ANNALS OF HEALTH LAW
Advance Directive

VOLUME 22 FALL 2012 PAGES 130-139

The Effect of Medicaid Reform and Expansion on the Future of Long-Term Service and Supports in Illinois

*Donna N. Miller**

I. INTRODUCTION

The Unites States has seen a dramatic shift towards universal healthcare as evidenced by individual state healthcare reform initiatives,[1] the enactment of the Patient Protection and Affordable Care Act (PPACA), and the recent Supreme Court decision upholding the majority of the PPACA as constitutional.[2] While the nation moves towards a model of universal and comprehensive care, the elderly and disabled population continues to be overlooked, suggesting that the trend towards universal care is not as inclusive as it may seem.

Medicaid is the health insurance program that pays for a large portion of healthcare services consumed by the elderly and disabled populations.[3] One of the most expensive services provided under the Medicaid program is

* Juris Doctor Candidate, Loyola University Chicago School of Law, Class of 2014. Ms. Miller is a staff member of *Annals of Health Law*.

1. *See* KAISER COMM'N ON MEDICAID AND THE UNINSURED, STATES MOVING TOWARD COMPREHENSIVE HEALTH CARE REFORM 1 (July 2009) *available at* http://www.kff.org/uninsured/upload/State-Health-Reform1.pdf ("Maine, Massachusetts and Vermont, have enacted and are implementing reform plans that seek to achieve near universal coverage of state residents. Many other governors and legislators have announced comprehensive reform proposals or have established commissions charged with developing recommendations on how to expand coverage.").

2. *See generally* KAISER FAMILY FOUND., A GUIDE TO THE SUPREME COURT'S AFFORDABLE CARE ACT DECISION 2-6 (July 2012) *available at* http://www.kff.org/healthreform/upload/8332.pdf [hereinafter A GUIDE TO THE SUPREME COURT'S DECISION].

3. *See* KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID AND LONG-TERM CARE SERVICES AND SUPPORTS 1 (June 2012) *available at* http://www.kff.org/medicaid/upload/2186-09.pdf [hereinafter LONG-TERM CARE SERVICES AND SUPPORTS] (stating that Medicaid pays for 43 percent of spending on long-term care in the United States).

long-term support and services (LTSS).[4] The elderly and disabled population makes up the majority of LTSS users,[5] and, despite recent reform movements, this population continues to face challenges in accessing and affording care. This article will explore the relationship between LTSS and Medicaid, how recent reform efforts may affect LTSS in Illinois, and the challenges that lie ahead for Illinoisans' who require LTSS.

II. MEDICAID OVERVIEW

A. Structure of Medicaid

Medicaid was established in 1965 and is an insurance program operated jointly by the Federal government and state governments.[6] Congress created Medicaid to help low-income Americans pay for health care and remains one of the largest health insurance programs in the nation, covering approximately sixty-eight million low-income Americans in 2010 alone.[7] Under the Medicaid program, payment for services that enrollees receive is made jointly by the federal government and state governments. The share of the Medicaid payment that the Federal government is responsible for is determined by the federal medical assistance percentage (FMAP).[8]

---

4. *See* KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID'S LONG-TERM CARE USERS: SPENDING PATTERNS ACROSS INSTITUTIONAL AND COMMUNITY-BASED SETTINGS 1 (Oct. 2011) *available at* http://www.kff.org/medicaid/upload/7576-02.pdf [hereinafter MEDICAID'S LONG TERM CARE USERS].

5. *Id.* at 2 ("Medicaid long-term care users were mostly elderly (52%), with persons with disabilities (40%) and other adults and children . . . making up the remainder of long term care users.").

6. MEDICAID & CHIP PAYMENT & ACCESS COMM'N, REPORT TO THE CONGRESS ON MEDICAID AND CHIP 27 (Mar. 2011) *available at* http://healthreform.kff.org/~/media/Files/KHS/docfinder/MACPAC_March2011_web.pdf, [hereinafter MACPAC REPORT].

7. *See id.*

8. *Id.* at 38 (stating that the federal share for Medicaid costs is determined by the federal medical assistance percentage (FMAP), a formula based on states' per capita income, and that FMAPs must be at least 50% but no more than 83%).

