HIV, Confidentiality, And Third-Party Billing: An Illinois White Paper

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Illinois Public Health Association
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INTRODUCTION

From the earliest days of the HIV epidemic in the United States nearly four decades ago, concerns about confidentiality have been paramount. Protecting the privacy of individuals living with or at risk for HIV has been an important priority for individual patients, health care providers, and policymakers. Numerous laws have been enacted to protect the confidentiality of HIV-related information. Nevertheless, confidentiality challenges continue to arise. Third-party billing and health insurance claims comprise an arena characterized by specific risks for widespread disclosure of sensitive health information, including information about HIV.

This white paper explores the obstacles and opportunities for protecting confidentiality in the context of third-party billing and health insurance claims for HIV prevention, testing, and treatment. Resolving this ongoing challenge is important for encouraging individuals to seek HIV services. Enabling health care providers to improve their capacity to secure third-party reimbursement while protecting confidentiality can increase the effectiveness of public health efforts to address the HIV epidemic.

The white paper was prepared as part of an Illinois Public Health Association project to increase the capacity of health departments and community-based organizations to bill for HIV services and secure reimbursement from health insurers and other third-parties. Their ability to do so ultimately turns on many factors including the federal and state laws that provide confidentiality protections or require disclosures of health information.

First, the white paper provides background on the demographics of HIV, the health services needed, the sources of financing for those services, the importance of confidentiality, the risks of disclosure, and the evolving legal protections. Next, it details the federal laws and the state laws that protect the confidentiality of sensitive health information, including about HIV, or require its disclosure, in the context of third-party billing and health insurance claims. Finally, it explores options for health care providers and policymakers in Illinois to improve the potential for securing reimbursement for essential HIV services while protecting confidentiality.

BACKGROUND

More than 1 million individuals are living with HIV in the United States.[1] In Illinois, in 2016 more than 35,700 adults and adolescents were living with an HIV diagnosis.[2] Overall, certain populations nationally and in Illinois are particularly affected—racial and ethnic minority groups and gay and bisexual men who have sex with men.[3,4] In addition, a wide variety of other individuals also are living with HIV or at risk for infection, including women, transgender individuals, youth, older people, and people living in rural areas.[5]

To address the needs of all individuals who are living with HIV or at risk, a broad range of health services is necessary. Available services must include HIV-specific services for prevention, testing, and treatment, including pre-exposure prophylaxis (PrEP) and anti-retroviral therapy (ART).[6,7] Comprehensive primary, acute, and home health care services are also essential to help ensure that individuals are informed about their risks for HIV infection, connected to HIV testing and other preventive services, engaged in ongoing treatment if HIV-positive, and supported in living with HIV.

The financing of HIV-specific services and other health care for individuals living with HIV comprises a complex and interconnected array of public and private sources, including health insurance, public health service programs, and pharmaceutical industry-funded initiatives.[8,9,10] Key sources of funding and coverage include:

- Medicaid/Medicaid managed care ('Medical Assistance")[11]
- Medicare[12]
- Private insurance, including ACA plans and employer-based coverage[13]
- Tri-Care, CHAMPUS, and the Veterans Administration[14]
- Ryan White HIV/AIDS Program, including the AIDS Drug Assistance Program[15,16]
- Illinois PrEP Assistance Program[17]
- Patient Assistance Programs[18]
- Medicaid Home and Community Based Waiver Services Program[19]

The funding complexity is increased by the diversity of settings in which HIV-specific services and other care for individuals with HIV are delivered. These settings include hospitals, private physician offices, public health clinics, federally qualified health centers (FQHCs), federally funded Title X family planning sites, and other community-based organizations (CBOs). Sites such as FQHCs, Title X health centers, and other CBOs that serve a high number of low-income individuals have a particular need to resolve the challenges associated with increasing third-party reimbursement while providing confidential care in order to address the growing demand for their services and burden on their budgets.

