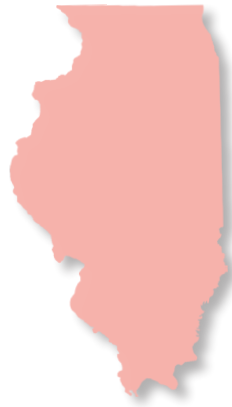


# CONFIDENTIAL + COVERED



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## Protecting Patients' Privacy in Health Insurance Billing & Claims: **An Illinois Profile**

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# Introduction

*Confidential & Covered* was a three-year research project led by the National Family Planning & Reproductive Health Association (NFPRHA) and funded by the US Department of Health & Human Services' Office of Population Affairs as part of its Affordable Care Act Collaborative. The project was designed to identify policies and practices to mitigate revenue loss at Title X-funded health centers due to the provision of confidential health services. The purpose was to improve service sites' sustainability while preserving one of Title X's core principles, namely the provision of confidential services for patients served by this essential program. *Confidential & Covered* partnered with the Center for Adolescent Health & the Law (CAHL), the George Washington University's Milken Institute School of Public Health, and the University of California, San Francisco's Bixby Center for Global Reproductive Health to conduct research on insurance use and confidentiality throughout the payment process—in other words, payment that does not breach privacy.<sup>1</sup>

Protecting confidentiality is complex and has presented particular challenges in the health insurance arena. The insurance landscape is replete with opportunities for disclosure of private information, some of which are the result of explicit legal requirements or insurance carriers' policies and practices, such as the sending of explanations of benefits (EOBs) when insurance claims are filed and acted upon. These disclosures may result in a patient's information reaching a family member, often the policyholder for the health insurance, even when the patient wants the information to remain private. In some cases, the information could pertain to family planning or other sensitive health services where the patient would be in jeopardy due to the disclosure. In this context, the *Confidential & Covered* project has worked to identify ways to protect patient confidentiality without forfeiting the opportunity of providers to secure health insurance payments for patients insured as dependents on a family member's policy.

In the first year of the project (2014-2015), the *Confidential & Covered* policy team at NFPRHA and CAHL undertook extensive research and detailed analysis of federal and state laws and policies relevant for publicly funded family planning that provide confidentiality protection or, on the other hand, can lead to the disclosure of confidential information via billing and health insurance claims. The team published a white paper<sup>2</sup> and policy guide<sup>3</sup> based on that research and analysis.

In the second and third years of the project (2015-2017), the team visited six states that have laws in place designed to enable individuals to use their health insurance coverage without foregoing confidentiality protection or triggering privacy breaches. Profiles of California, Colorado, and Washington were published in 2016; profiles of Maryland and Oregon were released in 2017 along with this profile of Illinois.

This report provides a profile of the current policy environment for confidentiality and insurance in Illinois based on a review of Illinois laws and in-person interviews with key informants conducted in August and September 2016. The informants included a variety of stakeholders, such as family planning providers, adolescent and young adult health experts, school-based health center staff, lawyers, advocates, and Medicaid agency officials.<sup>4</sup>

The profile offers background on the legal and policy framework for confidentiality and insurance in Illi-

1 Publications and other resources developed as part of the *Confidential & Covered* project are available at [www.confidentialandcovered.com](http://www.confidentialandcovered.com).

2 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, *Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X* (Washington, DC: National Family Planning & Reproductive Health Association, 2015). [http://www.confidentialandcovered.com/file/ConfidentialandCovered\\_WhitePaper.pdf](http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf).

3 Julie Lewis, Robin Summers, Abigail English, and Clare Coleman, *Proactive Policies to Protect Patients in the Health Insurance Claims Process* (Washington, DC: National Family Planning & Reproductive Health Association, 2015). [http://www.confidentialandcovered.com/file/ConfidentialandCovered\\_PolicyGuide.pdf](http://www.confidentialandcovered.com/file/ConfidentialandCovered_PolicyGuide.pdf).

4 A list of individuals interviewed is included in Appendix A.

nois, explains a state statute enacted in 2015<sup>5</sup> designed to improve privacy protection for individuals enrolled in Medicaid managed care, describes the origins and implementation of the statute, and considers positive features associated with the law as well as ongoing challenges. The report represents a composite picture drawn from the varied comments of the informants interviewed.

