weakness of current work, however, relates to uncertainty about the best measures to assist the implementation of projects, how best to target isolated groups, how to involve minority groups, and how to ensure the sustainability of projects. Some organizational developments (notably in the US) that emerged outside the age-friendly movement merit closer consideration: for example, the Village model and Naturally-Occurring Retirement Communities. The former is a grassroots approach that engages older community residents in developing membership associations that provide supportive services and social activities. The latter represent partnerships between statutory and voluntary bodies to enhance services for older people living in geographically defined areas with relatively high densities of older adults (Greenfield et al., 2012; Scharlach, 2012; Scharlach & Lehning, 2013). The effectiveness of these approaches needs to be tested in more detailed research than presently exists (see, for example, Graham et al., 2014); there is also the problem (notably with the Village movement) of membership being restricted to financially more secure older adults, with notable underrepresentation of minority groups. Nonetheless, testing these and similar models might be a valuable way of devising ways of translating the ideals of age-friendly work into sustainable projects within neighborhoods.

### *Strengthening Research Programs on Age-Friendly Issues*

Finally, the age-friendly movement has developed at a rapid rate, notably through the stimulus of the WHO Global Network and other international organizations. But this has occurred in the absence of research regarding the effectiveness and impact of such work: whether it benefits some groups rather than others, what contribution it makes to the wellbeing of older people, whether it leads to improvements in urban design, and whether it strengthens support networks within neighborhoods. Establishing answers to these questions will be vital if local authorities and cities are to extend financial support to age-friendly programs. In addition to measuring the impact of interventions, there is also a need for building *pro-*

*cess* evaluation activities into program implementation, using these to conduct continuous quality improvement (Greenfield et al., 2015). Encouraging comparative studies examining the various approaches to building age-friendly communities in different social, political, and economic contexts should also be an important element of future work (Moulaert & Garon, 2016). There is also an urgent need for research on building age-friendly communities in the Global South, recognizing the distinctive pressures arising from rapid urbanization, migration, and the impact of climate change.

Given the need for a stronger emphasis on research, a key task for the age-friendly movement will be to create stronger linkages with academic institutions and researchers from multiple disciplinary perspectives. One way forward could be through the development of an international research network, pioneering new research, technology, and solutions across a range of aging-related domains and supporting the research side of GNAFCC's policy work. An important role for such a research network would be to bring together academics from existing research centers supporting age-friendly issues, encourage the development of early-career researchers specializing on age-friendly issues, develop work on specific themes (e.g., the impact of gentrification, issues affecting migrant groups), and develop new methodological approaches for evaluating the benefits or otherwise of age-friendly interventions. This will be especially important to justify future funding for new age-friendly initiatives in times of austerity where the ability to demonstrate social and economic impact has become ever more important.

## Conclusion

The development of the age-friendly movement must now be considered an important dimension of public policy, reflected in the work of numerous organizations working at local, regional, national, and international levels. The movement has been able to achieve significant progress within a relatively short space of time. It has been able to develop a broad global policy response to the forces associated with urbanization and aging, encouraging and enabling cities and communities worldwide to develop and adapt age-friendly programs within their local neighborhoods. The WHO has provided a global network of support and dialogue between different cities and communities, in association with partners such as AARP and Age Platform Europe. Importantly, the WHO has developed an influential framework for action with its emphasis on areas such as the built environment, transportation, housing, and social participation.

But while the age-friendly project has made significant progress as a global movement, important issues—as highlighted in this paper—remain to be addressed. Most urgently, there is the question of how this type of activity can sustain itself within the context of austerity and budget cuts facing cities and communities, which have a direct impact on many of the services on which older people rely. Unless this

issue is addressed at a global, national, and regional level, the sustainability of age-friendly work is placed in some doubt. There is, at the same time, a broader issue surrounding the inclusivity of the age-friendly project. Although the movement has placed older people at the center of various initiatives, there has been a failure (as argued in this paper) to acknowledge the full diversity of aging experiences. Examples include the marginalization of many black and minority ethnic groups and those within the lesbian, gay, bisexual, transsexual, and queer community. More generally, the social exclusion experienced by many groups in urban areas—for example, migrants, refugees, and the rapidly expanding number of people without a home—have been largely ignored within the age-friendly movement. Given the pressures associated with globalization and economic recession, addressing social exclusion will be crucial to the successful development of the age-friendly project.

One response to this point might be to argue that the debate around age-friendly cities has created an important agenda for rethinking the way we both live in and manage our urban environments. Some of the questions being raised include *do older people have a "right" to a share of urban space? How can the resources of the city be best used to benefit the lives of older people? Is the idea of age-friendly caring communities compatible with modern urbanization?* However, in addition to these questions, we might note some fundamental issues that the age-friendly movement is likely to face in the next phase of its development. These can be summarized in terms of whether the idea of age-friendliness will progress mainly as a form of branding for cities concerned with improving their status in comparison with other cities. Alternatively, will the movement begin to engage with the serious problems facing urban environments, such as widening inequalities, problems of homelessness, and the lack of affordable housing? These issues have the potential to undermine interventions aimed at improving the lives of older people; they will almost certainly need a stronger response than presently exists from those involved in age-friendly work.

