Long-Term Care in Illinois: Illinois’s Need for Community-Based Care in an Institutional-Focused System

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I. INTRODUCTION

With an aging population of baby-boomers and major changes to health care payment and policy over the last several years, long-term care has come to the forefront of the health care discussion.¹ On July 22, 2013, the governor of Illinois expanded the eligibility criteria for Medicaid under Public Act 098-0104, which effectively implemented the Affordable Care Act (ACA) in Illinois.² In signing Public Act 098-0104 into law, Illinois expanded the number of individuals eligible to receive Medicaid, which would theoretically increase the number of Illinois residents able to access and receive long-term care.³ However, eligibility does not equate to receipt

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¹ Naomi Freundlich, Long-Term Care: What Are the Issues?, ROBERT WOOD JOHNSON FOUNDRY, 4 (Feb. 2014), http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf410654 (“In 2010, 40 million people age 65 and older accounted for 13 percent of the U.S. population. This number is expected to jump to 72 million people of 19 percent of the population by 2030. Even more significant, the number of people age 85 or older— who are most likely to need long-term care—is projected to grow from 5.5 million in 2010 to 8.7 million in 2030 and 19 million by 2050.”).


³ Under the ACA, Medicaid eligibility was expanded to adults ages 19-64 without a disability or dependent children and with incomes at or below 138% of the Federal Poverty Level. Answers to Frequently Asked Questions: The Affordable Care Act in Illinois, Ill.
of care, and many Illinois residents remain under the alarming misconcep-
tion that Medicare and Medicaid programs will cover all of their long-term
care needs. This article will argue that despite the expansion of Medicaid
and Illinois’s increasing focus on community-based care over institutional
care, the delivery and expense of long-term care remains a challenge and
must continue to be addressed, especially with the increasingly aging popu-
lation. While focusing on developing the infrastructure of community-based
care over institutional care, Illinois must also educate its residents about
long-term care payment options and encourage long-term care planning so
it can work towards enabling residents to actually receive the care they need
rather than merely expanding eligibility. Unless Illinois develops more
community-based services and policies to support more cost-effective ad-
ministration of long-term care, and unless Illinois helps residents to educate
themselves in planning for and utilizing more affordable long-term care,
residents will continue to be trapped in expensive institutional care, burden-
ning both the state and themselves.

II. LONG-TERM CARE FRAMEWORK

Long-term care includes both medical and non-medical services that help
disabled or elderly individuals meet their needs on a daily basis. This type
of care encompasses a wide range of support administered by both paid and
unpaid providers to help the individual receiving care maintain his or her
lifestyle and function to the best of his or her ability. Individuals with

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4. Health Policy Brief, The CLASS Act: The long-term care insurance program created
   by the Affordable Care Act will be reshaped to address concerns about solvency, ROBERT
   WOOD JOHNSON FOUND., 2 (May 21, 2011), http://healthaffairs.org/healthpolicybriefs/brief
   _pdfs/healthpolicybrief_46.pdf.
5. ROBYN STONE, LONG TERM CARE FOR ELDERLY 11 (Kathleen Courrier et al. eds.,
   2011) (“Rather, it is an array of personal care, health care, and social services and supports
   provided in various settings over a sustained period to persons with chronic conditions and
   functional limitations.”).
6. ROBYN STONE, HANDBOOK OF AGING AND THE SOCIAL SCIENCES 397 (Robert H.
long-term care needs may require assistance with “instrumental activities of daily living (IADLs),” like shopping and transportation, or even “basic activities of daily living (ADLs),” such as eating and bathing. Long-term care also includes the utilization of assistive devices, technology, and home modifications. Frequently, family members act as the primary providers and decision-makers for the individual in long-term care and benefit equally from support by paid caregivers or long-term care interventions because additional support helps to alleviate the burden placed upon them. Long-term care may be provided in institutional settings, predominantly provided by nursing homes, or in home- and community-based settings. Home- and community-based services provide the individual assistance with ADLs in various settings, generally such that the individual is able to stay in his or her home. Home- and community-based services may be administered in the individual’s own home, assisted living facility, adult foster home, or other supportive housing.

