The Medicaid Applicant and Beneficiary Information Safeguards (Medicaid Information Safeguards) require states with Medicaid programs to adopt statutory safeguards for protecting Medicaid information relating to applicant, beneficiary, and non-applicant (i.e., a household member included for eligibility determinations) individuals. The state Medicaid plan must “restrict the use or disclosure of information concerning applicants and beneficiaries to purposes directly connected with the administration of the plan.” Under the Medicaid Information Safeguards, state Medicaid agencies must have the authority to implement and enforce the required standards.

To whom does the law apply?
The Medicaid Information Safeguards regulate state Medicaid plans. Accordingly, states with Medicaid programs must comply with these federal requirements.

How is “identifiable” information defined?
The Medicaid Information Safeguards do not distinguish between identifiable and non-identifiable data. The Safeguards provide some flexibility for states to determine the types of applicant and beneficiary information that will be protected. However, the state Medicaid agency must protect the following: 1) names and addresses; 2) medical service information; 3) Social and economic information; 4) agency evaluations of personal information; 5) medical data; 6) information used in verifying income eligibility and amount of medical assistance payments; 7) information relating to legally liable third parties (e.g., private insurance carriers); and 8) social security information.

Does this law allow identifiable data to be shared?
The Medicaid Information Safeguards restrict the use or disclosure of applicant and beneficiary information to purposes directly related to plan administration (e.g., for determinations relating to eligibility or benefits, or for law enforcement or legal proceedings related to Medicaid administration).
Among who?
The Medicaid Information Safeguards do not limit the use or disclosure of applicant or beneficiary information to specified individuals or entities. Generally, access to applicant or beneficiary information is restricted to “persons or agency representatives who are subject to standards of confidentiality that are comparable to those of the [state Medicaid] agency.”

What are the prerequisites and conditions?
The Medicaid Information Safeguards require state Medicaid agencies to establish criteria for the release and use of applicant or beneficiary information. State Medicaid agencies cannot publish applicant or beneficiary names. If possible, state Medicaid agencies must get permission from a family or individual before disclosing protected information outside the agency (unless the disclosure relates to certain eligibility or benefit determinations). Data exchange agreements are required for disclosures involving other agencies for income and eligibility determinations and disclosures involving other agencies for identifying legally liable third parties. State Medicaid agencies are required to publicize and make these provisions available to applicants, beneficiaries, and information recipients.

SHARING OF DE-IDENTIFIED DATA

Does this law allow de-identified information to be shared?
The federal Medicaid Information Safeguards do not distinguish between identifiable and non-identifiable data.

Does this law define de-identification or standards to render the data de-identified?
Not applicable to this law.

DATA SHARING IMPLICATIONS FOR PUBLIC HEALTH

Does this law support data sharing to improve the health of communities?
The Medicaid Information Safeguards permit sharing information directly connected with the administration of the Medicaid program. The Safeguards also permit information sharing for determining eligibility for programs under the Child Nutrition Act of 1966 (e.g., free or reduced price breakfasts) or the National School Lunch Act (e.g., school lunch program).

How does this law hinder data sharing to improve the health of communities?
The Medicaid Information Safeguards do not contain specific exceptions permitting uses and disclosures for general public health or research purposes. Consequently, uses and disclosures of applicant and beneficiary information are generally restricted to purposes directly connected to Medicaid program administration.
Does this law establish prerequisites, conditions, or limitations for data sharing, not previously identified?
When an emergency prevents a state Medicaid agency from seeking consent to disclose information, the agency must notify the family or individual immediately afterward. The Medicaid Information Safeguards contain specific requirements and limitations for materials distributed to applicants, beneficiaries, and providers.

What other terms apply to sharing this data?
Information received by other agencies (i.e., Social Security Administration or the Internal Revenue Service) is subject to the safeguard requirements of the furnishing agency. State Medicaid agencies are bound by other federal and state laws, including the Health Insurance Portability and Accountability Act of 1996.

What remedies or solutions might be employed to support data sharing while complying with this law?
The Health Care Financing Administration, Health Resources and Services Administration, and Centers for Disease Control and Prevention produced a model data use agreement that could be adapted to facilitate sharing between state Medicaid agencies and departments of health. The agreement uses matching registry data for improving outreach or expanding Medicaid coverage as an example of permissible data use.

What ethical considerations apply to the exercise of discretion to share data under this law?
The Medicaid program serves many vulnerable populations (e.g., low income individuals). Some Medicaid applicants and beneficiaries might feel coerced to provide information to gain access to needed Medicaid services. Moreover, Medicaid data can contain highly sensitive information that could lead to economic or social harms if inappropriately disclosed.

SUPPORTERS

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation.

This document was developed by Cason Schmit, Research Assistant Professor, Texas A&M University and reviewed by Jennifer Bernstein, Deputy Director, Mid-States Region of The Network for Public Health Law. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.

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