## **Background: Confidentiality & Insurance in Illinois**

Since the Affordable Care Act (ACA) was enacted in 2010, Illinois has experienced an increase in the number of individuals with health insurance.<sup>6</sup> The increase has largely been driven by successful enrollment in marketplace plans through the state's health insurance exchange, GetCoveredIllinois;<sup>7</sup> via the state's expansion of Medicaid;<sup>8</sup> and as a result of the ACA provision allowing young adults to remain on a parent's health insurance up to age 26 and a similar pre-existing Illinois law.<sup>9</sup> In particular, the Illinois Medicaid expansion resulted in the enrollment of more new Medicaid recipients than expected.<sup>10</sup>

Many of the newly insured individuals who gained commercial health insurance coverage as a result of the ACA as well as those with coverage under employer-based plans are covered as dependents on a family member's plan.<sup>11</sup> These include young adults and adolescents, as well as spouses and domestic partners, some of whom are affected by intimate partner violence. When health insurance reimbursement is sought for dependents' care, these individuals may have their privacy infringed. This occurs due to legal and policy requirements for disclosure of information in the health insurance billing and claims process, or as a result of health plan contracts and practices, and in spite of existing legal protections for the confidentiality of health information.

Several states, including Illinois, have adopted regulations or enacted statutes to address this privacy risk, as *Confidential & Covered* has reported in its series of state profiles.<sup>12</sup> In five states, the new laws were directed primarily at increasing privacy protections in the commercial insurance arena. In Illinois, however, the new statute did not directly address the commercial insurance market. Rather, it focused on adding requirements to the state's Medicaid law designed to ensure that confidential information of enrollees in Medicaid managed care plans is protected.<sup>13</sup>

## **HIPAA Privacy Rule Protections**

In Illinois, as in every state, the federal HIPAA Privacy Rule requires health care providers and health insurers to protect patients' privacy. Of particular importance, the rule includes two special protections that restrict disclosure of protected health information (PHI) and provide for confidential communications. The first allows patients to request restrictions on the disclosure of their PHI.<sup>14</sup> Health care providers and health

5 305 Ill. Comp. Stat. 5/5-30(i). The text of this section is included in Appendix B. This subsection (i) is part of a larger section 305 Ill. Comp. Stat. 5/5-30 that contains detailed requirements on "Care Coordination" as part of Illinois' Medicaid statute.

6 Assistant Sec'y for Planning & Eval., U.S. Dept. of Health & Human Services. *Compilation of State Data on the Affordable Care Act*. <https://aspe.hhs.gov/compilation-state-data-affordable-care-act>; Namrata Uberoi, Kenneth Finegold, and Emily Gee. *Health Insurance Coverage and the Affordable Care Act, 2010-2016*. Mar. 3, 2016. <https://aspe.hhs.gov/system/files/pdf/187551/ACA2010-2016.pdf>.

7 <https://getcovered.illinois.gov/en>.

8 Louise Norris. *Illinois and the ACA's Medicaid Expansion: Medicaid Expansion Enrollment Far Above Projections*. Jan. 5, 2017. <https://www.healthinsurance.org/illinois-medicaid/>; Ass't.

Sec'y for Planning & Eval., U.S. Dept. of Health & Human Services. *Medicaid Expansion Impacts on Insurance Coverage and Access to Care*. Jan. 18, 2017. <https://aspe.hhs.gov/system/files/pdf/255516.medicaidexpansion.pdf>.

9 Illinois Dept. of Insurance. *Illinois Insurance Facts: Young Adult Dependent Coverage*. February 2011. <http://insurance2.illinois.gov/pressRelease/pr10/hb5285DepCov.pdf>. Prior to the ACA, Illinois enacted the Young Adult Dependent Coverage Law, effective June 1, 2009, allowing parents with insurance policies that cover dependents the right to elect coverage for certain dependents up to age 26 and for military veteran dependents up to age 30. 215 Ill. Comp. Stat. 356z.12.

10 Louise Norris. *Illinois and the ACA's Medicaid Expansion: Medicaid Expansion Enrollment Far Above Projections*. Jan. 5, 2017. <https://www.healthinsurance.org/illinois-medicaid/>.

11 The U.S. Department of Health & Human Services' Assistant Secretary for Planning Evaluation tracks and disseminates insurance enrollment. Enrollment numbers can be found at <https://aspe.hhs.gov/affordable-care-act-research>.

12 <https://www.confidentialandcovered.com/research-and-findings#Publications>.

13 305 Ill. Comp. Stat. 5/5-30(i), added by S.B. 1253 and H.B. 2812, 99th Gen. Assem., Reg. Sess. (Il. 2015), 2015 Ill. Laws 181.

14 45 C.F.R. § 164.522(a)(1).

plans are not generally required to comply with such requests unless they agree to do so, but they must agree if the care has been fully paid for by the patient or someone other than the health plan. The second special protection allows patients to request that they “receive communications of protected health information ... by alternative means or at alternative locations.”<sup>15</sup> It is noteworthy that with respect to requests for confidential communications the HIPAA rule for health care providers differs from the requirement for health plans. Health care *providers* must accommodate reasonable requests and may not require patients to claim they would be endangered by disclosure; health *plans* must accommodate reasonable requests when there is a claim of endangerment. Thus, plans are only required to comply with requests if endangerment is claimed.