Approximately seventy percent of individuals over the age of sixty-five

7. STONE, supra note 5, at 2-3 (“Services provide assistance with basic activities of daily living (ADLs)—dressing, bathing, toileting, eating, and getting in and out of bed or chairs—as well as help with instrumental activities of daily living (IADLs), including household chores like meal preparation and cleaning; life management tasks, such as shopping, money management and medication management; and transportation.”).

8. These assistive devices and technologies include: canes, walkers, wheelchairs, computerized medication reminders, electronic monitoring systems to aid dementia patients, ramps, grab bars, among other things. Id.

9. STONE, supra note 6, at 397 (“It frequently involves intense participation wives and adult daughters, as providers and decision makers. Families are often equal beneficiaries of long-term care interventions, because care and supports provided by paid caregivers to the older person who is disabled are an important respite for the family caregiver.” (citation omitted)).


11. SUSAN C. REINHARD, ET AL., RAISING EXPECTATIONS: A STATE SCORECARD ON LONG-TERM SERVICES AND SUPPORTS FOR OLDER ADULTS, PEOPLE WITH PHYSICAL DISABILITIES, AND FAMILY CAREGIVERS 20, 112 (2d ed., 2014). (“Services that are designed to support community living and delay or prevent admission to an institution for people with various disabilities [False] HCBS can include personal care (help with ADLs), transportation, shopping and meal preparation, home health aides, adult day services, and homemaker services. Assistance with managing medications or money may be provided.”).

12. Id.
will need long-term care at some point in their lives. Moreover, individuals in need of long-term care are more likely than their peers who do not need long-term care to require medical care for both acute and chronic medical conditions. Of the ten million American individuals in need of long-term care, roughly fifty percent are over sixty-five years old, and roughly fifty percent are under sixty-five years old with disabilities. Individuals under the age of sixty-five with long-term care needs include children with intellectual and developmental disabilities, individuals with spinal cord injuries, traumatic brain injuries, or suffering mental illness, to name a few. While an increasing portion of individuals receiving long-term care require on-going treatment for medically complex health conditions or loss of cognitive capacity, long-term care also encompasses individuals that require rehabilitation or “post-acute care” for a short period of time following hospitalization.

III. PAYMENT OPTIONS FOR LONG-TERM CARE IN ILLINOIS

Individuals pay for long-term care with a combination of federal, state, and private funding. In Illinois, there are five primary avenues to pay for long-term care: private pay, long-term care insurance, veteran’s benefits

14. STONE, supra note 6, at 13 (“The average annual Medicare expenditures for elderly people with no long-term care needs in 2005 were $4,289. The comparable expenditures for those with one or more ADL limitations and those with three or more ADL limitations were $14,775 and $18,902, respectively.” (citation omitted)); See also STONE, supra note 5, at 398 (“Often people who need long-term care also require primary and acute care when they are sick.”).
15. According to a 2010 survey, 49.8% of people requiring long-term care were over 65 and 50.2% were under 65 with a disability. Kaiser Commission on Medicaid Facts, Medicaid and Long-Term Care Services and Supports, THE HENRY J. KAISER FAMILY FOUND., 1 (June 2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/2186-09.pdf.
16. Id.
17. STONE, supra note 5, at 2-3.
18. Id. at 41.
available for long-term care, Medicare’s limited benefit, and Medicaid.\textsuperscript{19} Additionally, Illinois offers several public assistance programs that assist in supplementing Medicaid payments for long-term care: Illinois’s Long-Term Care Partnership Program; Home and Community Based Waiver Programs; and Money Follows the Person.\textsuperscript{20}

\textbf{A. Private Pay}

The first option for Illinois residents seeking long-term care is to pay completely out of pocket. Currently, the yearly cost of care for one individual in Illinois is estimated as follows: $43,472 - $46,904 for home health care, $48,600 for assisted living facilities, and $62,050 - $70,455 for nursing homes.\textsuperscript{21} Unfortunately, these exorbitant costs are out of reach for the majority of Illinois residents.\textsuperscript{22} For instance, individuals who work in the service sector for many years earning low wages are most likely unable to save for retirement and their jobs are even less likely to offer retirement or health benefits.\textsuperscript{23} Many seniors in Illinois survive on a “modest fixed income from social security and maybe a pension.”\textsuperscript{24} With a minimal income, most Illinois seniors or disabled individuals cannot afford to pay for an extended institutional stay on their own without threat of poverty or re-


\textsuperscript{22} Long-term care services are unaffordable for middle-income families in the United States. Nursing home costs consume well over 100 percent of the annual income of older adults. Reinhard, \textit{supra} note 11, at 10 (reporting that nursing home costs “consume 246 percent of the median annual household income of older American adults”).