Dawson (2017) identifies the rise of what he terms "extreme cities," with a new precariousness to urban life given the impact of climate change-induced disasters. Evidence already exists regarding the disproportionate impact of hurricanes (Katrina in New Orleans in 2005), heat waves (Chicago in 1995, France in 2003), and tsunamis (Tōhoku, Japan in 2011) on older people. Such examples underline the need to rethink approaches to age-friendly work in the context of increasingly unequal cities facing environmental and related threats. The question arising from this can be defined as *how can movements representing aging and urban interests work together to resolve some of the major issues facing society*? Age-friendly initiatives could drive forward new ideas relating to improving urban environments (e.g., highlighting the impact of pollution), developing new forms of community organization and solidarity (food and energy co-operatives),

and supporting intergenerational cohesion (e.g., older people working with younger people in schools and other organizations). The argument is that doing age-friendly work also means recognizing and challenging the wider inequalities and injustices that affect city life. Standing apart from these will inevitably limit the scope both of the age-friendly movement and many other campaigns working to improve the lives of those living in cities.

In conclusion, there is considerable scope for the age-friendly movement to contribute to a more equal geographical distribution of society's wants and needs, such as access to health and social services, community support, good air quality, and inviting public spaces. Questions of accessibility, housing and transport equity, and walkability can all be seen as important dimensions of the distribution of spatial resources. However, the age-friendly approach has yet to develop policies that can prevent or reduce the inequalities associated with urban living, especially as regards their impact on neighborhoods in which people may spend the majority of their lives. Ensuring spatial justice (Soja, 2010) for different groups of older people should, therefore, become a crucial part of the age-friendly debate, with strategies that enable communities to increase control over the conditions that shape their lives representing a key task for public policy.

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## Notes

1 "According to WHO's most recent survey of 4300+ cities worldwide, only 20 percent of the urban population surveyed live in areas that comply with WHO air quality guideline levels for [fine particulate matter]. Average particulate air pollution levels in many developing cities can be 4-15 times higher than WHO air quality guideline levels, putting many at risk of long-term health problems." https://www.who.int/sustainable-development/cities/health-risks/air-pollution/en/. (retrieved November 16, 2019)

2 https://extranet.who.int/agefriendlyworld/who-network/. (retrieved November 16, 2019)

3 See, for example, the Atlanta Regional Commission. https://atlantaregional.org/community-development/comprehensive-planning/local-comprehensive-planning/. (retrieved March 24, 2020)

# Public Guardianship: Policy and Practice

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Abstract

Guardianship is a process by which a court delegates to a person or entity the duty and power to make personal, property, or both person and property decisions for another individual based upon a determination that he or she is unable able to make decisions for him- or herself. Guardianship has at its foundation the protection and care of individuals unable to make decisions about their person, their property, or both; however, far too little is known about this creature of the court system. Public guardianship, or guardianship of last resort, refers to the appointment and responsibility of a public official or publicly funded entity who serves as a legal guardian in the absence of willing, able, and responsible family members or friends to serve as, or without resources to employ, a private guardian. Problems with the guardianship system include prolonged delays for an appointment, a far-too-close relationship between judges and guardians, guardians' lack of familiarity with the individuals they serve, their limited expertise in medical decision-making, and their unconscionably large caseloads. The purpose of this article is to provide a description of the guardianship system, explain what is known in the available research, and identify recommendations for policy and practice.

***Keywords:*** public guardianship, protection, responsibility, policy, surrogate decision-maker

# Tutela pública: política y práctica

Resumen

La tutela es un proceso mediante el cual un tribunal delega en una persona o entidad el deber y el poder de tomar decisiones perso-

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nales, de propiedad o de persona y propiedad para otra persona en función de la determinación de que él o ella no puede tomar decisiones por él. o ella misma. La tutela tiene como fundamento la protección y el cuidado de las personas que no pueden tomar decisiones sobre su persona, su propiedad o ambos; sin embargo, se sabe muy poco sobre esta criatura del sistema judicial. La tutela pública, o la tutela de último recurso, se refiere al nombramiento y la responsabilidad de un funcionario público o entidad financiada con fondos públicos que sirve como tutor legal en ausencia de familiares o amigos dispuestos, capaces y responsables para servir como, o sin recursos emplear, un tutor privado. Los problemas con el sistema de tutela incluyen demoras prolongadas para una cita, una relación demasiado estrecha entre jueces y tutores, la falta de familiaridad de los tutores con las personas a las que sirven, su experiencia limitada en la toma de decisiones médicas y su gran cantidad de casos. El propósito de este artículo es proporcionar una descripción del sistema de tutela, explicar lo que se conoce en la investigación disponible e identificar recomendaciones para políticas y prácticas.