## **Illinois Privacy Laws**

Several Illinois laws protect the privacy of individuals' health information. For example, the public health code contains a Medical Patient Rights Act that includes detailed protections for the “right of each patient to privacy and confidentiality.”<sup>16</sup> The Managed Care Reform and Patient Rights Act, which applies to the Illinois Medicaid program, includes a section that expressly provides: “A patient has the right to privacy and confidentiality in health care.”<sup>17</sup> Other provisions of Illinois law address the confidentiality and disclosure of insurance information<sup>18</sup> and of hospital records.<sup>19</sup> Some of the sections are similar to requirements of the HIPAA Privacy Rule or explicitly refer to sections of HIPAA.<sup>20</sup> Illinois Law also contains specific protections for information related to substance use disorders, consistent with federal regulations for drug and alcohol programs,<sup>21</sup> and for mental health records and information.<sup>22</sup> Health care providers and insurers in Illinois are also required to adhere to the extensive federal confidentiality laws that have been described elsewhere.<sup>23</sup>

## **Minor Consent Laws**

In addition to the laws that provide confidentiality protection for individuals of all ages, Illinois has detailed laws that allow minors to consent for their own care in a broad range of situations and protect the confidentiality of health information associated with that care.<sup>24</sup> Some minors are allowed to consent for most of their own health care: married minors, pregnant minors, and minor parents.<sup>25</sup> Minors who are age 14 or older, living apart from their parents, managing their own financial affairs, and unable or unwilling to return home are allowed to consent for primary care services.<sup>26</sup> “Mature minors” also may be allowed to consent for or refuse medical treatment.<sup>27</sup> Minors of any age may receive birth control services and information without parental consent.<sup>28</sup> They are also allowed to consent for diagnosis or treatment

15 45 C.F.R. §§ 164.502(h); 164.522(b)(1).

16 410 Ill. Comp. Stat. 50/3(d).

17 215 Ill. Comp. Stat. 134/5(a)(4). A similar section provides that dental patients have the same right to confidentiality. 215 Ill. Comp. Stat. 109/5(b)(4).

18 Insurance Information and Privacy Protection Act, 215 Ill. Comp. Stat. 5/1001-5/1024.

19 Hospital Licensing Act, 210 Ill. Comp. Stat. 85/6.17.

20 E.g., 410 Ill. Comp. Stat. 50/3(d).

21 20 Ill. Comp. Stat. 301/30-5(bb).

22 Mental Health & Disabilities Confidentiality Act, 740 Ill. Comp. Stat. 110/9 - 110/17.

23 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X (Washington, DC: National Family Planning & Reproductive Health Association, 2015). [http://www.confidentialandcovered.com/file/ConfidentialandCovered\\_WhitePaper.pdf](http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf).

24 E.g., Consent by Minors to Medical Procedures Act, 410 Ill. Comp. Stat. 210/1 et seq.

25 410 Ill. Comp. Stat. 210/1 and 210/2.

26 410 Ill. Comp. Stat. 210/1/5. “Primary care services” include those that are customarily provided by licensed professionals in an outpatient setting. 410 Ill. Comp. Stat. 210/1.5(e). To consent for primary care services a minor who has these characteristics also must be designated as “a minor seeking care” by an adult relative or a specified official, agency, or organization.

27 *In re E.G.*, 133 Ill. 2d 98, 549 N.E. 2d 322 (1989). A “mature minor” is one who is able to appreciate the consequences of her actions and exercise the judgment of an adult. *Id.* Although the criteria were set forth in a court decision, ordinarily the determination of maturity would be made by a treating health care professional.

28 “Birth control services and information may be rendered by doctors licensed in Illinois to practice medicine in all of its branches to any minor: 1. who is married; or 2. who is a parent; or 3. who is pregnant; or 4. who has the consent of his [sic] parent or legal guardian; or 5. as to whom the failure to provide such services would create a serious health hazard; or 6. who is referred for such services by a physician, clergyman or a planned parenthood agency.” 325 Ill. Comp. Stat. 10/1.

of diseases or injuries arising from a sexual assault.<sup>29</sup> Minors age 12 or older are allowed to consent for medical care or counseling related to diagnosis or treatment of sexually transmitted disease<sup>30</sup> or drug or alcohol use,<sup>31</sup> and for outpatient counseling or psychotherapy.<sup>32</sup>

When a minor has consented to care, Illinois law contains several provisions that protect the confidentiality of the information associated with that care. Although in some situations the health care professional is permitted, or encouraged, to inform the parents or to assist the minor to share information with parents, the laws do not require a health care professional to disclose the information in these situations.<sup>33</sup> Moreover, the laws do not allow for disclosures that would be detrimental to the minor,<sup>34</sup> that do not serve the minor's best interest,<sup>35</sup> or that are not necessary to ensure the minor's safety.<sup>36</sup> Disclosure would not be allowed when a minor has consented to family planning services that are funded by Title X or Medicaid and subject to the confidentiality requirements of those programs.