\textsuperscript{23} STONE, \textit{supra} note 6, at 101.

\textsuperscript{24} Siebers & Hesselbaum, \textit{supra} note 19.
ceiving inadequate care. Even the more cost-effective options of home- and community-based care may present an unsustainable drain on an individual’s assets if care must be administered for a long period of time without alternative financial assistance. By educating residents about these figures, Illinois may encourage better long-term care planning and personal research into other options, such as long-term care insurance or community services, before long-term care is needed, and the individual in need of care becomes bound to costly institutional care. If individuals are encouraged to plan better, they may be able to first utilize a community-based option and use it longer before they must resort to more costly institutional care.

B. Long-Term Care Insurance

One such way Illinois residents may plan for and fund their long-term care needs is by obtaining private long-term care insurance. Unlike Medicare, Medicaid, and typical health insurance plans, long-term care insurance provides per diem reimbursements for ADLs and is designed for long-term support of the individual beneficiary’s needs. However, according to some studies, only ten to twenty percent of the population can afford long-term care insurance, and even less actually have it. Experts suggest a person seeking long-term insurance should have at least $40,000 of liquid assets prior to purchasing such insurance. Further, older couples must purchase coverage individually and pay several thousand dollars for coverage

25. Stone, supra note 6, at 101.
26. Reinhard, supra note 11, at 10 (“Home care generally is more affordable than nursing home care, allowing consumers to stretch their dollars further. But at an average of 84 percent of median income, the typical older family cannot sustain these costs for long period.”).
27. What Is Long-Term Insurance?, U.S. DEPT OF HEALTH AND HUMAN SERVS., http://longtermcare.gov/costs-how-to-pay/what-is-long-term-care-insurance/ (“Unlike traditional health insurance, long-term care insurance is designed to cover long-term services and supports, including personal and custodial care in a variety of settings such as your home, a community organization, or other facility.”); see also Siebers & Hesselbaum, supra note 19.
28. Long-Term Care: What Are the Issues?, supra note 1, at 3 (estimating “7-8 percent of Americans have insurance for long-term care”).
29. Stone, supra note 6, at 403.
each year.\textsuperscript{30} According to the American Association of Retired Persons (AARP), only ten percent of adults over fifty years old have long-term insurance policies, and those who do not purchase them typically blame the high cost of such insurance.\textsuperscript{31} Those who are able to afford the high cost of long-term care insurance may have sixty to seventy-five percent of their benefits provided for by their carriers.\textsuperscript{32} As such, long-term insurance is not a viable option for individuals without significant savings, although it would likely prove most beneficial to those who cannot afford it because those individuals also cannot afford to pay out-of-pocket for care.\textsuperscript{33}

To promote the purchase of long-term care insurance, Illinois has participated in a long-term care insurance partnership program since 2007.\textsuperscript{34} Under the Illinois Long-Term Care Partnership Program Act (Long-Term Care Partnership Act), the Department of Healthcare and Family Services and the Department of Financial and Professional Regulation provide incentives for Illinois residents to procure long-term care insurance to prevent, delay, or eliminate dependence on Medicaid.\textsuperscript{35} Specifically, an insured does not have to spend-down his or her assets after exhausting the benefits of his or her policy because those assets, up to the amount of benefits received under the long-term partnership policy, are disregarded in calculating the insured’s eligibility for Medicaid.\textsuperscript{36} In other words, for each dollar paid for the individual under the long-term partnership policy, he or she may retain the value of that dollar above the amount he or she would need to qualify for Med-