***Palabras clave:*** tutela pública, protección, responsabilidad, política, tomador de decisiones sustituto

# 公共监护：政策与实践

## 摘要

监护是一个过程，法院通过该过程赋予个人或实体职责与权力，替另一个无法为自身做决定的个体做有关个人、财产、或二者兼有的决定。监护最根本的是为那些无法就自身、财产或二者兼有做决定的个人提供保护和关爱；然而，关于这种法律体系者的了解知之甚少。公共监护，或被称为最后手段的监护，指的是对一名公共官员或公立实体赋予责任，在缺少有意愿、有实力、有责任的家庭成员或朋友作为私人监护人，或后者没有资源雇佣一名私人监护人的情况下充当法定监护人。监护体系的问题包括预约延期的时间更长，法官与监护人之间的关系过于密切，监护人对其监护对象的不熟悉，监护人在医疗决策方面的经验有限，以及监护人过多的工作量。本文目的是对监护体系提供一个描述，解释现有研究中的已知部分，并为政策与实践提供相关建议。

关键词：公共监护，保护，责任，政策，代理决策者

> The single greatest category of problems we encounter are those that address the care of decisionally incapable patients ... who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die, no one's life will be fundamentally changed by the death of the resident. We owe these patients the highest level of ethical and medical scrutiny; we owe it to them to protect them from over-treatment and from under-treatment; we owe it to them to help them to live better or to die in comfort and not alone.
>
> —Nancy Dubler, LLB, Professor Emerita, The Albert Einstein College of Medicine/Montefiore Medical Center; Consultant for Ethics, New York City Health and Hospitals, Letter 2001

## Introduction

Many of the patients Dubler describes above are people with public guardians. Budget constraints, the increasingly complex health needs of younger and older individuals, and a rising number of persons needing services generally reduce the ability of public programs to adequately serve persons under guardianship needing their help. Persons under guardianship are frequently older people with dementia; adults of any age with intellectual or developmental disabilities; and individuals with mental illness, brain injuries, or substance abuse. In many cases, the people whose civil rights are transferred to a guardian have a combination of these conditions. Too often, people under guardianship, who have usually lost all their decisional rights, are ensnared in a backwater of under-resourced governmental social service and welfare machinery.

People needing public guardians as surrogate decision-makers are especially vulnerable because they rely on others for care and/or are unable to advocate for themselves. Also, the issue of abuse, neglect, and exploitation (ANE) by guardians has been highly visible nationally, with reports of systemic problems documented by the Government Accountability Office (2010; 2016), testimony before the US Senate Committee on Aging and Social Security Administration (Teaster, 2018), and a flurry of media attention in *Forbes, The Huffington Post, NPR On Point,* and *Senior Living*. Aviv (2019) describes egregious treatment by paid professional guardian April Parks. Ms. Parks warehoused people under her care in unacceptable facilities, charged unreasonably high fees, and made it impossible for concerned family members or friends to have contact with loved ones. Parks was indicted on over 250 felony counts (one for each person she served)

and sentenced to up to forty years in prison (Ferrara, 2019). Rebecca Fierle, a former guardian from Orlando, Florida, is under criminal investigation for excessive, unnecessary, and inappropriate billing for her vulnerable clients living in assisted living facilities and giving each a Do-Not-Resuscitate order (Cordeiro, 2019).

Guardianship has at its foundation the protection and care of individuals unable to make decisions about their person, their property, or both; however, far too little is known about this creature of states and the court system that was regarded by John Regan (1980) as "part Santa Claus and part ogre." The purpose of this article is to provide a description of the guardianship system, discuss the available research, and identify recommendations for policy and practice in the public guardianship system.

## Private and Public Guardianship

Guardianship is a legal process by which a court delegates to a person or entity the duty and power to make personal, property, or both person and property (plenary) decisions for another individual based upon a determination that he or she is unable able to make decisions for him- or herself. A judge's decision is predicated on a finding of "incapacity," a judgment that may be founded on medical, cognitive, and functional components, as specified in state law. Judges hear clinical and lay evidence and have the authority to exercise broad discretion in determining a person's capacity, choice of the guardian(s), and the extent of the court order that conveys decision-making authority to the guardian. People subject to guardianship are any individuals deemed decisionally incapacitated.

A guardian might have complete or limited authority over a person's health and personal affairs, financial and property affairs, or both. Guardians are fiduciaries with a high duty of care and degree of accountability. Following the appointment of a guardian, in theory, and under state law, the court maintains vigilant oversight and receives regular reports and accountings concerning the person under guardianship. In practice, courts' monitoring varies widely; in too many jurisdictions across the country, guardians have little to no supervision at all (Karp & Wood, 2007).

Guardianship information is sparse to non-existent at state and local court levels. A national estimate put the number of adults under guardianship (both private and public) at 1.5 million, but cautioned that the number could be as low as one million or as high as three million (Uekert & Van Duizend, 2011). Although legal experts have tracked guardianship law for the past three decades, little data and empirical research exist concerning actual practices by judges, attorneys, guardians, and people under guardianship. Wood, Teaster, and Cassidy (2017) reviewed press articles, internet discussion forums, and anecdotal reports and found that "practice varies on a continuum from the heroic to the satisfactory to the deficient to the abusive, but the proportions in each category are unknown" (p. 19).