### **Insurance Disclosure Laws**

As in other states, the confidentiality protections for medical and health information in Illinois law are not absolute. In particular, the insurance laws contain various requirements for the disclosure of otherwise confidential information, sometimes with the individual's authorization, sometimes without. For example, Illinois laws specify when authorization is required for disclosure of personal health information and when disclosure may occur without authorization and some refer explicitly to provisions of the HIPAA Privacy Rule.<sup>37</sup>

One Illinois statute of note contains explicit requirements for the information a health insurer must provide on an explanation of benefits (EOB) or claims summary statement, including: "(1) The total dollar amount submitted to the insurer for payment. (2) Any reduction in the amount paid due to the application of any co-payment or deductible, along with an explanation of the amount of the co-payment or deductible applied under the insured's policy. (3) Any reduction in the amount paid due to the application of any other policy limitation or exclusion set forth in the insured's policy, along with an explanation thereof. (4) The total dollar amount paid. (5) The total dollar amount remaining unpaid."<sup>38</sup> These requirements could result in the disclosure of confidential information by identifying a provider of sensitive services or by triggering additional inquiries by a policyholder.

Illinois law also includes provisions related to denials of claims that could result in the disclosure of otherwise confidential information to a policyholder for claims based on services provided to an insured dependent. For example, when a claim is denied, Illinois regulations require that health insurers and managed care plans provide a written explanation of the reason for the denial.<sup>39</sup> In addition to the requirements of Illinois law, federal law contains important requirements for notice to be given when claims are denied; these requirements also risk disclosure of an insured dependent's confidential health information. (See text box.) The federal requirements for notice of denials apply in Medicaid managed care as well as in the commercial insurance arena.

<sup>29</sup> 410 Ill. Comp. Stat. 210/3(b).

<sup>30</sup> 410 Ill. Comp. Stat. 210/4 and 325/3(3); 77 Ill. Comp. Stat. 693/20.

<sup>31</sup> 410 Ill. Comp. Stat. 210/4.

<sup>32</sup> 405 Ill. Comp. Stat. 5/3-501.

<sup>33</sup> E.g., 410 Ill. Comp. Stat. 210/4 and 210/5; 410 Ill. Comp. Stat. 305/9; 410 Ill. Comp. Stat. 5/3-501.

<sup>34</sup> E.g., 410 Ill. Comp. Stat. 210/4.

<sup>35</sup> E.g., 410 Ill. Comp. Stat. 305/9.

<sup>36</sup> E.g., 410 Ill. Comp. Stat. 210/5.

<sup>37</sup> E.g., 410 Ill. Comp. Stat. 50/3(d)(3) and (4).

<sup>38</sup> 215 Ill. Comp. Stat. 5/143.31(c).

<sup>39</sup> 50 Ill. Adm. Code 919.50(a)(1) and 5420.70.

### **Federal Notice Requirements for "Denials"**

Federal law requires that insurers and health plans share information about denials of claims with policyholders, subscribers, and enrollees – as detailed in the Affordable Care Act (ACA), Employee Retirement Income Security Act (ERISA), and Medicaid Managed Care regulations.<sup>40</sup> These denial notices are commonly sent in a format that looks like an explanation of benefits (EOB). See *Confidentiality, Third-party Billing, and the Health Insurance Claims Process: Implications for Title X for a robust discussion of federal insurance law and its impact on privacy.*<sup>41</sup>

### **Illinois Medicaid**

The structure and evolution of Medicaid in Illinois serves as the backdrop to the statute Illinois enacted in 2015 to protect the privacy of Medicaid enrollees from the breaches associated with disclosures that often are part of the processing of insurance claims. Medicaid covers more than 3 million individuals in Illinois, or nearly 25% of the state's population.<sup>42</sup> Illinois elected to expand Medicaid under the ACA and enrollment in the expansion was much larger than expected, totaling nearly 500,000 new beneficiaries in three years.<sup>43</sup>

The Illinois Medicaid program includes strong support for family planning services. Although its Medicaid family planning waiver program, Illinois Healthy Women, ended in December 2014 after operating for 11 years,<sup>44</sup> the state reaffirmed its commitment to Medicaid support for family planning in a Family Planning Action Plan.<sup>45</sup> The Illinois Medicaid population includes both adolescents and young adults who may still be living with their parents as well as other individuals living in households with family members or others with whom they may not want to share confidential health information.

