

Long-term Care Reform in Illinois

2019 Agenda for Change



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 Policy Research Group (Health & Medicine) and our [Center for Long-Term Care Reform](#) are committed to improving the way older adults in Illinois live and enjoy their final years with dignity in their homes and communities. We work to ensure that everyone has the supports and services they need when and where they need them. This is an especially challenging goal given the history and continuing experience of racism and discrimination against people of color, LGBTQ communities, and other marginalized groups, which can be exacerbated by lifetimes of poverty and related social and economic stresses.

Through a health equity and trauma-sensitive lens, Health & [Medicine recently examined more than 20 issues](#) and prioritized these five concerns based on their overall importance and potential for immediate impact.

- 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 cutbacks in 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. As an initial activity, Health & Medicine will invite unions, advocates, and researchers to a “Round Table” to learn about current activities and priorities, identify common interests for broader advocacy and research projects, and then develop strategy for statewide initiatives.*
- ii. **Medicaid managed care**—With Medicaid contracts now covering LTSS, managed care entities are changing the way HCBS and all LTSS providers get paid, which ones get paid, requirements they must meet, what services they provide, etc. Illinois was a “leader” in incorporating LTSS into managed care contracts but did not set rates to discourage nursing home placements. *Health & Medicine will engage with the state and its Medicaid managed care organizations to closely monitor the way Illinois pays for, measures, and rewards quality and identify best practices around the country. Health & Medicine will advocate for continuing and expanding the quality and outcome studies by UIC of the initial Integrated Care Program and advise advocates grappling with this in other states. Pressure should also be applied on the new governor’s administration to ensure continuity for community-based providers and integration with the existing Aging Network.*
- iii. **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 IDPH, reports continue to describe substandard and dangerous conditions

for residents that should not be tolerated. While working to reduce the numbers of older adults unnecessarily residing in nursing homes, *Health & Medicine is positioned to draw attention to substandard and dangerous conditions, gather information on best practices from other states, and galvanize public opinion for permanent increased oversight, enforcement, and quality.*

- iv. **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 model extends Health & Medicine's commitment to health equity-in-all-policies to older adults. 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 with the new mayor and governor.*
- v. **Growing population of aging immigrants**—There is a growing population of aging residents, 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 advocate to ensure such individuals' right to health care is honored and that they have access to culturally sensitive long-term services and supports and ensure that the burden of providing care is not borne solely by close family and friends.*

Health & Medicine intends to take action to ensure that these issues are prioritized by the new Pritzker administration, as well as advocating nationally for adequate funding and rational policies to support home and community-based services and supports.

Although each issue requires its own course of action, Health & Medicine will apply the following methods:

- Meet individually or in small affinity groups with stakeholders, interested parties, reporters, editorial boards, legislators, and providers.
- Review literature of best practices in cities and states nationally and internationally.
- Conduct research and analyze data, as appropriate and available, to fill gaps in knowledge.
- Convene small round table discussions to bring different perspectives together around specific topics.
- Organize and host public forums where speakers and panelists can illuminate particular issues and concerns and give the public an opportunity to learn and share their perspective.
- Develop legislation where necessary to ensure public policy is facilitating desired outcomes and work with legislators and stakeholders to support its passage.
- Advocate for strong government policies through appropriations, regulation, other policy-making means, and prioritization within state agencies.

Based on results and outcomes of these options Health & Medicine will develop an Action Plan to ensure these issues continue to receive the attention and interest necessary to support our aging society.

Health & Medicine hopes to organize an Aging in Illinois 2019 Agenda for Change Convention to rally agencies and organizations in support of the Action Plan and organize commitments to execute it. Please email mhiggins@hmprg.org if you'd like to receive periodic updates on activities, events and efforts to ensure healthy aging for all.