Privacy is an important concern for patients generally and a particular concern with respect to HIV. The obligation to protect patients' privacy and to maintain the confidentiality of patients' health information has its roots historically in the Hippocratic Oath and in modern times is a foundational principle of ethics in health and medicine. Medical codes of ethics and policies of health care professionals' organizations contain strong privacy protections.[20] Medical confidentiality is also protected extensively in federal and state laws. Increasingly, over the past several years a few states have enacted statutes or promulgated regulations to address the confidentiality issues that arise in relation to health care billing and insurance claims.[21]

Despite strong legal protections for confidentiality, the risk of disclosure remains high in the billing and health insurance claims process.[22] Many adolescents are covered on their parents' health insurance and, under the Affordable Care Act (ACA), many young adults remain on their parents' plans until age 26. Myriad communications from health care providers and insurers can result in the disclosure of HIV-related information to individuals other than patients themselves, including parents, spouses, children, domestic partners, housemates, and others. This is a particularly high risk when patients are covered on a family member or domestic partner's health insurance and the policyholder receives information directly. It can also occur in other situations when information is sent in a format that reveals its contents to people other than the intended recipient, or is accessed intentionally or accidentally by others, as occurred in a landmark case involving disclosure of HIV information in a mailing from an insurer.[23]

Types of communications that can result in unwarranted or problematic disclosures are bills, prior authorization requests, health insurance claims, explanation of benefits (EOBs), denials of claims, laboratory test results, and information about prescription medications. Many of these communications fall under the terms of both laws protecting confidentiality and laws requiring disclosure.

Information about services for the prevention, testing, and treatment of HIV involve highly sensitive and personal issues; disclosure of this information carries a risk of stigma and discrimination even decades into the HIV epidemic.[24] Decades of research findings have documented that privacy concerns influence the behavior of individuals with respect to whether, where, and when they seek health care, and how candid they are with their health care providers. Therefore, strong confidentiality protection for HIV information is essential to encourage individuals to seek HIV services. Such protection is especially important but challenging to implement in the arena of third-party billing and health insurance claims. This white paper discusses the confidentiality and disclosure laws relevant to this challenge and the options available to health care providers and policymakers to address it.

FEDERAL CONFIDENTIALITY AND DISCLOSURE LAWS

Numerous federal laws both protect confidentiality and require or allow disclosure of health information; others primarily do one or the other. Relevant federal laws include the HIPAA Privacy Rule; the Part 2 confidentiality regulations for substance use disorder programs; disclosure requirements under the ACA and ERISA; Medicaid; and the statutes and regulations for federally funded health service delivery programs such as the Ryan White HIV/AIDS Programs, FQHCs, and the Title X Family Planning Program.

HIPAA Privacy Rule

The HIPAA Privacy Rule[25,26]—the federal medical confidentiality regulations issued in final form in 2002 under the Health Insurance Portability and Accountability Act—governs the use and disclosure of individuals' "protected health information" (PHI). The HIPAA privacy protections allow individuals, including young adults and some adolescents who are minors, to access their PHI and to control the disclosure of that information in some circumstances. Additional specific requirements apply to the information of adolescents who are legally minors.[27] When the HIPAA Privacy Rule was originally adopted, the preamble to the rule acknowledged the importance of protecting the privacy of HIV information and the need for additional protections.[28]

Disclosures Under HIPAA

The HIPAA Privacy Rule allows for disclosure of PHI in a wide variety of circumstances, subject to detailed regulatory requirements.[29] PHI may be disclosed with the authorization of an individual or the individual's authorized representative. It may also be disclosed without authorization for purposes of treatment, payment, or health care operations, although many entities choose to seek patients' consent for doing so.[30,31,32] PHI may also be disclosed without an individual's authorization in public health emergencies,[33] for research uses,[34] and when required by law.[35]

Special Privacy Protections Under HIPAA

In all states, including Illinois, the HIPAA Privacy Rule requires heath care providers and health insurers, including Medicaid, to protect patients' privacy. In addition to the general requirements related to access and control of disclosure, the rule includes two special confidentiality protections.

The first of these protections allows patients to request restrictions on the disclosure of their PHI.[36] Health care providers and health 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."[37] This protection is often referred to as allowing patients to "redirect communications" or as a "request for confidential communications" from health insurers and plans. 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, health plans are only required to comply with requests if endangerment is claimed. The HIPAA Privacy Rule does not specifically define "endangerment" but the Preamble to the rule includes some explanation.[38]

Disclosure Requirements Under ACA, ERISA, and Medicaid Managed Care

Insurers and health plans often refer to "federal law" as an obstacle to implementing certain confidentiality protections, especially for individuals who are insured on a family member's plan. Although federal law contains many confidentiality protections, it also includes some important requirements for disclosure. One of the main requirements of federal law that may lead to the disclosure of confidential health information by some insurers through the billing and insurance claims process is the requirement to send notices when claims are denied. 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.[39] These denial notices are commonly sent in a format that is or looks like an "explanation of benefits" (EOB).[40]