B. Medicaid in Illinois

In 2008, approximately 2.4 billion individuals were enrolled in Illinois' Medicaid program.[9] The program cost a total of nearly $15 billion to operate in 2010 and the state of Illinois was responsible for approximately $6.3 billion with the Federal government responsible for the remaining approximately $9.7 billion.[10]

III. THE RELATIONSHIP BETWEEN MEDICAID AND LONG-TERM SERVICES AND SUPPORTS

Medicaid covers a diverse group of low-income individuals, many of whom are battling complex health problems.[11] Low-income seniors and individuals with disabilities are included in the Medicaid population, and in Illinois these groups make up sixteen percent of the state's Medicaid enrollees.[12] Although seniors and individuals with disabilities make up a small percentage of total Illinois Medicaid enrollees, these groups account for nearly fifty-five percent of total Medicaid spending in Illinois.[13] Part of the reason that seniors and individuals with disabilities make up such a large portion of Medicaid spending is because these groups are the primary users of LTSS.[14]

Long-term services and supports (LTSS) refers to a multitude of services designed to assist individuals with daily activities and can include institutional nursing home care, community based services, and home

9. *Id.* at 78.
10. *Id.* at 86.
11. *Id.* at 2 ("The populations enrolled in Medicaid and CHIP are diverse, by definition low-income, but also may have chronic and complex health needs resulting in substantial spending.").
12. *Medicaid 101*, ILL. DEP'T OF HEALTHCARE AND FAMILY SERVS. 2 http://www2.illinois.gov/hfs/agency/Documents/Medicaid101.pdf (last visited Nov. 1, 2012).
13. *Id*.
14. *See* MEDICAID'S LONG TERM CARE USERS, *supra* note 4, at 2.

health services.[15] Private insurance benefits that include LTSS are typically limited in scope and LTSS are often not covered by traditional private health insurance.[16] LTSS are expensive[17] and private insurance policies rarely include such benefits,[18] because of these factors, many people who need LTSS spend down their assets in order to become eligible for Medicaid.[19] Due to the expense and limited availability of insurance that offers LTSS benefits, Medicaid has become one of the most prominent payers of LTSS.[20] In 2010, LTSS cost the Illinois Medicaid program nearly $4 billion.[21]

IV. HOW EFFORTS TO REFORM HEALTHCARE MAY AFFECT LTSS IN ILLINOIS

A. Illinois Smart Act

On June 14, 2012, Illinois Governor Quinn signed multiple Medicaid reforms with the intention of saving the state's Medicaid system from collapse and increasing the programs sustainability.[22] The new laws include

15. MACPAC REPORT, *supra* note 6, at 34; s*ee generally* LONG-TERM CARE SERVICES AND SUPPORTS *supra* note 2 (discussing the services Medicaid provides for LTSS populations).

16. MACPAC REPORT, *supra* note 6, at 32.

17. *See* LONG-TERM CARE SERVICES AND SUPPORTS, *supra* note 3, at 2 ("Paying for long-term services is expensive and can quickly exhaust lifetime savings. Nursing home care averages $74,800 per year, assisted living facilities average $39,500 per year, and home health services average $21 per hour.").

18. *See* MACPAC REPORT, *supra* note 6, at 32.

19. *See* ILL. DEP'T OF HEALTHCARE AND FAMILY SERVS., HFS 591SP MEDICAID SPENDDOWN, http://www2.illinois.gov/hfs/MedicalPrograms/Brochures/Pages/HFS591SP.aspx (last visited Nov. 1, 2012). The spenddown program is a way for some individuals who do not meet the low-income requirements of HFS programs to become eligible. *Id.*

20. *See* LONG-TERM CARE SERVICES AND SUPPORTS, *supra* note 3, at 1 (stating that Medicaid pays for 43 percent of spending on long-term care in the United States).

21. MACPAC REPORT, *supra* note 6, at 88.

22. ILL. GOV. NEWS NETWORK, GOVERNOR QUINN SIGNS LAWS TO SAVE MEDICAID, RESTRUCTURING PACKAGE STABILIZES MEDICAID AND PRESERVES CARE FOR MOST VULNERABLE, (Jun. 14, 2012), http://www.illinois.gov/PressReleases/

the Save Medicaid Access and Resources Together Act (SMART Act) and an increase on the price of cigarettes with the dual purpose of creating state funds for Medicaid and discouraging smoking throughout the state.[23] The SMART Act, which took effect July 1, 2012, includes revisions for Medicaid coverage.[24] The SMART Act contains specific coverage changes for treatment at long-term care facilities, including "an average 2.7% rate decrease," restructured financial requirements for spouses of patients at long-term care facilities, limited prescriptions for pharmaceuticals, and an increased "look back period for review."[25]

The revised financial requirements result in stricter regulation regarding who can become eligible for Medicaid and long term care assistance, and the length of time it will take individuals to become eligible.[26] For example, the extended "look-back" period of sixty months, which had previously been thirty-six months, means that it will take longer for many seniors to become eligible for Medicaid and long-term care coverage.[27] Similarly, categories of income and assets, such as spousal income and money spent on legal assistance before applying for Medicaid, have become stricter.[28]

ShowPressRelease.cfm?SubjectID=2&RecNum=10307.