Although Illinois Medicaid historically operated on a fee-for-service basis, recently the state has altered its policies in favor of a transition to managed care for the Medicaid population. Medicaid managed care will be extended to all Illinois counties by January 2018, with 65% of the state's Medicaid beneficiaries already enrolled in a managed care plan as of April 2017.<sup>46</sup> Medicaid managed care in Illinois consists of four separate programs and numerous health plans within them; a majority of the Medicaid population is mandated to enroll in a managed care plan whereas enrollment for others is voluntary.<sup>47</sup> The mandatory groups include, for example, children and families traditionally eligible for full Medicaid benefits as well as adults newly covered under the ACA.<sup>48</sup> Notably, the new beneficiaries pursuant to the ACA Medicaid expansion are mandatorily enrolled in managed care;<sup>49</sup> many of these new beneficiaries are young adults.<sup>50</sup> At the same time, Illinois continues to recognize the free choice of provider requirements of

40 45 C.F.R. § 147.136; 26 C.F.R. § 54.9815-2719; 29 C.F.R. § 2590.715-2719; 42 C.F.R. § 438.404.

41 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, *Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X* (Washington, DC: National Family Planning & Reproductive Health Association, 2015). [http://www.confidentialandcovered.com/file/ConfidentialandCovered\\_WhitePaper.pdf](http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf).

42 Louise Norris. *Illinois and the ACA's Medicaid Expansion: Medicaid Expansion Enrollment Far Above Projections*. Jan. 5, 2017. <https://www.healthinsurance.org/illinois-medicaid/>.

43 *Id.*

44 Illinois Dept. of Health & Family Services. *Illinois' Family Planning Expansion Initiative Under Medicaid: Final Program Report*. Mar. 31, 2015. [https://www.illinois.gov/hfs/SiteCollectionDocuments/IHWFinalReports\\_032015.pdf](https://www.illinois.gov/hfs/SiteCollectionDocuments/IHWFinalReports_032015.pdf).

45 Illinois Dept. of Health & Family Services. *Illinois Family Planning Action Plan*. <https://www.illinois.gov/hfs/MedicalClients/FamilyPlanning/Pages/IllinoisFamilyPlanningActionPlan.aspx>.

46 Illinois Dept. of Health & Family Services. *Medicaid Managed Care Transformation*. Apr. 7, 2017. <https://www.illinois.gov/hfs/MedicalProviders/notices/Pages/prn170407a.aspx>.

47 Illinois Dept. of Healthcare & Family Services. *Managed Care Manual for Medicaid Providers*. January 2016. <https://www.illinois.gov/hfs/SiteCollectionDocuments/1.14.16%20Managed%20Care%20Manual%20for%20Medicaid%20Providers.pdf>.

48 *Id.*

49 Illinois Dept. of Healthcare & Family Services. *Managed Care Manual for Medicaid Providers*. January 2016. <https://www.illinois.gov/hfs/SiteCollectionDocuments/1.14.16%20Managed%20Care%20Manual%20for%20Medicaid%20Providers.pdf>.

50 About 44% of new Medicaid enrollees under the ACA were ages 19-34. Illinois Dept. of Health Care & Family Services. *Affordable Care Act Enrollment by Age, Race, and Gender through April 2016*. <https://www.illinois.gov/hfs/SiteCollectionDocuments/ACAEnrollmentSummaryData.pdf>. See also Sargent Shriver National Center on Poverty Law, *Aids Foundation of Chicago, and EverThrive Illinois. The Affordable Care Act Keeps Illinois Healthy*. [http://everthriveil.org/sites/default/files/docs/hr/Talking%20Points.%20Messaging.%20December%206.%20Final\\_\\_Branded.pdf](http://everthriveil.org/sites/default/files/docs/hr/Talking%20Points.%20Messaging.%20December%206.%20Final__Branded.pdf).

federal Medicaid law, so that Medicaid beneficiaries are allowed to see any Medicaid provider of their choice for family planning and reproductive health services and are not restricted to using a provider within the managed care network even if they are enrolled in a managed care plan.<sup>51</sup>

Confidential health information about individuals enrolled in the Illinois Medicaid program is affected both by laws protecting privacy and by laws requiring certain disclosures. For example, both federal Medicaid law<sup>52</sup> and the Illinois Managed Care Reform and Patient Rights Act expressly protect privacy and confidentiality.<sup>53</sup> The HIPAA Privacy Rule also protects Medicaid beneficiaries. At the same time, even though there is no general federal requirement for EOBs to be sent in Medicaid, and the Illinois Medicaid agency traditionally has not sent EOBs, some requirements for notices when claims are denied apply to Medicaid managed care plans under federal law, which could lead to disclosure of confidential health information (see “Federal Notice Requirements for “Denials” above).<sup>54</sup> It is against this background that Illinois added a new confidentiality protection to its Medicaid program.

## The Illinois Law

In 2015, Illinois added a section to its Medicaid statute that requires managed care entities to take specific steps to avoid breaching enrollees' privacy.<sup>55</sup> The law is designed to make sure that Medicaid managed care plans disclose information about sensitive services only to enrollees, to their providers and care coordinators, and to plan employees and business associates for specific permissible purposes.