A key provision of ERISA requires most commercial health insurance plans[41] to "provide adequate notice in writing to any participant or beneficiary whose claim for benefits under the plan has been denied, setting forth the specific reasons for such denial, written in a manner calculated to be understood by the participant," and to provide an opportunity for a "full and fair review" of the denial.[42,43] The ERISA definitions of "participant" and "beneficiary" suggest that these notices could be sent either to the employee/policyholder or to another individual who is covered and entitled to benefits under the plan.[44]

Regulations issued to implement ACA requirements related to group health plans and health insurers include procedures for claims and appeals. Pertinent requirements relating to denial of claims were issued jointly by the U.S. Treasury Department, the Department of Labor, and the Department of Health and Human Services.[45] These regulations require most commercial health plans and insurers to comply with the same requirements regarding notices when claims are denied and added greater specificity to the content of the notices required by the previous Department of Labor regulations for ERISA.

Thus, for example, as explained in the preamble to the joint regulations: "A plan or issuer must ensure that any notice of adverse benefit determination . . . includes the date of service, the health care provider, and the claim amount (if applicable), as well as the diagnosis code (such as an ICD–9 code, ICD–10 code, or DSM–IV code), the treatment code (such as a CPT code), and the corresponding meanings of these codes."[46] The preamble to regulations also states: "A denial, reduction, or termination of, or a failure to provide or make a payment (in whole or in part) for a benefit can include both pre-service claims (for example, a claim resulting from the application of any utilization review), as well as post-service claims. Failure to make a payment in whole or in part *includes any instance where a plan pays less than the total amount of expenses submitted with regard to a claim, including a denial of part of the claim due to the terms of a plan or health insurance coverage regarding copayments, deductibles, or other costsharing [sic] requirements* [emphasis added]."[47]

This language suggests that virtually all actions on claims made by health insurers are likely to be considered a denial, because the full amount of the charges submitted by health care providers is rarely paid by insurers due to a combination of the contractual discounts negotiated between the insurer and the provider and the terms of the covered individual's health insurance policy with respect to deductibles, copayments, and coinsurance. Any policies and practices designed to limit communication of sensitive information to individuals other than patients, including policyholders, must consider the implications of the federal requirements for notices of denials of claims and other adverse benefit determinations.

"Part 2" Substance Use Disorder Regulations

An additional important set of federal regulations—contained in 42 CFR Part 2 and often referred to as "Part 2"—establish special confidentiality protections for substance use records;[48,49] they apply to "substance use disorder programs" that meet certain very broad criteria of being "federally assisted."[50] These regulations have particular significance for health care sites providing HIV services in light of the risks of HIV transmission for injection drug users. The rules protect both adults and minors; when minors are allowed to consent for treatment under state law, they have independent rights under the federal regulations.[51]

For those providers and programs that must comply with Part 2, the regulations impose strict confidentiality requirements that do not allow disclosure without the consent of the patient except in specific circumstances that pose a substantial threat to the life or physical wellbeing of the patient or another person.[52] The Part 2 regulations are more restrictive than the HIPAA Privacy Rule with respect to when disclosures are permitted without an individual's explicit authorization.[53] To the extent that these federal regulations are more protective of confidentiality, they take precedence over state law; if they are less protective, state law controls.[54]

Medicaid

Many people at risk for HIV or living with HIV are eligible for or enrolled in Medicaid. Federal Medicaid law is mixed in terms of the level of protection it provides for Medicaid enrollees' privacy. Three key areas of Medicaid law and policy affect the disclosure of confidential patient information: patient records, enrollment, and decision-making; Medicaid program communications; and third-party payment requirements.[55] Although federal Medicaid law requires protection of confidentiality and does not specifically require the sending of EOBs, other aspects of Medicaid law and policy entail disclosure risks for confidential health information.

Patient Records, Enrollment, and Decision-Making

The potential release of Medicaid patient records—including information about enrollment, providers visited, or services received—to parents, spouses, and others carries a risk of harm for some patients. Federal Medicaid law includes confidentiality protection, requiring that state Medicaid plans include safeguards restricting the "use or disclosure of information concerning applicants and recipients to purposes directly connected with . . . the administration of the plan" and other limited purposes designed to benefit enrollees.[56]

Federal Medicaid law also requires that enrollees be able to choose freely among family planning providers.[57] This "freedom of choice" protection enables them to choose to receive services from providers that adhere to a high standard of confidentiality protection—such as Title X providers and FQHCs—even if those providers are outside of a patient's managed care network; this can be useful to individuals living with HIV who need family planning services.