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  \item \textsuperscript{30} Id.
  \item \textsuperscript{31} Reinhard, supra note 11, at 10.
  \item \textsuperscript{32} Kathleen Ujvari, \textit{Long-Term Care Insurance: 2012 Update}, AARP PUBLIC POLICY INST., 1 (June 2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/ltc-insurance-2012-update-AARP-ppi-ltc.pdf.
  \item \textsuperscript{33} Id.
  \item \textsuperscript{34} Illinois Long-Term Care Partnership Program Act, 215 ILL. COMP. STAT. 132/1 et seq. (eff. Aug. 16, 2007).
  \item \textsuperscript{35} 215 ILL. COMP. STAT. 132/5.
  \item \textsuperscript{36} 215 ILL. COMP. STAT. 132/15(b)(1); NAT’L ASS’N OF INS. COMM’RS, \textit{A Shopper’s Guide to Long-Term Care Insurance}, 12 (2013) available at https://app.box.com/embed/8cli4i0dy5rh.swf.
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icaid so that he or she does not need to expend all of his or her assets to become eligible to receive Medicaid benefits.37

Despite the benefit of the Long-Term Care Partnership Act and of knowing that a majority of one’s long-term care would be paid for by long-term care insurance if one needed it, many residents still do not use long-term care insurance.38 As previously discussed, educating Illinois residents about the benefits of these partnership programs before they become ineligible for long-term care insurance would likely be one way to alleviate the burden on Medicaid and individuals’ families. Further, by promoting the purchase of long-term care insurance through the use of the partnership plans, residents may receive care earlier than they would if they did not have any benefits and could possibly prevent or stave off the need to receive costly institutional care.

C. Veterans’ Benefits

Alternative options for payment for long-term care in Illinois exist for its approximately 740,000 veterans.39 Veterans and their surviving spouses can apply for federal benefits under the United States Department of Veterans Affairs and Veterans Administration pension, and for state benefits under the Illinois Department of Veterans Affairs.40 Illinois offers long-term nursing and health-care services to veterans that served at least one day of

37. 215 ILL. COMP. STAT. 132/15 (b)(1); http://www.aaltci.org/long-term-care-insurance/learning-center/long-term-care-insurance-partnership-plans.php#approved (“Here’s an example. Stephanie buys a PQ policy and needs care one day. Her policy pays out $150,000 of insurance claim benefits. Stephanie earns a Medicaid asset disregard that allows her to keep an additional $150,000 over the asset level she would otherwise have to meet in order to be eligible for Medicaid coverage. The Partnership Program also protects those assets after death from Medicaid estate recovery.”).
38. Long-Term Care: What Are the Issues?, supra note 1, at 3.
military service during a period of war recognized by the United States Department of Veterans Affairs. Veterans that served during peacetime and surviving spouses may qualify if the wait list of veterans has been exhausted.

While these services provide a well-earned source of payment for veterans, they do not provide coverage or payment for the vast majority of the Illinois population. In the interest of increased administration of long-term care, this option provides only minor assistance to the population of Illinois; however, it is important for the government to continue to educate those residents who are eligible as these benefits offer an affordable alternative to other costly options.

D. Medicare

Another payment option for small portions of long-term care for certain qualified individuals is Medicare. Medicare provides limited coverage for home care services and skilled nursing facilities for Medicare beneficiaries that are in need of skilled nursing services or therapy. Medicare will fund the first twenty days of care and part of an additional eighty days of care in a skilled nursing facility following a hospital stay of three days or more. Additionally, Medicare will temporarily pay for "skilled nursing, therapy, and aide services" if an individual is incapable of leaving his or her home due to a medical condition. However, Medicare and many insurance plans

42. Id.
44. STONE, supra note 6, at 402; See also Reinhard, supra note 11, at 25 (“Medicare does cover limited post-acute home health care and skilled nursing facility services that follow a hospitalization – both under very specific circumstances – but these distinctions are often not clear to consumers. Medicare and other forms of health insurance cover only health services, not [long-term care].”).
45. STONE, supra note 6, at 402.
46. Id.
will not cover “custodial care,” which includes assistance with ADLs and personal administration of medication, such as taking eye-drops.\textsuperscript{47}

As previously discussed, many individuals approach their long-term care planning under the misconception that Medicare will cover the cost of custodial care in addition to traditional health care costs.\textsuperscript{48} As Medicare does not cover care for long periods of time, it is not a viable option for long-term care payment for the majority of Illinois residents and should be used only as a supplementary funding source. To clarify that Medicare does not provide custodial care, Illinois should educate and train both doctors and Medicare administrators to better inform the public that they need to seek out other options to fund their long-term care needs well in advance of requiring them. Residents may waste precious time and resources believing that Medicare will cover their long-term care needs in the future, when in reality they could be saving or purchasing long-term care insurance to ensure they will be provided for when they require long-term care.