Guardianship has its genesis in the medieval English concept of *parens patriae,* which declares that the sovereign has a duty to care for people (subjects) who cannot care for themselves (Wood, 2005). In order to protect subjects from harming themselves or being harmed by others, a court appoints a guardian to make decisions safeguarding them from risk or harm. The appointment of a guardian removes a person's fundamental rights, conveying an individual's voice and decision-making authority to a legally designated, appropriate, and beneficent surrogate, radically reducing the person's legal status. In most instances, guardianship curtails a person's right to make decisions about income or assets, healthcare and treatment, marriage, voting, sexual choices, participation in social networks, and routine lifestyle choices—and can "un-person" an individual (Bayles & McCartney, 1987).

Since the 1980s, and despite reform efforts stressing the duty of the guardian to consider a person's values and preferences in making decisions, state protection nearly always eclipses individual autonomy (Center for Elders and the Courts, 2019). Guardianship's inherent tensions between autonomy and beneficence, between rights and needs, and between protection and self-determination manifest themselves in ethical conundrums, in both theory and practice.

Most guardians are private guardians and are typically family members or friends, but sometimes attorneys, corporate trustees, agencies, or even volunteers serve in this role (Bandy et al., 2014; Bayles & McCartney, 1987; Lisi & Barinaga-Burch, 1995; Teaster et al., 2005). Unlike persons with family and friend connections, at-risk and/or low-income people usually have no one to help them and frequently fall through societal cracks. Many fail to receive needed services; fall prey to third party interests; become victims of ANE; receive inappropriate or insufficient healthcare, and have an inappropriate placement in facilities that are too restrictive for their needs (Bandy et al., 2014; Chamberlain, et al., 2019). For such individuals, who may be incapacitated and alone, the courts assign a public guardian.

## *Public Guardianship*

Public guardianship, or guardianship of last resort, refers to the appointment and responsibility of a public official or publicly funded entity who serves as a legal guardian in the absence of willing, able, and responsible family members or friends to serve, or without resources to employ, a private guardian (Teaster, et al., 2010). Public guardian programs are funded through state appropriations, Medicaid funds, county monies, and legislated fees from the person under guardianship or some combination of these. Public guardian programs usually serve three distinct populations: (1) persons under guardianship who have lost decisional capacity, sometimes due to age-related dementia; (2) individuals age eighteen years of age and older with intellectual disabilities who may or may not ever have had decisional capacity; and (3) adults of all ages with mental illness or brain injury.

## *Research on Public Guardianship*

Public guardianship emerged in the peer-reviewed research in the 1980s following a series of press reports detailing allegations of ANE and ageism in the public guardianship system (Bayles & McCartney, 1987). Winsor Schmidt, a pioneer in guardianship research, detailed concerns over the non-existent national reporting of guardianship, limiting the ability to identify and assess the quality of care and quality of life of those under public care (Bell, Schmidt, & Miller, 1981; Schmidt, 1984; 1990; Schmidt, et al., 1988). In the nearly forty years since his initial research, guardianship research in the United States has increased; however, critical gaps remain in knowledge with respect to prevalence, demographic characteristics, decision-making, and quality of care (Chamberlain, Baik, & Estabrooks, 2018; Kim & Song, 2018; Montayre, Montayre, & Thaggard, 2018).

As alluded to above, the number of individuals under public guardianship in the United States is unknown, due to non-existent federal surveillance and variable monitoring of state guardianship programs (Chamberlain et al., 2018; Teaster et al., 2010). However, the number of individuals requiring public guardianship is increasing, due to increasing numbers of older adults generally, coupled with the rising prevalence of age-related dementia and geographically dispersed family and friends (Carney, Fujiwara, Emmert, Liberman, & Paris, 2016). Studies in intensive care units revealed that 16 percent of patients admitted have no family or friend guardian (White, Curtis, Lo, & Luce, 2006), and these patients account for 5.5 percent of deaths annually (White et al., 2007). For those assessed in acute care settings, a large proportion of individuals without a family or friend guardian are admitted from nursing homes (Cohen, Benjamin, & Fried, 2019; Courtwright, Abrams, & Robinson, 2017; Griggins, Blackstone, McAliley, & Daly, 2019). Research estimates that older adults under public guardianship comprise 3 to 4 percent of the nursing home population, an estimate based on anecdotal information from focus groups of healthcare leaders (Karp & Wood, 2003). Similarly, a Canadian study found a provincial (equivalent to state) prevalence of just over 4 percent of all nursing home residents under the care of a public guardian (Chamberlain, Duggleby, Fast, Teaster, & Estabrooks, 2019). Prevalence of public guardianship varied: a higher proportion of residents under public guardianship lived in larger (>135 beds) public not-for-profit urban-located nursing homes (Chamberlain, Duggleby, Fast, et al., 2019).