23. *Id.*

24. *Coverage Changes Resulting from the Save Medicaid Access and Resources Together (SMART) Act*, ILL. DEP'T OF HEALTHCARE AND FAMILY SERVS. http://www.hfs.illinois.gov/html/062912n1.html (last visited on Nov. 1, 2012) [hereinafter *Coverage Changes*].

25. *Id*.

26. *See* JOINT COMM. ON ADMIN. RULES ILL. GEN. ASSEMB., *The Flinn Report*, Vol. 36 Iss. 28, 2 (July 13, 2012), *available at* http://www.ilga.gov/commission/jcar/flinn/20120713_July%2013,%202012%20-%20Issue%2028.pdf [hereinafter *The Flinn Report*].

27. *Coverage Changes*, *supra* note 23 (stating that the look back period for review increased from thirty-six months to sixty months, and applies to transfers as of January 1, 2001).

28. *See The Flinn Report*, *supra* note 25 ("The rulemaking imposes stricter limits on certain assets and asset transfers for persons seeking Medicaid assistance for long-term

B. Money Follows the Person: Pathways to Community Living

The Deficit Reduction Act (DRA) of 2005 changed Medicaid policies nation-wide regarding long-term care services and created the Money Follows the Person Rebalancing Demonstration program (MFP Program).[29] The MFP program is administered by the federal Centers for Medicare and Medicaid Services (CMS) and awarded original grants to thirty states.[30] Illinois received a grant totaling $55,703,078 to implement its own MFP program:[31] Pathways to Community Living.[32] Section 2403 of the PPACA extended the program through 2016 and provided an increase in funding for the MFP program.[33]

Illinois' MFP program, Pathways to Community Living, focuses on decreasing the number of individuals using institution-based services by increasing the use of Home and Community Based Services (HCBS).[34] In other words, the goal of the program is to decrease spending on institutional LTSS, such as costly nursing homes, and shift spending towards community services so individuals requiring LTSS can receive care at home or within their communities.[35]

---

care.").

29. MATHEMATICA POLICY RESEARCH, INC., MONEY FOLLOWS THE PERSON DEMONSTRATION GRANTS: SUMMARY OF STATE MFP PROGRAM APPLICATIONS 1 (Aug. 21, 2007) *available at* http://www.cms.gov/Regulations-and-Guidance/Legislation/DeficitReductionAct/downloads/StateMFPGrantSummaries-All.pdf [hereinafter MONEY FOLLOWS THE PERSON] (stating that the DRA created the MFP program and authorized $1.75 billion to help states move people in institutional settings back home to their community, and to help states reorganize their LTSS systems in a way that emphasizes HCBS over institutional placement).

30. *Id.*

31. *Id.*at 45.

32. *Pathways to Community Living*, MONEY FOLLOWS THE PERSON, http://www.mfp.illinois.gov/ (last visited Nov. 1, 2012) [hereinafter *Pathways*].

33. *Money Follows the Person (MFP)*, MEDICAID.GOV, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html (last visited Nov. 1, 2012).

34. *Pathways*, *supra* note 32.

35. *See* MONEY FOLLOWS THE PERSON, *supra* note 29, at 45-47. Examples of

In 2008, operational protocol was approved for Illinois' Pathways to Community Living and transitions began in 2009.[36] While the program is only a few years old, the outcomes have already failed to meet the targets set forth in Illinois' original program proposal.[37] Furthermore, the program is very limited because it only focuses on individuals who seek to leave an institutional setting, and does little to improve existing HCBS in communities.[38]

C. PPACA Changes to LTSS

Following the Supreme Court decision on the PPACA, some of the mystery surrounding the future of Medicaid has been lifted; however, there are still questions left unanswered. The PPACA expands Medicaid access in all states by requiring that each state cover all individuals under 133% of the federal poverty level (FPL), in addition to those who may qualify under a specific category of eligibility.[39] Under the PPACA, the federal government would fund the total cost of the expansion for two years, and states would gradually become responsible for 10% of the funding for the expansion as it progresses.[40] Under the PPACA as originally drafted by Congress, the Secretary of Health and Human Services would retain the authority to withhold all of a state's federal funds for Medicaid for failure to

community based care include personal assistant and medication management services for the elderly, peer training for physically disabled individuals, and skills training in community living environments for mentally ill individuals. *Id.*

36. *Presentation from MFP Meeting, February 29, 2012*, MONEY FOLLOWS THE PERSON, http://mfp.illinois.gov/stakeholder/022912_presentation.html (last visited Nov. 1, 2012) [hereinafter *Presentation from MFP Meeting*].