## Elements of the Statute

The new Illinois code section contains several definitions delineating the scope of its protections as well as specific obligations for Medicaid managed care plans to meet unless “otherwise required by federal law.”<sup>56</sup>

### Definitions

#### Medicaid Managed Care Entity

Managed care entities include:

- Care Coordination Entities
- Accountable Care Entities
- Managed Care Organizations
- Managed Care Community Networks

#### Sensitive Health Services

Sensitive health services include prevention, screening, consultation, examination, treatment, or follow up for:

- Mental health
- Substance abuse
- Reproductive health
- Family planning
- Sexually transmitted infections and sexually transmitted diseases, sexual assault, or domestic abuse

#### Protected Individuals

Enrollees of a Medicaid Managed Care Entity

51 Illinois Dept. of Healthcare & Family Services. Informational Notice to Providers: Family Planning & Reproductive Health Services. June 26, 2014. <https://www.illinois.gov/hfs/MedicalProviders/notices/Pages/prn140626a.aspx>.

52 42 U.S.C. § 1396a(a)(7); 42 C.F.R. §431.306.

53 215 Ill. Comp. Stat. 134/5(a)(4). A similar section provides that dental patients have the same right to confidentiality. 215 Ill. Comp. Stat. 109/5(b)(4).

54 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X (Washington, DC: National Family Planning & Reproductive Health Association, 2015). [http://www.confidentialandcovered.com/file/ConfidentialandCovered\\_WhitePaper.pdf](http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf).

55 305 Ill. Comp. Stat. 5/5-30(i). The text of this section is included in Appendix B. 305

56 305 Ill. Comp. Stat. 5/5-30(i).



## Legislative Elements

### Obligations of Medicaid Managed Care Entities

Managed care entities must refrain from disclosing information about sensitive health services received by an enrollee:

- Directly or indirectly
- Including by sending a bill or explanation of benefits
- Other than as expressly permitted or required

### Permissible Disclosures by Managed Care Entities

Managed care entities may disclose information about sensitive services received by an enrollee to:

- Providers and care coordinators caring for the enrollee
- Employees of the entity for internal operations
- Business associates and covered entities for purposes permissible under federal and state law
- The enrollee who requests the information and has authorized the sending of a bill or explanation of benefits
- Comply with:
  - STD reporting requirements
  - Child abuse reporting requirements
  - Other requirements of state or federal law

### Individual Right

Enrollees have a right:

- To have information about sensitive services they receive protected from disclosure by the Managed Care Entity other than as expressly permitted
- To receive information concerning the sensitive services if they authorize the sending of a bill or explanation of benefits by the Managed Care Entity

### Obligation of Department of Healthcare & Family Services

The Department is required to create policy to implement the statute

## Origins of the Statute

The Illinois statute grew out of a recognition that confidentiality protection, especially for family planning services and other reproductive health care, is at risk when individuals are insured on a family member's plan in the commercial insurance arena. This recognition was accompanied by an awareness—heightened by incidents of confidentiality breaches in a few specific cases reported anecdotally by Title X providers that their Medicaid patients had received EOBs—that Medicaid managed care plans, accustomed to sending EOBs to policyholders or patients in their commercial plans, might also send them to Medicaid enrollees. A special impetus emerged from a collaborative initiative among the Illinois Department of Public Health, Planned Parenthood of Illinois, and the Chicago Public Schools to do STI testing in districts with the highest STI rates. A desire and need to bill Medicaid for these tests was tempered by a countervailing concern that although Medicaid had not been sending EOBs the transition to managed care might lead to EOBs being sent by managed care plans.

**“The Illinois statute grew out of a recognition that Medicaid managed care plans, accustomed to sending EOBs to policy holders or patients in their commercial plans, might also send them to Medicaid enrollees.”**

To address the EOB concern, EverThrive Illinois (formerly the Illinois Maternal and Child Health Coalition) convened an informal coalition of health care providers and advocates that included Planned Parenthood of Illinois, EverThrive Illinois, the ACLU of Illinois, school-based health centers, and other policy advocates. The group embarked on a collaborative effort to develop a strategy.

Initially, the coalition researched policies developed in other states such as California, Colorado, and Washington to learn whether a best model was available that could be implemented in Illinois. This early research and strategy development took place at a time of significant changes in health insurance policy in the state, including implementation of the ACA health insurance exchange, the expansion of Medicaid, and the transition to Medicaid managed care. These changes had required intense work on the part of the state legislature, the state insurance department and Medicaid agency, health insurers, and the health advocacy community. Consequently, the coalition concluded that seeking to codify the existing Medicaid practice of not sending EOBs in a statute applicable to Medicaid managed care would be a more feasible and less complex task than developing a new policy for the commercial insurance arena. At the same time, members of the coalition believed that it was important and might be possible with a sympathetic legislative sponsor to address the commercial insurance problem.