Only a small number of studies have conducted interviews with persons who are under public guardianship (Teaster, 2002; Teaster et al., 2010). These studies indicate that people under public guardianship experience loneliness and unmet psychosocial needs (Teaster, 2002). Persistent issues revealed in these studies show that guardians spend limited time with persons under guardianship. Guardians are surrogate decision-makers, making

personal decisions for individuals that they have little connection to and limited personal knowledge of their values or wishes (Teaster, 2002). Work to date suggests a critical need to discern more explicit pathways for discussing ethical priorities and challenges in caring for this highly vulnerable population (Moye, 2017; Verma, et al., 2019).

Recent studies of persons under public guardianship have found that they are typically older (older than sixty-five years of age) and male (Chamberlain, Duggleby, Fast, et al., 2019; Cohen et al., 2019; Courtwright et al., 2017; Griggins et al., 2019; White et al., 2006). These more recent studies examined individuals living in nursing homes or who were admitted to acute care (hospital) settings. These findings differ from earlier studies, which focused on community-dwelling populations and found that most persons under public guardianship were older women (Reynolds, 2002; Reynolds & Wilber, 1997). Public guardians who were interviewed described their perception that there had been a shift in the demographic profile of those under public guardianship, previously composed of older women who had outlived family and now reflect an increasingly complex population with mental illness and histories of marginalization (Chamberlain, Duggleby, Teaster, et al., 2019). Multiple chronic conditions, dementia, and depression are common in persons under public guardianship (Chamberlain et al., 2018; Kim & Song, 2018). Chamberlain et al. (2019) examined the characteristics and unmet needs of nursing home residents under public guardianship and found that these residents are frequently marginalized, often having been previously homeless, and many have histories of drug and/or substance abuse and complex psychiatric conditions. They have limited or nonexistent financial resources and struggle to access even basic items (e.g., clothing, toiletries) and services outside the home.

Individuals under public guardianship are at risk of poor quality of care. Risks include overtreatment, under-treatment, or delayed treatment (Chamberlain, Duggleby, Teaster, et al., 2019; Cohen, Wright, Cooney, & Fried, 2015). Cohen et al. (2019) conducted a retrospective chart review to examine end-of-life decision-making by professional, court-appointed guardians. They found delays in decision-making for patients under guardianship (compared to those not under guardianship). Delays in care resulted in prolonged hospital stays and potentially negative consequences of hospitalization (e.g., hospital-related infection, pressure ulcers) (Cohen et al., 2019; Moye, 2017). A one-year matched retrospective cohort study in one hospital compared the length of stay for patients for whom the hospital had initiated guardianship procedures because the patient had impaired decision-making and no designated surrogate decision-maker. This study compared patients for whom the hospital had initiated a petition to the court to appoint a guardian as surrogate decision-maker (e.g., volunteer, public, family member) compared to patients that did not have a guardian appointment (Ricotta, Parris, Parris, Sontag,

& Mukamal, 2018). The guardianship process resulted in prolonged hospital stays (twenty-nine days compared to eighteen days for controls) and one in six had a hospital-associated complication upon discharge.

A qualitative study of nursing home staff found the quality of care issues for residents under public guardianship, particularly at end-of-life. Care problems included excessive medical testing, multiple trips to the hospital, and more (sometimes unwarranted) aggressive interventionist approaches (e.g., full resuscitation) (Chamberlain, Duggleby, Teaster, et al., 2019). These studies suggest that the quality of care is of critical concern for such individuals; however, studies often rely on small samples at single sites. There are currently no state or federal level data on the quality of care or health service use of individuals under public guardianship. Policies that require reporting in routinely collected administrative data are essential to identifying and mitigating the risk of care issues for these vulnerable individuals. Monitoring the use of health services and quality of care seems problematic given the recent news reports (e.g., April Parks and Rebecca Fierle, mentioned above) that describe potentially unethical care practices overseen by guardians for individuals living in care facilities.

## *Medical and End-of-life Decision Making*

Kim and Song (2018) reviewed the literature on individuals without available or willing surrogate decision-makers and found a variety of approaches to decision-making, including the interdisciplinary care team, physicians, judicial review, guardianship, ethics committees, or an external multidisciplinary team. They note that while there are various decision-making mechanisms, there is little understanding of the implications of these different approaches on patient/client health outcomes. Professional societies, state legislation, and hospital policies all vary on how to care for patients whose wishes and preferences might be unknown (Blackstone, Daly, & Griggins, 2019; Pope, 2017).

Associations such as the American Geriatrics Society recommend that the patient's care team make care decisions rather than a public guardian (Farrell et al., 2017). The American Medical Association (AMA) advocates that clinicians consult an institutional ethics committee for medical decisions for persons without a family or friend surrogate (American Medical Association, 2017). Institutional ethics committees are often called upon to oversee decision-making for unrepresented individuals. Some states mandate an ethics committee, and some only recommend that the care team consult with a committee. Griggins et al. (2019) described one urban hospital's development and implementation of a subcommittee within the larger institutional ethics committee that was composed of community members. Community members make recommendations to the attending physician, and disagreements or discrepancies are reviewed by the hospital ethics committee. While the use of ethics committees is relatively

widespread, they are not without their detractors (Courtwright et al., 2017).