Medicaid Program Communications

EOBs and other communications that convey information on Medicaid payment for services to enrollees can be a significant concern for providers as they consider billing Medicaid. As with commercial insurance, when information concerning Medicaid claims is communicated to patients, such communications may inadvertently reveal to parents, spouses, family members, and others that a patient has sought or received HIV services or other sensitive services, putting the patient at risk of harm.[58]

Federal law does not explicitly require that state Medicaid programs always send EOBs when services are provided to beneficiaries or paid for by Medicaid. Instead, federal regulations require that, in order to combat fraud, state Medicaid agencies "have a method for verifying *with beneficiaries* whether services billed by providers were received."[59] Federal regulations, adopted pursuant to the Balanced Budget Act of 1997, also specify that state Medicaid program contracts with Medicaid managed care organizations (MCOs) must require them to "give the enrollee written notice of any decision by the MCO . . . to deny a service authorization request,

or to authorize a service in an amount, duration, or scope that is less than requested."[60] Thus some form of written notice to Medicaid enrollees is required by federal law when services are denied in whole or in part by a Medicaid MCO. The extent to which an EOB is the specific mechanism used to comply with this requirement is not clear, although even if the written notice is not an EOB it nevertheless can result in a breach of confidentiality. Notably, CMS, the federal agency that oversees Medicaid, recently posted a sample EOB online to explain to beneficiaries that they might receive an EOB and what it would contain,[61] suggesting that use of EOBs in the Medicaid context is continuing in some situations, even if not federally mandated.

Medicaid Third-Party Liability

One complex legal issue related to protecting confidentiality in Medicaid relates to third-party liability. Medicaid is a payer of last resort, which means that states are required by federal law to implement practices to secure payments from any liable third parties.[62] State Medicaid agencies are required to "take reasonable measures to determine the legal liability of the third parties who are liable to pay for services furnished under the [Medicaid state] plan,"[63] The steps to determine the liability of third parties include obtaining health insurance information during the initial Medicaid application and redetermination processes.[64] The type of information that is obtained from applicants for Medicaid "may include, but is not limited to, the name of the policy holder, his or her relationship to the applicant or beneficiary, the social security number (SSN) of the policy holder, and the name and address of insurance company and policy number."[65] Medicaid regulations specify detailed procedures for ensuring that payment from liable third parties is collected, usually before Medicaid can issue payment on a claim.[66] They also require applicants to assign any rights they may have for medical support to the state Medicaid agency and to cooperate with collection efforts.[67] This is affirmed on the Medicaid website, which states: "By law, all other available third-party resources must meet their legal obligation to pay claims before the Medicaid program pays for the care of an individual eligible for Medicaid."[68]

Most states have adopted statutes, regulations, or state Medicaid agency policies to implement the third-party liability requirements of federal Medicaid law, although variations exist among the states. Illinois, for example, requires Medicaid beneficiaries to tell the Medicaid agency about medical benefits they receive or should receive.[69]

Federal statutes and regulations provide a "good-cause" exception to the requirement that individuals identify and provide information to assist in the pursuit of third parties who may be liable to pay for care and services under the plan when "it is anticipated that cooperation will result in reprisal against, and cause physical or emotional harm to, the individual or other person."[70]

The good-cause exception was written when the primary means for a state Medicaid program to identify potentially liable third-party payers was through information provided by the

patient; if a patient claimed the exemption and did not turn over their health insurance information, the likelihood was minimized that other payers would be billed, and their privacy breached by that means. However, with the advent of electronic storage of information and the expansion of commercial health insurance coverage under the ACA, alternate ways exist to identify and bill potential third-party payers, such as by conducting data matches with various public entities.[71]

Ryan White HIV/AIDS Program

The major domestic federal service delivery program focused exclusively on HIV is the Ryan White HIV/AIDS Program (Ryan White). Some FQHCs, Title X health centers, and other CBOs receive funds from Ryan White to support medical services they provide for patients with HIV. By statute, Ryan White is a payer of last resort and Ryan White funds cannot be used if payment has been made, or can reasonably be expected to be made, by any other payer.[72] Ryan White fills the gaps for individuals with HIV who have no other source of coverage or face coverage limits.[73]