The resulting strategy unfolded in two parts. In 2015, a bill was introduced to require Medicaid managed care entities to refrain from sending EOBs or otherwise disclosing information about sensitive services received by Medicaid managed care enrollees without their authorization, except as required or permitted by state and federal law, including the HIPAA Privacy Rule.<sup>57</sup> That bill was enacted relatively easily and with little opposition from the insurance industry or other interests.<sup>58</sup> Subsequently, in 2016 another bill was introduced, as an amendment to a piece of pending legislation, to address confidentiality issues in commercial insurance.<sup>59</sup> This bill built on the HIPAA Privacy Rule protections and was similar to the statute enacted in California in 2013; it would have required insurers to accept and act on requests from patients for confidential communications with respect to sensitive services. The bill focusing on the commercial insurance arena drew opposition from insurers, concerns on the part of some legislators about limiting parents' knowledge of health care provided to their children, and general objections related to the need for transparency for policyholders. It was not enacted.

## **Implementation Progress**

Once 305 Ill. Comp. Stat. 5/5-30(i) had been codified as part of the Illinois statutes governing Medicaid managed care, the Department of Healthcare & Family Services (HFS) moved promptly to implement it. Prior to the statute's enactment, HFS had already begun to include a requirement in Medicaid managed contracts that EOBs not be sent; following enactment this requirement became a routine part of the contracts. The Medicaid agency discussed this requirement not to send EOBs at its quarterly meetings with the managed care entities.

Previously, Title X and other family planning providers had been comfortable billing Medicaid because they knew that EOBs would not be sent and confidentiality would be protected. However, with the transition to managed care, concern grew about whether confidentiality would continue to be protected. Enactment of the new statute and inclusion of its requirements in managed care contract language provided some reassurance. In the few instances where breaches occurred, HFS moved assertively to rectify the situation by investigating what had occurred and addressing the problem directly with the managed

<sup>57</sup> S.B. 1253 and H.B. 2812, 99th Gen. Assem., Reg. Sess. (Il. 2015), 2015 Ill. Laws 181.

<sup>58</sup> The bill was codified as 305 Ill. Comp. Stat. 5/5-30(i) and made effective July 29, 2015. A subsequent amendment, effective January 1, 2017, incorporated some language from the HIPAA Privacy Rule regarding business associates. S.B. 2331, 99th Gen. Assem. Reg. Sess. (Il. 2016), 2016 Ill. Laws 566.

<sup>59</sup> Amendment to H.B. 887, 99th Gen. Assem. Reg. Session, filed Mar. 28, 2016.

care plans. This approach was consistent with the good relationship that had historically existed in Illinois between Medicaid and Title X.

### **Positive Features and Challenges**

This Illinois statute has several noteworthy positive aspects. The new law:

- imposes affirmative obligations on Medicaid managed care entities that do not depend on action initiated by enrollees;
- adopts a broad definition of sensitive services that addresses the interests of many of the groups with heightened confidentiality concerns;
- incorporates the existing Illinois practice of not sending EOBs in fee-for-service Medicaid into the Medicaid managed care arena; and
- maintains consistency in Illinois law with the disclosures permitted under federal law by the HIPAA Privacy Rule.

The policy environment in which the new law is being implemented also is characterized by significant challenges. These challenges include:

- a high percentage of safety net providers' patient populations who are Medicaid recipients transitioning into managed care;
- a need for family planning providers, school-based health centers, and other safety net groups to negotiate contracts to become part of Medicaid managed care networks;
- unfamiliarity on the part of managed care organizations with the "free choice of provider" requirement in Medicaid;
- inconsistent practices by managed care organizations with respect to sending of EOBs to the homes of Medicaid and commercially insured patients of safety net providers; and
- a greater risk of confidentiality breaches associated with billing for lab tests and pharmacy filling of prescriptions than for communications sent directly by managed care organizations.

## Conclusion

Illinois has been experiencing rapid changes in health policy associated with implementation of the ACA and the state's decision to transition Medicaid to managed care. These changes have had significant implications for Title X, family planning, and other safety net providers and their patients. The Medicaid population grew rapidly with the ACA Medicaid expansion. At the same time, the state ended its operation of a Medicaid family planning waiver that had allowed large numbers of low-income women to receive family planning services through Medicaid. The family planning environment in Illinois is one in which the relationship between Title X and Medicaid as well as Medicaid support for family planning have been strong. Nevertheless, with the transition to Medicaid managed care, concerns grew about whether confidentiality might receive less protection—such as through the sending of EOBs or similar communications by managed care plans—than had been the case historically under the fee-for-service system. At the initiation of a coalition of providers and advocates, Illinois enacted a statute to limit confidentiality breaches by managed care organizations and the state's Medicaid agency moved promptly to implement it, developments that could provide significant protection for many low-income patients enrolled in Medicaid managed care in Illinois. Other challenges remain: unexpected privacy breaches can occur even in the Medicaid arena, especially through billing for lab tests and filling of prescriptions; and a policy has not been enacted to address the confidentiality of insurance communications in the commercial sector. Even so, the Illinois statute represents an important strategy that thus far remains unique among state approaches to confidentiality in health insurance billing and claims.