Research on decision-making for persons without a family or friend guardian in intensive care units found that most end-of-life decisions were made by the attending physician and not an ethics committee, external judicial review, or public guardian (White et al., 2007). This is consistent with other studies of incapacitated, hospitalized patients that found that decisions to withdraw or limit treatment to patients were most often made by physicians and without external consultation (Bandy, Helft, Bandy, & Torke, 2010; White et al., 2006). There remains a prevailing concern over clinicians as sole decision-makers due to the complex social and legal considerations required to make decisions, potential conflicts of interest, and procedural fairness and equity across patients (White, Jonsen, & Lo, 2012). Critics of physicians as sole decision-makers indicate that decisions that can influence an individual's life and death should involve a diversity of expertise and points of view afforded by multidisciplinary teams and perhaps external committees (Pope, 2013).

Cohen et al. (2015) analyzed state guardianship legislation specific to guardian decision-making authority for treatment at the end-of-life. They found that there is little guidance specific to end-of-life and guardian authority over decision-making. Most states (thirty-seven) had no language related to a guardian's authority. Some states allow guardians to make decisions independently, albeit with contingencies. The variation and complexity across the state legislation poses significant concerns about how different decision-making policies may influence the care provided to people under public guardianship.

Variation in legislation and no comparative research on the implications of decision-making mechanisms pose a substantial risk to vulnerable individuals and their care providers. Verma et al. (2019) interviewed stakeholders from healthcare, social services, and legal sectors involved in the decision-making processes for unrepresented adults. Ethical challenges include respecting autonomy when an individual's decision-making rights have been revoked, balancing safety and autonomy. Safety concerns may be associated with prolonged hospitalization and risk of moral distress among those tasked with caring for them. Caring for unrepresented individuals places an ethical and moral toll on care teams as they try to navigate making care decisions for vulnerable individuals (Chamberlain, Duggleby, Teaster, et al., 2019; Verma et al., 2019).

## *Disparagers and Reformers*

Disparagers of guardianship regard it as an extreme form of surrogate decision-making that unnecessarily removes an individual's most basic civil rights and one that should be completely terminated. These individuals stress that the disadvantages of guardianship outweigh the potential benefits (Pope, 2017). They point out problems with the guardianship system: prolonged de-

lays in appointing a guardian, a far-too-close relationship between judges and guardians, guardians' lack of familiarity with the individuals for whom they are the decision-maker, their limited expertise in medical decision-making, and unconscionably large caseloads limiting guardians' availability to properly direct the care of individuals for whom they are responsible (Chamberlain, Duggleby, Teaster, et al., 2019; Cohen et al., 2019; Moye, 2017; Teaster, 2002). These relationships can result in unfair decisions and priorities, suspect practices, and unnecessary delays or far too hasty decisions, which affect a host of actors in the guardianship process (e.g., social work, law, medicine, finance), and most importantly, the person under guardianship.

The reformers represent a more moderate response to the many problems of public guardianship (Chamberlain et al., 2018; Karp & Wood, 2007; Moye, 2017; Teaster, 2016). Rather than dismantle and eradicate the system, the reformers sympathize with the disparagers but suggest that guardianship serves an important protective function for those who are unable to advocate and make decisions for themselves. They recommend that the processes of guardianship should be improved and stress the importance of scrutinizing who really needs guardians. Also, they call for person-centered guardianship and improvements in guardianship monitoring, including an accurate and computerized accounting of each person under guardianship in each state. The Working Interdisciplinary Network of Guardianship Stakeholders (WINGS), discussed later in this article, is an example of a reform effort whereby people representing the multiple, converging systems that deal with guardianship attempt to make changes to the system.

### *Standards for Public Guardians and Decision-Making*

According to the National Guardianship Association (NGA) Standards of Practice (2013), "the guardian shall protect the rights of the person with regard to sexual expression and preference. A review of ethnic, religious, and cultural values may be necessary to uphold the person's values and customs." Public guardians may serve as guardian of the property, guardian of the person, and sometimes, and in addition to guardian, as a representative payee or another surrogate decision-maker. Public guardians can also provide case management, financial planning, public education, social services, adult protective services, or serve as guardian *ad litem* or court investigator and as advisors to private guardians. The primary task of public guardianship is to serve as surrogate decision-maker (Schmidt et al., 1988; Teaster et al., 2010). In addition to the standard mentioned above, the following NGA (2013) standards provide a strong basis from which guardians should make decisions.

- Std 6(V)(F) – "Determine whether the person has previously stated preferences in regard to a decision of this nature."
- Std 7(II) – "The guardian shall

identify and advocate for the person's goals, needs and preferences."

