

Center for Long-Term Care Reform

Current Issues in Illinois

Our aging society is affecting every aspect of our overall economy, workforce, health care delivery and financing systems. As the baby boom generation ages past their employable years, they will experience greater need for long-term services and supports (LTSS), shifting their role from wage-earners and caregivers (often for their children and parents) to fixed incomes and care-receivers.

Health & Medicine and our [Center for Long-Term Care Reform](#) are committed to countering all systems of oppression, injustice, and structural inequity in society and will apply this equity lens to the specific issues of aging. We recognize that those with low and modest incomes who face class inequity; people of color who suffer the effects of racism and ethnocentrism; immigrants facing resurgent nationalism; other marginalized groups facing systems of oppression, violence, and injustice; and those experiencing mental illness, developmental disabilities, and other isolating risk factors tend to fare the worst at younger ages and are frequently at high risk for suffering dementia and other conditions associated with aging that further exacerbate their challenges.

Positioned at the junction of health policy, equity work, and the social determinants of health, Health & Medicine is well prepared to assume a more influential role developing and advocating for public policies that:

- a) Reflect everyone's mutual interdependence
- b) Support people in the most community-integrated settings possible, discouraging use of hospitals and institutions for long-term care needs
- c) Encourage family caregiving without overburdening families of older adults
- d) Reflect local community values and interests
- e) Support evidence-based, cost-effective approaches to helping older adults live their final years in dignity, as close to family, friends, and neighbors as possible
- f) Provide paid caregivers with living wages and benefits, including family leave, sufficient to meet minimum standards given the local cost of living

In particular, LTSS is extremely important to our society as it ages, affecting the fastest growing population cohort—individuals who are 85 and older—and those caring for them or financially responsible for them, usually their children, as well as younger paid caregivers who are often people of color and/or immigrants.

Current issues Health & Medicine's Center for Long-Term Care Reform hopes to address:

- i. **Workforce**—Health care workforce is an overarching issue that has particular relevance for labor-intensive LTSS, whether in institutional or home- and community-based services (HCBS) settings. There is now a shortage of paid caregivers, which will be exacerbated by reduced immigration and any further decrease in unemployment rates

locally. Burnout and turnover are major issues for the health workforce, generally, and for LTSS workers particularly. Health & Medicine will build on its workforce research and advocacy to provide data, analysis, and advocacy on workforce challenges and solutions.

- ii. **Costs**—LTSS is hugely expensive with costs likely to increase due to higher demand, increased minimum wages, and as worker shortages require employers and families to pay higher wages and benefits. Health & Medicine will oppose the tendency for governments, which are the largest payer for LTSS, to cut back on services covered, the amount and duration of services, and the amount paid for these essential services. We will advocate that any ethical approach to paid caregiving requires workers to earn a living wage. Health & Medicine will advocate for funding mechanisms and revenue options to sustainably provide LTSS.
- iii. **Community-integrated services**—The battle between home- and community-based services and institutional services continues to rage with a for-profit nursing home industry demanding their “fair-share” of the population of older adults and rates sufficient to maintain their profitability and attractiveness to investors and lenders. Health & Medicine will support disability rights advocates and laws, rules, and policies that place the well-being of older adults, their families, and people with disabilities ahead of the needs of institutions.
- iv. **Medicaid managed care**—Managed care is changing the way HCBS and all LTSS providers get paid, which ones get paid, requirements they must meet, what they can do, etc. Health & Medicine will engage with the state and its Medicaid managed care organizations (MCOs) to closely monitor the way Illinois measures and rewards quality. We will also work with other advocacy organizations committed to similar principles to identify best practices and address deficiencies. Illinois was a leader in incorporating LTSS into managed care contracts. The quality and outcome studies by UIC of the initial Integrated Care Program should be continued, expanded, and could provide a model to advise advocates grappling with this in other states around the country.
- v. **Role for community-based organizations**—MCO contracts will impact community-based organizations’ (CBOs’) ability to continue providing services to members of their community. The impacts could be positive or negative but should be monitored closely and publicly discussed in the context of Illinois Department of Healthcare and Family Services LTSS policy. There is currently very little public discussion of this very important issue, the consequences of which will likely have lasting impacts for decades. Health & Medicine will use its respected leadership role to examine current and future consequences and bring policymakers and providers together to negotiate fair, cost effective, and reasonable policies.
- vi. **Nursing home safety and accountability**—Many nursing home residents continue to suffer neglect and abuse. Although laws were enacted that increased quality standards, fines, and other penalties for nursing homes that violate those standards, as well as increased staffing for nurse inspectors at the Illinois Department of Public Health, reports continue to describe substandard and dangerous conditions that our society should not tolerate. Health & Medicine is positioned to draw attention to such atrocities and galvanize public opinion to support increased oversight and enforcement.