Ryan White grantees and their contractors are expected to vigorously pursue Medicaid enrollment as well as other funding sources such as state-funded HIV/AIDS Programs, employer-sponsored health plans, and other public and commercial health insurance coverage.[74] They also should conduct eligibility determinations, perform insurance verification, make every effort to identify primary payers, and coordinate their services with other payers.[75] Thus the payer of last resort status of Ryan White and the obligation for recipients of Ryan White funds to seek other sources of payment available for individuals to whom services are being provided raises the possibility of disclosure of confidential information pertaining to individuals in need of or receiving HIV services. Many Ryan White service providers and patients have significant concerns about confidentiality that can complicate the process of sharing data to secure third-party payments,[76] but the Ryan White law includes strong and explicit confidentiality protections that could help in resolving these concerns and determining when it is and is not appropriate and safe to bill third parties.[77]

FQHCs

Federally qualified health centers (FQHCs) funded under Section 330 of the Public Health Service Act, frequently referred to as community health centers, provide many HIV-specific services as well as primary care to individuals with HIV.[78] They also are required to provide voluntary family planning services and supplies.[79] FQHCs are required to maintain the confidentiality of patient records[80] but they are also required to make every reasonable effort to collect reimbursement for costs of providing health services to patients who are entitled to medical assistance under Medicaid or under any other public assistance program or commercial health insurance program.[81] Centers are required to maintain a schedule of fees, with discounts

applicable to patients based on their ability to pay, but are not allowed to deny services to anyone based on inability to pay.[82]

The confidentiality regulation for FQHCs specifically provides that: "All information as to personal facts and circumstances obtained by the project staff about recipients of services shall be held confidential, and shall not be divulged without the individual's consent except as may be required by law or as may be necessary to provide service to the individual or to provide for medical audits by the Secretary or his designee with appropriate safeguards for confidentiality of patient records. Otherwise, information may be disclosed only in summary, statistical, or other form which does not identify particular individuals."[83] This language is virtually identical to the confidentiality regulations for the Title X Family Planning Program. Thus, Title X providers and FQHCs are in similar positions, with strong confidentiality requirements in place but also clear obligations to seek revenues from third-party payers. Consequently, the evolving approaches discussed later in this white paper would likely benefit FQHCs, Title X providers, and other CBOs in similar ways.

Title X Confidentiality Protections

The Title X confidentiality regulations are exceptionally strong and almost identical to the confidentiality rules for FQHCs.[84] They protect adolescents who are minors as well as adults.[85] When documented consent for disclosure is not obtained because disclosure is necessary to provide services to the patient or is required by law, appropriate safeguards for confidentiality must still be in place. Examples of disclosures that are required by law include mandatory reporting of child abuse,[86] intimate partner violence,[87] and STDs.[88]

Generally, Title X law provides that individuals from low-income families—defined as having incomes at or below 100% of the federal poverty level (FPL) or having a higher family income but being unable to pay for family planning services—must not be charged for services unless the charges will be paid by a third party, including a government agency such as Medicaid that is authorized or legally obligated to pay.[89] However, Title X providers are required to engage in reasonable efforts to secure third-party payment without application of discounts for low-income individuals.[90]

On March 4, 2019 the U.S. Department of Health and Human Services published a final rule, "Compliance with Statutory Program Integrity Requirements," that would significantly alter the federal regulations for the Title X Program.[91] The new rule has been challenged in numerous lawsuits, but has been allowed by the courts to go into effect pending the outcome of the litigation; detailed analysis of the rule and updates on its status are available elsewhere.[92]

ILLINOIS CONFIDENTIALITY & DISCLOSURE LAWS

In addition to the federal laws, numerous state laws in Illinois also protect patients' privacy and the confidentiality of their health information.[93] Confidentiality protection is not absolute under these laws and they exist alongside other Illinois laws that sometimes require or allow disclosure of confidential patient information. An important Illinois statute enacted in 2015 provides specific protections for Medicaid patients.

Illinois Health Privacy Laws

The public health code in Illinois contains a Medical Patient Rights Act that includes detailed protections for the "right of each patient to privacy and confidentiality" as well as restrictions on disclosures by physicians, healthcare providers, health services corporations and insurance companies.[94] 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."[95] Other provisions of Illinois law address the confidentiality and disclosure of insurance information[96] and of hospital records.[97] Some of the sections are similar to requirements of the HIPAA Privacy Rule or explicitly refer to sections of HIPAA.[98] Illinois law also contains specific protections for information related to substance use disorders, consistent with federal regulations for drug and alcohol programs,[99] and for mental health records and information.[100] Several Illinois laws also address the confidentiality of HIV information.