## Appendix A: List of Key Informants

The *Confidential & Covered* project staff would like to thank the many key informants that contributed to this work. All comments are a composite of interviews conducted, and comments should not be construed to represent the views of the organizations listed below.

| <b>Organization</b>   | <b>Name</b>              | <b>Title</b>  |
|---|--------------------------|---|
| Ann & Robert H. Lurie Children's Hospital of Chicago  | Robert Garofalo MD, MPH  | Division Chief, Adolescent Medicine; Director, Center for Gender, Sexuality and HIV Prevention            |
| EverThrive Illinois   | Nadeen Israel, AM        | Policy Director   |
| EverThrive Illinois   | Kathy Waligora, MSW      | Director, Health Reform Initiative  |
| Legal Council for Health Justice  | Thomas Yates, JD         | Executive Director  |
| Illinois Department of Healthcare & Family Services   | Linda Wheal              | Maternal Health Program Manager (former)  |
| Planned Parenthood of Illinois  | Brigid Leahy             | Director of Public Policy   |
| Roger Baldwin Foundation of the ACLU of IL  | Lorie Chaiten, JD        | Director, Women's and Reproductive Rights Project   |
| Rush School Based Health Centers and the Adolescent Family Center /Rush University Medical Center | Sally Lemke DNP, WHNP-BC | Director, Community Based Practices/ Instructor, Department of Women, Children, and Family Health Nursing |
| The University of Chicago   | Lee Hasselbacher, JD     | Senior Policy Researcher, Section of Family Planning & Contraceptive Research                             |

## Appendix B: The Illinois Law

### **305 Ill. Comp. Stat. 5/5-30 (i) provides:**

Unless otherwise required by federal law, Medicaid Managed Care Entities and their respective business associates shall not disclose, directly or indirectly, including by sending a bill or explanation of benefits, information concerning the sensitive health services received by enrollees of the Medicaid Managed Care Entity to any person other than covered entities and business associates, which may receive, use, and further disclose such information solely for the purposes permitted under applicable federal and State laws and regulations if such use and further disclosure satisfies all applicable requirements of such laws and regulations. The Medicaid Managed Care Entity or its respective business associates may disclose information concerning the sensitive health services if the enrollee who received the sensitive health services requests the information from the Medicaid Managed Care Entity or its respective business associates and authorized the sending of a bill or explanation of benefits. Communications including, but not limited to, statements of care received or appointment reminders either directly or indirectly to the enrollee from the health care provider, health care professional, and care coordinators, remain permissible. Medicaid Managed Care Entities or their respective business associates may communicate directly with their enrollees regarding care coordination activities for those enrollees.

For the purposes of this subsection, the term "Medicaid Managed Care Entity" includes Care Coordination Entities, Accountable Care Entities, Managed Care Organizations, and Managed Care Community Networks

For purposes of this subsection, the term "sensitive health services" means mental health services, substance abuse treatment services, reproductive health services, family planning services, services for sexually transmitted infections and sexually transmitted diseases, and services for sexual assault or domestic abuse. Services include prevention, screening, consultation, examination, treatment, or follow-up. For purposes of this subsection, "business associate", "covered entity", "disclosure", and "use" have the meanings ascribed to those terms in 45 CFR 160.103.

Nothing in this subsection shall be construed to relieve a Medicaid Managed Care Entity or the Department of any duty to report incidents of sexually transmitted infections to the Department of Public Health or to the local board of health in accordance with regulations adopted under a statute or ordinance or to report incidents of sexually transmitted infections as necessary to comply with the requirements under Section 5 of the Abused and Neglected Child Reporting Act [325 Ill. Comp. Stat. 5/5] or as otherwise required by State or federal law.

The Department shall create policy in order to implement the requirements in this subsection.

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## **About *Confidential & Covered***

*Confidential & Covered* is a multi-year research project designed to understand the factors that may make it difficult for Title X-funded family planning providers to seek reimbursement due to patient privacy concerns. Learn more at [www.confidentialandcovered.com](http://www.confidentialandcovered.com).

## **About NFPRHA**

NFPRHA represents the broad spectrum of family planning administrators and clinicians serving the nation's low-income and uninsured. NFPRHA serves its members by providing advocacy, education, and training to those in the family planning and reproductive health care fields. For over 40 years, NFPRHA members have shared a commitment to providing high-quality, federally funded family planning care - making them a critical component of the nation's public health safety net.