- Std 8(IV)(B) – "The guardian shall strive to know the person's goals and preferences."
- Std 9 (III) – "The guardian shall encourage the person to participate, to the maximum extent of the person's abilities, in all decisions that affect him or her ... "
- Std 9(IV) – "The guardian shall make and implement a plan that seeks to fulfill the person's goals, needs, and preferences."[1]

### *Advance Directives and Advance Care Planning*

An approach frequently highlighted to mitigate the risk of inappropriate or inconsistent decision-making for unrepresented older adults is to emphasize pro-active advance care planning (Carney et al., 2016; Montayre et al., 2018; Thaggard & Montayre, 2019). Documenting values and goals of care prior to being incapacitated is a critical step to reducing the uncertainty that arises when individuals become incapacitated and a surrogate is unavailable. When information is known about the person's preferences, there is a lower likelihood that there will be an external judicial review and less high-intensity treatment will be initiated (Cohen et al., 2019).

### *Supported Decision-Making*

One important way to reduce vulnerability is to restore a person's voice and, concomitantly, respect their remaining rights. A mechanism to respect the rights of persons under guardianship is through supported decision-making. Supported decision-making is a process to assist persons in providing their wishes and preferences concerning decisions about themselves (Gooding, 2013). This process is meant to engage people in as many ways as possible to ensure that their voice and values are at the core of the decision-making process. This may include various accommodations, such as communication supports and engaging with individuals (family and friends) known to the person who may be able to assist in interpretation and the ultimate decision-making process. In instances where supported decision-making is used, the legal right to make decisions remains with the person; accommodations are provided to ensure that the person has enough supports to make his or her decision an authentic one that *he* or *she* makes (American Bar Association, 2019).

A mechanism with commonalities with supported decision-making and legislated in the Commonwealth of Virginia is the completion of a values history for all people under public guardianship (Teaster, 2016). Completion of and reference to a values history can serve as an important mechanism to ensure that, as much as possible, decisions that public guardians make are informed by client preferences and adhere to a substituted judgment standard rather than defaulting to a best interests standard because client preferences are

1 Note that the NGA regards the guardianship plan different from a care plan.

unknown because of a lack of investigation and documentation.

### *Current Policy Efforts on Public Guardianship*

Two major policy efforts related to public guardianship at the federal level are underway. The first is an effort to hold public hearings on issues that guardianship presents and solutions to its problems. In April 2018, the Senate Special Committee on Aging convened a hearing entitled *Abuse of Power: Exploitation of Older Americans by Guardians and Others They Trust.* In the 116th Congress in 2019, Senator Susan Collins (R-ME) introduced S.581, the Guardianship Accountability Act of 2019, which proposed designating a national online resource center on guardianship, authorized grants to develop state databases, and established procedures for sharing background information related to appointed guardians with other jurisdictions. The bill was read twice and referred to the Committee on the Judiciary **(US Senate 2019)**.

A second national effort is to establish WINGS. The development of WINGs programs was conducted by the ABA Commission on Law and Aging and was supported by a grant from the Administration for Community Living. Over fifteen states received a combination of ACL-sponsored WINGS funding and state justice-initiated projects. Over ten states created a WINGS program on their own. The purpose of WINGS is to "bring stakeholders to the table for joint problem-solving and action–and to open doors to communication" (ABA 2019). WINGS efforts include statements to the national news media, restoration of rights wherever possible, collection of reliable and uniform data, enhanced oversight and record-keeping, establishment of statutorily mandated guardian-to-protected person ratios, use of supported decision-making whenever appropriate, and reference to and recognition of the values and wishes of the people under guardianship when making decisions (ABA 2019).

## Recommendations and Conclusion

Both authors of this article have studied the issue of guardianship deeply. Because of their disciplinary grounding (public administration, nursing, ethics, and gerontology), they are able to stand outside the court system and make observations concerning the system as a whole. One of the authors has even served as a court-appointed private guardian, and more than once. Bearing our scholarship and experience in mind, we make the following recommendations for the system of public guardianship.

First, better data systems for guardianship programs need to be built. In this age of bigger, better, and faster technology, it is astounding that, as of this writing, no one state knows how many of its people are under guardianship. Without a reliable data collection system, it is impossible to properly monitor the system. Senator Collins' approach to system building should be supported, adequately funded, and im-

plemented. A similar approach to data collection was developed by the Administration for Community Living for Adult Protective Services (the National Adult Maltreatment Reporting System or NAMRS) and could be implemented with state public guardianship systems. Furthermore, moving beyond basic monitoring, we recommend concerted efforts to track the service use and quality of care provided to individuals in guardianship programs.

Second, more states should adopt workable guardian to person under guardianship ratios. Currently, only seven states even reference staffing ratios in their legislation or administrative regulations contracts, ranging from 1:40 (Florida) to 1:20 (Virginia) (Teaster 2008). Without a ceiling, the ratio of guardians to person under guardianship can balloon (examples in 2010 were in Kentucky and Illinois, where at one time, the ratio was as high as 1:100). Occasion for mistreatment and misuse of the system can easily follow when numbers are far too high and monitoring is far too infrequent.