The AIDS Confidentiality Act[101] provides extensive protections for HIV-related information, which is defined as including: "the identity of a person upon whom an HIV test is performed, the results of an HIV test, as well as diagnosis, treatment, and prescription information that reveals a patient is HIV-positive . . . [.]"[102] The Act contains requirements for: informed consent for HIV testing as well as exceptions to informed consent;[103] confidentiality protection and circumstances allowing disclosure of HIV-related information;[104] and disclosure in various circumstances provided for under HIPAA, such as for treatment, payment, and health care operations, research, and other purposes.[105] Additional Illinois laws specific to confidentiality and disclosure of HIV information include the HIV/AIDS Confidentiality and Testing Code[106] and the HIV/AIDS Registry Act.[107]

Illinois Disclosure Laws

Every state, including Illinois, has numerous laws that explicitly require or indirectly result in disclosure of confidential health information as part of the health care billing and health insurance claims process. Two leading types of communications that are addressed in these statutes, regulations, and policies are EOBs and denials of claims; others include communications related to acknowledgment of claims, requests for additional information, and payment of claims.[108]

Illinois 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.[109]

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."[110] These requirements could result in the disclosure of confidential information about a patient insured on a family member's policy 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.[111]

2015 Illinois Law to Protect Privacy in Medicaid

Recognizing the potential for confidentiality to be compromised in the billing and health insurance claims process, in 2015, Illinois added a section to its Medicaid statute that requires managed care entities to take specific steps to avoid breaching enrollees' privacy.[112,113] The law was adopted at a time when the Illinois Medicaid program was going through a transition that would result in most Medicaid beneficiaries being enrolled in Medicaid managed care plans.

The law emerged from the efforts of 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.[114] A desire and need to bill Medicaid for these tests was tempered by a countervailing concern that although historically Medicaid had not been sending EOBs the transition to managed care might lead to EOBs being sent by managed care plans. Medicaid managed care plans, accustomed to sending EOBs to policyholders or patients in their commercial plans, might also send them to Medicaid enrollees. Although legislation to address the confidentiality issues in the commercial insurance arena was introduced in 2016, it was not enacted.[115, 116] Nevertheless, the law enacted to ensure increased confidentiality in Medicaid

managed care is potentially an important element in any strategy to protect the confidentiality of HIV services while securing third party reimbursement.

Elements of the Law

The 2015 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. 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."[117] A table setting forth the definitions and other elements of the statute is included in Appendix B.

The law protects individuals who are enrollees of Medicaid managed care entities and imposes obligations on these entities—which include care coordination entities, accountable care entities, managed care organizations, and managed care community networks. Medicaid 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 by law.

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. Thus, information about HIV would be covered.

Managed care entities may disclose information about sensitive health 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, or if the enrollee requests the information and has authorized the sending of a bill or explanation of benefits. Managed care entities may also disclose information about sensitive health services to comply with: STD reporting requirements, child abuse reporting requirements, and other requirements of state or federal law. Individual enrollees have a right: to have information about sensitive health services they receive protected from disclosure by the managed care entity other than as expressly permitted and to receive information concerning the sensitive health services if they authorize the sending of a bill or explanation of benefits by the managed care entity.

Implementation

Once the Medicaid privacy law 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 care contracts that EOBs not be sent; following enactment this requirement became a routine part of the contracts. The Medicaid agency also discussed this requirement not to send EOBs at its quarterly meetings with the managed care entities.[118]

A research project that explored the origins and implementation of the Illinois law two years after it was enacted identified both positive features and challenges. The study found that positive features of the law include:

- affirmative obligations for Medicaid managed care entities that do not depend on action initiated by enrollees;
- a broad definition of sensitive services that addresses the interests of many of the groups with heightened confidentiality concerns;
- incorporation of the past Illinois practice of not sending EOBs in fee-for-service Medicaid into the Medicaid managed care arena; and
- consistency in Illinois law with the disclosures permitted under federal law by the HIPAA Privacy Rule.[119]

The policy environment in Illinois also presented significant challenges:

- a high percentage of safety net providers' patient populations who are Medicaid recipients transitioning into managed care;
- a need for safety net providers 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.[120]