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- vii. **Financial protection, planning, and literacy**—As people age, they can become more vulnerable to financial abuse, fraud, and identity theft. Financial abuse and fraud can have a drastic impact on an individuals’ autonomy, short- and long-term financial well-being, access to services, and health. Improved financial planning and literacy can help individuals and families to develop safeguards that protect against such abuse. Health & Medicine will consider the effectiveness of existing elder abuse, neglect, and exploitation programs and recommend improvements to help reduce such occurrences.
- viii. **Livable communities for all**—While there are several similar definitions, AARP defines a livable community as “one that is safe and secure, has affordable and appropriate housing and transportation options, and offers supportive community features and services. Once in place, those resources enhance personal independence; allow residents to age in place; and foster residents' engagement in the community's civic, economic, and social life.” This extends Health & Medicine’s commitment to health equity-in-all-policies to older adults, as well as people with disabilities. Chicago Aging Collaborative, Jane Addams Senior Caucus, Caring Across Generations, and Jobs for Justice are among the organizations that support a livable communities framework. New York is the first state to formally adopt livable communities in its state plan on aging and it can serve as a focus for advocacy in Illinois.
- ix. **Single-payer**— Health & Medicine will work with the Illinois Single Payer Coalition, Physicians for a National Health Program, and other single-payer advocates to ensure their proposals include a long-term care funding mechanism built on the social insurance model. Health & Medicine is in a unique position to promote increased attention to long-term care in a way that broadens single-payer’s appeal to the general public, particularly those focused on aging populations.
- x. **End-of-life planning**—U.S. residents are unprepared for end-of-life decisions regarding care options, legal guardianship, etc. Health & Medicine can help focus attention on these often contentious issues, which have, unfortunately, become politicized since conservative forces wrongfully criticized the ACA for sponsoring “death panels.” Health & Medicine can focus on provider readiness to guide families in reaching decisions and build bridges between primary care providers and individuals, their families, and community.
- xi. **Housing and Financial Stability**—Many studies highlight the low savings and asset base of baby-boomers as their earning potential diminishes due to forced retirement and diminishing physical and cognitive capabilities. African Americans and other people of color were especially hurt by the Great Recession’s impact on overall savings, especially home equity, leaving many to live in substandard housing. Many families in communities of color have also been impacted by high incarceration rates, which has forced many older adults to assume responsibility of caring for their grandchildren, as well as themselves. Health & Medicine will highlight the need for additional research, programs, and supports for those who cannot afford to retire and yet are no longer capable of earning sufficient income to meet their needs.
- xii. **Consumer Direction**—Other than Social Security, government support programs generally pay agencies to assess client needs and pay for the supports and services that are essential to meet those needs. This approach may leave the individual older adult or

person with disabilities with limited control over who provides personal assistance or how that person is trained and supervised and without other supports necessary for them to remain in the community. Health & Medicine will highlight successful, cost-effective programs that enable the individual and family to manage their spending directly, budget for high personal priority needs, and increase dignity by regaining control over important life decisions.

- xiii. **Growing population of aging immigrants**—There is a growing population of aging immigrants, many of whom immigrated to the U.S. when they were children or of working age. As this group ages, there will be continued growth of a population group that may not qualify for basic benefits such as Social Security and Medicare. Health & Medicine will advise on how these individuals can receive health care and long-term services and supports, ensuring that the burden of providing care is not borne solely by close family and friends.
- xiv. **Funding**— Health & Medicine can also address the shortfall in the financing structures for existing programs, as well as address funding for additional supports and services as defined above. In particular, Health & Medicine can advocate for raising or eliminating the ceiling on the Social Security tax, which could sustain the program and potentially allow for increasing cost of living allowances or earlier retirement ages. This is essential given the importance of Social Security to aging individuals' ability to direct their own lives both financially and in terms of their overall agency and dignity.