Third, states should explore increased use of mechanisms that support and restore rights completely. As discussed above, these include crafting limited orders, i.e., the creative use of least restrictive options, meaning that all rights given to the guardian do not have to be exercised solely by the guardian and that greater use of supported decision-making processes should be employed wherever possible, whether doing so eliminates the need for public guardians or enhances the ability of the individual under guardianship to direct decisions made on his or her behalf. Better communication with the person under guardianship is also critical; one vehicle for doing so is the use of the values history form, which, in Virginia, is created, referenced, updated, and maintained in the files of each person with a guardian (Teaster 2016). Better communication with public guardians across states is another important mechanism for making practice change, and WINGS states or the NGA should commence this long-overdue initiative with dispatch.

Fourth, in many situations, guardians are called upon to make end-of-life decisions. We believe that **well-informed, well-educated, and trained guardians who know the people they serve** are in an excellent position to make medical decisions for people under guardianship. When the system works as it should, guardians are in an outstanding position to know best the values and preferences of the person(s) they serve. They are, after all, the legally designated surrogate decision-maker, a point we made above. However, to our knowledge, no evidence-based answer is available concerning the best approach. We believe that the best standards from which guardians can draw are those of the NGA (2013). The authors are not ignorant of the current realities of some public guardian programs (e.g., underfunded, a lack of training, high caseloads), which preclude public guardians from having the appropriate context for making such important decisions. For now, we believe that public guardians should make decisions in concert with

patient care teams, rather than solely making such important decisions. We do not agree that they should be excluded from the patient care team.

Finally, and not surprisingly, it is critical that more funding is provided to state guardianship programs. On the federal level, funding should be allocated to investigate the outcomes of public guardianship. Guardianship has the power to return entirely or bolster the remaining rights that an individual might have rather than eradicating all of them. To this end, it is important to both investigate the outcomes of guardianship and to establish benchmarks for acceptable public guardianship practices. Nowhere does this need arise more than in the arena of healthcare, an example of which is the COVID-19 pandemic with which we are now grappling.

To conclude, we find public guardianship only slightly changed from research conducted over ten years ago (Teaster et al., 2010). From that study, here are our slightly edited concluding paragraphs (143), entitled *The Postlude:*

> ... like scholars before us, guardianship continues to be instituted for third party interests rather than the best interests of the person under guardianship and who are still living in environments too restrictive due to funding inadequacies and residual ageism and other societal biases. We urge that the banner of least restriction be held high and that limited guardianships be sought, guardianships overturned whenever possible, and that individuals under guardianship be consulted and their wishes considered when at all possible.
>
> Public guardianship is not social work, although it involves important elements of it. Conversely, guardianship, a creature of the courts, is not completely law. Guardianship is an amalgam of many disciplines—law, medicine, social work, psychology—most importantly, those aspects of being a human being, those under the care of the state, are still not afforded considerations as such. Living the decisional life for people under guardianship is perhaps the most important and complex state function performed. It remains shrouded in mystery for most of the public, yet, the public guardian performs a highly important state function for the most vulnerable, who deserve no less than excellence from public servants. We believe that, to live the decisional life of another person, as public guardians do, they must have the tools to perform this essential function. If not, then public guardianship does greater harm in its presence executed poorly than in its absence.

Let us not be writing these same lines ten years hence.

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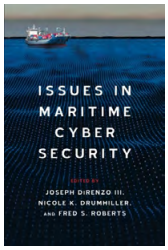


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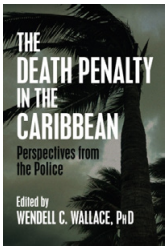


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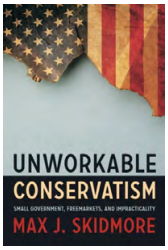


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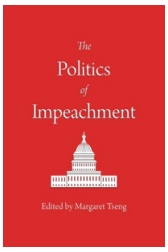


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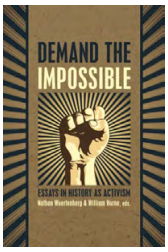


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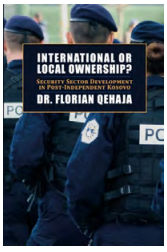


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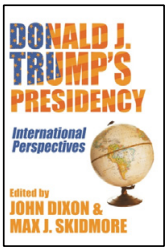
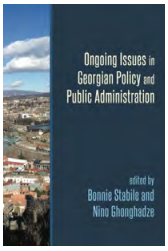



President Donald J. Trump's foreign policy rhetoric and actions become more understandable by reference to his personality traits, his worldview, and his view of the world. As such, his foreign policy emphasis was on American isolationism and economic nationalism.

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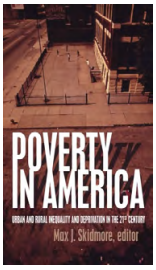


Poverty in America too often goes unnoticed, and disregarded. This perhaps results from America's general level of prosperity along with a fairly widespread notion that conditions inevitably are better in the USA than elsewhere. Political rhetoric frequently enforces such an erroneous notion.

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