OPTIONS FOR INCREASING CONFIDENTIALITY PROTECTION

Health care providers and sites offering HIV services and primary care to individuals affected by HIV face significant challenges. Many of the patients they serve have low incomes, experience limited health care access, and routinely encounter discrimination and stigma. Important sources of care are safety net providers whose budgets are strained as direct funding streams for service delivery decrease or remain flat at the same time that the need for services increases. HIV services, including PrEP and ART, are expensive; and many individuals living with HIV have a variety of other health conditions requiring primary care. At the same time, many of these patients do have insurance coverage through employer-based plans, ACA exchange plans, Medicaid, Medicare, or a program for veterans. Therefore, it is critically important for health departments, CBOs, and other providers offering HIV services to find ways to bill third parties for the care they provide to individuals affected by HIV. Increasing their capacity to do so will require action both on the part of providers themselves and on the part of policymakers.

Strategies for Providers

Providers can implement various strategies to improve their capacity to bill third parties while protecting confidentiality. Significant resources have already been developed that can assist providers to engage effectively in these strategies.[121,122,123] Some key approaches include:

- understanding the confidentiality protections that exist in federal and Illinois laws;
- understanding the disclosure requirements in federal law and Illinois that can lead to disclosures of patients' information to individuals other than patients;
- learning about the specific Illinois law that requires Medicaid managed care entities to protect enrollees' sensitive health information;
- clarifying the relationships among different funding sources with respect to their status as "payer of last resort" and what steps that requires of providers with respect to third-party billing;
- communicating with health insurers and managed care entities to learn about their policies and practices with respect to privacy practices under the HIPAA Privacy Rule and Illinois law;
- training staff on laws that protect confidentiality and require disclosure;
- developing protocols for communicating with patients about whether they have insurance coverage, are willing to use it, and have concerns about confidentiality breaches in connection with doing so;
- educating staff and patients about individuals' rights under the HIPAA Privacy Rule to request restrictions on disclosure and confidential communications and helping patients to make such requests; and
- advocating with health insurers to improve their privacy practices and with policymakers to expand confidentiality protections for health care billing and insurance claims.

Implementing these strategies requires time and financial support but the effort potentially can result in increased reimbursement from third parties without sacrificing patients' privacy in ways that cause them harm.

Options for Improved Policies

Health care providers acting alone cannot maximize their capacity to bill third parties while protecting patients' privacy. In order for this effort to be as effective as possible it must include improved policies—in state law, in agency guidance, and in the policies and practices of health insurers. Illinois took an important step when it enacted the law in 2015 to require Medicaid managed care entities to protect sensitive health information of enrollees. Further action would be beneficial, particularly with respect to commercial insurance, including employer-based plans and ACA exchange policies. Significant work has already been done in at least six other states to enact statutes or promulgate regulations to improve confidentiality in the health insurance arena. Lessons learned from those states could be useful in pursuing further policy changes in Illinois.[124,125,126]

CONCLUSION

Since the beginning of the HIV epidemic, the possibilities for prevention and treatment have improved dramatically. Availability of ART allows for management of HIV as a chronic illness and reduced risk of transmission. The advent of PrEP offers opportunities for effective prevention. These measures have significant positive public health implications. They also present major challenges for health care providers, particularly publicly funded health departments and CBOs, by increasing demand for HIV services and primary care for individuals with HIV. In order to meet this need, these providers must be able to bill third parties while protecting confidentiality. Some options for doing so are available under existing laws, but challenges remain. Strategies to implement existing options can result in positive change while efforts to improve policies continue.

APPENDIX A: 305 ILLINOIS COMPILED STATUTES 5/5-30(I)

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 ILCS 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.

APPENDIX B: ELEMENTS OF THE 2015 ILLINOIS MEDICAID PRIVACY LAW

305 Illinois Compiled Statutes 5/5-30(i) 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."

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
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: ▪ To providers and care coordinators caring for the enrollee ▪ To employees of the entity for internal operations ▪ To business associates and covered entities for purposes permissible under federal and state law ▪ If the enrollee requests the information and has authorized the sending of a bill or explanation of benefits ▪ To 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

Source: English A, Mulligan A, Coleman C. Protecting Patients' Privacy in Health Insurance Billing & Claims: An Illinois Profile, 2017. https://www.nationalfamilyplanning.org/file/confidential--covered/Illinois_StateProfile_CC.pdf.

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