37. *See* MONEY FOLLOWS THE PERSON, *supra* note 29, at 46. Illinois' original MFP proposal identified annual transition targets of 720 individuals in 2009; 765 individuals in 2010; and 815 individuals in 2011. *Id.* However, the actual transitions that occurred were 57 in 2009; 184 in 2010; and 237 in 2011. *See Presentation from MFP Meeting, supra* note 36.

38. *See generally* MONEY FOLLOWS THE PERSON, *supra* note 29, at 45-49.

39. A GUIDE TO THE SUPREME COURT'S DECISION, *supra* note 2, at 3.

40. *Id.*

comply.[41]

The Supreme Court held that the statute, as drafted, was unconstitutionally coercive because states would essentially have no choice but to comply.[42] The Court held that the remedy to this dilemma is to simply adjust the authority of the Secretary to only withhold expansion funds.[43] In effect, this means that the Medicaid expansion proposed under the PPACA is optional for states, though there is an incentive for states to comply in order to receive the additional federal funds.[44]

The PPACA focuses on utilizing HBCB services as opposed to the alternative—costly institutional care.[45] For example, the Community First Choice Option under the PPACA attempts to encourage more use of home-based treatment. The provision "provides states choosing to participate in this option a six percentage point increase in federal Medicaid matching funds for providing community-based attendant services and supports to beneficiaries who would otherwise be confined to a nursing home or other institution."[46]

Another provision in the PPACA, which has since been abandoned,[47] is the Community Living Assistance Services and Supports (CLASS) Act.[48]

---

41. *See id.* at 5.
42. *See id.*
43. *Id.*
44. *Id*. at 7.
45. *See* Tammy Worth, *Helping Seniors Live at Home Longer: The New Patient Protection and Affordable Care Act Aims to Provide At-Home Alternatives to Nursing Home* Care, L.A. TIMES, Jun. 19, 2011, *available at* http://articles.latimes.com/print/2011/jun/19/health/la-he-long-term-care-20110612.
46. U.S. DEP'T OF HEALTH AND HUMAN SERVS, *HHS announces new Affordable Care Act options for community-based care*, HHS.GOV (Apr. 26, 2012), http://www.hhs.gov/news/press/2012pres/04/20120426a.html.
47. *See* MEDICAID'S LONG TERM CARE USERS, *supra* note 4, at 5.
48. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM, HEALTH CARE REFORM AND THE CLASS ACT 1 (Apr. 2010) *available at* http://www.kff.org/healthreform/upload/8069.pdf [hereinafter CLASS ACT].

"CLASS is a national, voluntary insurance program that offers working individuals some protection against the cost of paying for long-term services and supports."[49] This innovative program illustrated an attempt to spread the responsibility of paying for long-term care between multiple payers, instead of relying primarily on Medicaid, and could have created an option for adults to plan for their long-term care needs.[50] Had the CLASS Act remained and implemented by the states, it could have addressed the issue of providing and expanding access to long-term care, which has historically been expensive and difficult to obtain for most Americans.[51] Instead, Secretary Sebelius released a report that the program would not be implemented following a determination that no benefit plan existed that would be both actuarially sound for seventy-five years and meet the statutory requirements under the PPACA.[52] The abandonment of the CLASS Act provided yet another example of how the elderly and disabled population, specifically those who require LTSS, continued to be overlooked within the movement towards universal healthcare.

IV. CONCERNS MOVING FORWARD

As the population of elderly people in the United States continues to grow, so does the demand for LTSS.[53] One thing that has remained consistent, however, is the ease with which LTSS are overlooked. Even in the midst of national healthcare reform and a movement towards universal healthcare, the difficulty in affording and accessing LTSS for elderly and

49. *Id.* at 2.
50. *See id.* at 3 (stating that CLASS would work together with other LTSS programs, including Medicaid, and that an individual eligible for CLASS benefits and benefits under Medicaid, the CLASS benefits would be used to offset Medicaid costs).
51. *See id.*
52. MEDICAID'S LONG TERM CARE USERS, *supra* note 4, at 5.
53. *See id.*

disabled individuals remains problematic. Although there have been minor recognitions of the need to address the problem of accessing and receiving LTSS, both nationally and in Illinois specifically, little progress has been made. The ease at which the CLASS act of the PPACA was abandoned exemplifies how LTSS remains a low priority with regards to overall healthcare reform. Further, the limited reform of LTSS in Illinois, coupled with the unremarkable results of programs already implemented, suggests that the accessibility and funding of LTSS for elderly and disabled populations will continue to be a challenge. In order to actually achieve a universal model, legislators on both the state and federal level will need to recognize how problematic the LTSS system is, and commit to reform that will increase the accessibility, quality, and cost-efficiency of LTSS.