\textbf{E. Medicaid}

Medicaid provides the largest section of long-term care funding, and not only offers payment for services received in institutional settings but for services needed by individuals living in the community in home- and community-based care situations.\textsuperscript{49} Thus, Medicaid fills the gap of services for

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\textsuperscript{47} Medicare and You, CTR. FOR MEDICARE AND MEDICAID SERV., 1, 146 (2015), http://www.medicare.gov/publications/pubs/pdf/10050.pdf (defining custodial care as “Non-skilled personal care, like help with activities of daily living like bathing, dressing, eating, getting in or out of a bed or chair, moving around, and using the bathroom. It may also include the kind of health-related care that most people do themselves, like using eye drops.” According to the Centers for Medicare and Medicaid Services, Medicare does not pay for custodial care in most cases.).

\textsuperscript{48} Health Policy Brief, supra note 4, at 2.

\textsuperscript{49} See Kaiser Commission on Medicaid Facts, Medicaid and Long-Term Care Services and Supports, THE HENRY J. KAISER FAMILY FOUND., 1 (June 2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/2186-09.pdf (“Medicaid is the nation’s major public health coverage program designed to address the acute and long-term care needs of millions of low-income Americans of all ages.”).
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which Medicare and private insurance do not pay.\textsuperscript{50} Further, Illinois expanded Medicaid under the ACA to all individuals and families below 138\% of the Federal Poverty Level, which is $16,105 for a single person in 2014.\textsuperscript{51} Medicaid was previously available to low-income individuals over sixty-five years old and disabled individuals; however, Illinois’s implementation of Medicaid expansion makes all individuals under 138\% of the federal poverty line eligible.\textsuperscript{52} As such, not only are a greater number of elderly individuals enabled to receive benefits by qualifying for Medicaid, but a greater number of individuals under the age of sixty-five are enabled to receive preventive care to maintain their health and stave off the necessity of long-term care services.

Illinois has several programs that supplement and support Medicaid payment for services that promote community-based care as a less expensive alternative to institutional care. First, Illinois’s adoption of the ACA allowed expansion of Home and Community Based Services (HCBS) Waiver programs.\textsuperscript{53} HCBS waiver programs enable qualified Medicaid beneficiaries to receive services in a community setting or in their homes as an alternative to receiving care in institutional settings.\textsuperscript{54} Supportive living

\textsuperscript{50} See id. (stating “[m]any of these critical services are not covered by Medicare or private insurance).\
\textsuperscript{52} Answers to Frequently Asked Questions: The Affordable Care Act in Illinois, supra note 3.\
\textsuperscript{53} Application for a §1915(c) Home and Community-Based Services Waiver, IL DEP’T OF HUMAN SERVS., https://www.dhs.state.il.us/onemlibrary/27896/documents/by_division/division%20of%20d/childsupportamend0314.pdf.\
\textsuperscript{54} Ill. DEP’T OF HEALTHCARE AND FAMILY SERVS., supra note 20 (listing the nine categories of waivers: Children and Young Adults with Developmental Disabilities-Support Waiver, Children and Young Adults with Developmental Disabilities – Residential Waiver, Children that are Technology Dependent/Medically Fragile, Persons with Disabilities, Persons with Brain Injuries (BI), Adults with Developmental Disabilities, Persons who are Elderly); Section 1915(c) of the Social Security Act enables the Department of Health and Human Services to allow long-term care to be delivered in community settings through a waiver of applicable Medicaid provisions. Reinhard, et al. supra note 11, at 112.
facilities (SLFs) are an example of an HCBS waiver. SLFs serve both disabled individuals twenty-two years or older and individuals sixty-five years old or older that meet certain other requirements as an alternative to nursing homes. These facilities aim to maintain patient autonomy and privacy in an environment that is also able to provide health and wellness services akin to a nursing home. While as of July 2013, Medicaid per diem rates for SLFs dropped 2.7%, this change only made SLFs slightly more accessible to individuals. These programs engender a greater focus on consumer-based community long-term care rather than institutionalized care.

One specific instance of direct promotion of community care is Illinois’s adoption of Pathways to Community Living: Money Follows the Person Program (MFP)—a federal grant offered by the Centers for Medicare & Medicaid Services (CMS) that Illinois and forty-two other states have utilized to combat the great cost of long-term care. Under this program, the Department of Healthcare and Family Services, Department of Human Services, Department of Aging, and Department of Housing Development Authority collaborate to promote the use of community services and assist individuals with chronic conditions and disabilities wishing to transition from institutional to community-based care. This is another program that helps ease the financial burden of institutionalized long-term care by promoting

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55. 89 ILL. ADMIN. CODE tit. 146 § 200(a) (eff. May 1, 2006) (listing other requirements: The Department or other State screening agency must determine the individual is “in need of nursing facility level of care and that SLF placement is appropriate to meet the needs of the individual” 89 ILL. ADMIN. CODE tit.146.220(a)(2) (eff. Aug. 1, 2009)). Additionally, the individual cannot have “a primary or secondary diagnosis of developmental disability or serious and persistent mental illness.” 89 ILL. ADMIN. CODE tit.146.220(a)(3) (eff. Aug 1, 2009); see also Illinois Supportive Living Program, (last visited Sept. 28, 2014), http://www.slfillinois.com.


57. 89 ILL. ADMIN. CODE 153.126(g) (eff. June 27, 2013) (amended at 37 ILL. REG. 10529).

58. Pathways to Community Living, supra note 20; Reinhard, supra note 11, at 112.

59. Pathways to Community Living, supra note 20; Long Term Care, ILL. DEP’T OF HEALTHCARE AND FAMILY SERV., http://www2.illinois.gov/hfs/MedicalCustomers/LTC/Pages/default.aspx (last visited Sept. 28, 2014); Reinhard, supra note 11, at 112.
utilization of a cheaper and often more desirable community-based care. As of August 1, 2014, the Illinois MFP assisted 1,104 qualified individuals transition back into the community.\footnote{Pathways to Community Living, supra note 20.}

These programs effectively refocus the scope of long-term care on community-based as opposed to institutional care; however, their implementation still presents some issues. Primarily, residents transitioning from nursing homes to the community are frequently re-institutionalized due to the lack of infrastructure in the community to properly support their needs.\footnote{The Path to Transformation: Illinois 1115 Waiver Proposal, https://www.2.illinois.gov/hfs/PublicInvolvement/1115/Pages/1115.aspx (last visited Oct. 27, 2014) (“Illinois is also currently implementing consent decrees related to three Olmstead-related class action lawsuits, by helping residents of nursing homes and other institutions to transition to the community. We have learned through the early implementation of these consent decrees, as well as implementation of the Money Follows the Person Program, that existing community infrastructure needs to be strengthened through the addition of community-based services that will enable individuals to remain in their own community post-transition and avoid re-institutionalization.”).} In order to make long-term care more affordable for its residents and enable its programs to be successful, Illinois must focus on developing the community infrastructure in addition to educating residents about their options, with the goal of allowing residents in need of long-term care to stay in the community.

\section*{IV. CONCLUSION}

In light of the expense of institutional care and the number of people in community care, Illinois should focus on more community-based care rather than institutional care. Of the ten million individuals in need of long-term care, 8.4 million of these individuals live in community care settings, and only 1.6 million in institutional settings.\footnote{Kaiser, supra note 49, at 1.} Although the expansion of Medicaid under the ACA and the various programs utilized by Illinois have attempted to change the focus of payment of long-term care away from institutional to community-based care, the rates and options available make
even community-based long-term care unaffordable and unreachable for many residents. Illinois must focus on educating its residents on the benefits of insurance partnership programs, so they can make informed decisions as to whether to purchase costly (but beneficial) long-term care insurance and clarify that Medicare will not cover residents’ custodial needs. Further, if it continues to focus on developing the infrastructure of community settings, the waiver programs will enable residents to more successfully remain in community-based settings rather than institutional settings as a way to both save money and promote independence and a sense of self-worth. The road has been paved for possible success in the long-term care for Illinois; however, much work remains to be done.