SENATE JUDICIARY COMMITTEE
Senator Thomas Umberg, Chair
2023-2024 Regular Session

AB 1011 (Weber)
Version: April 27, 2023
Hearing Date: June 27, 2023
Fiscal: Yes
Urgency: No
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SUBJECT

Social care: data privacy

DIGEST

This bill prohibits participating entities in a closed-loop referral system from selling social care information, as defined, and prohibits using the information for purposes other than the purposes for which it was collected, except as provided.

EXECUTIVE SUMMARY

Coordination of care for target populations is not a new concept. The idea being that information sharing within a contained system to identify and serve all the needs of those being served is an efficient and holistic way of carrying out the mission, whether this involves services for students or unhoused individuals or other populations.

With advances in technology, these closed-referral systems are becoming streamlined on platforms and networks that increase efficiencies, but as often is the case, bring some concerns regarding the privacy of those whose information is being shared.

This bill regulates "closed-loop referral systems" (CLRS), which are defined as technology platforms or networks that store and enable the sharing of social care information between "participating entities" for the purpose of referring individuals for social care and to track progress and outcomes of those referrals. "Social care" is defined as care, services, goods, or supplies related to an individual's social needs.

Responding to privacy concerns about the data being shared within these CLRS, the bill prohibits the selling of social care information, as defined, and prohibits using the information for purposes other than the purposes for which it was collected, as provided. This bill is sponsored by Findhelp. It is opposed by several organizations, including Unite Us.

PROPOSED CHANGES TO THE LAW

Existing federal law:

1) Establishes the Health Insurance Portability and Accountability Act (HIPAA), which provides privacy protections for patients' protected health information and generally prohibits a covered entity, as defined (health plan, health care provider, and health care clearing house), from using or disclosing protected health information except as specified or as authorized by the patient in writing. (45 C.F.R. § 164.500 et seq.)

2) Provides that if HIPAA's provisions conflict with a provision of state law, the provision that is the most protective of patient privacy prevails. (45 C.F.R. § 164.500 et seq.)

Existing state law:

1) Provides, pursuant to the California Constitution, that all people are by nature free and independent and have inalienable rights. Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and privacy. (Cal. Const., art. I, § 1.)

2) Establishes the CMIA, which establishes protections for the use of medical information. (Civ. Code § 56 et seq.)

3) Prohibits providers of health care, health care service plans, or contractors, as defined, from sharing medical information without the patient's written authorization, subject to certain exceptions. (Civ. Code § 56.10.)

4) Establishes the CCPA, which grants consumers certain rights with regard to their personal information, including enhanced notice, access, and disclosure; the right to deletion; the right to restrict the sale of information; and protection from discrimination for exercising these rights. It places attendant obligations on businesses to respect those rights. (Civ. Code § 1798.100 et seq.)

5) Defines "personal information" pursuant to the CCPA as information that identifies, relates to, describes, is reasonably capable of being associated with, or could reasonably be linked, directly or indirectly, with a particular consumer or household. The CCPA provides a nonexclusive series of categories of information deemed to be personal information, including identifiers, biometric information, and geolocation data. (Civ. Code § 1798.140(v).) The CCPA defines and provides additional protections for sensitive personal information, as defined, that reveals specified personal information about consumers. (Civ. Code § 1798.140(ae).)

6) Provides a consumer the right, at any time, to direct a business that sells personal information about the consumer to third parties not to sell the consumer's personal information. A consumer shall have the right, at any time, to direct a business that collects sensitive personal information about the consumer to limit its use of that information, as provided. (Civ. Code §§ 1798.120-1798.121.)

7) Defines "selling" for purposes of the CCPA as selling, renting, releasing, disclosing, disseminating, making available, transferring, or otherwise communicating orally, in writing, or by electronic or other means, a consumer's personal information by the business to a third party for monetary or other valuable consideration. (Civ. Code § 1798.140(ad).)

8) Provides that a county may establish a homeless adult and family multidisciplinary personnel team (homeless MPT) to facilitate expedited identification, assessment, and linkage of homeless individuals to housing and supportive services within that county and to allow provider agencies to share confidential information for the purpose of coordinating housing and supportive services to ensure continuity of care. (Welf. & Inst. Code § 18999.8.)

9) Authorizes homeless MPT members engaged in the identification, assessment, and linkage of housing and supportive services to homeless adults or families to disclose to, and exchange with one another, information and writings that relate to any information that may be designated as confidential under state law if the member believes it is generally relevant to the identification, reduction, or elimination of homelessness or the provision of services. Designates any discussion relating to this information as confidential and inadmissible in court proceedings. Establishes clear and stringent information sharing protocols for MPTs. (Welf. & Inst. Code § 18999.8.)

This bill:

1) Prohibits a participating entity from selling, renting, releasing, disclosing, disseminating, making available, transferring, or otherwise communicating orally, in writing, or by electronic or other means, social care information stored in or transmitted through a closed-loop referral system in exchange for monetary or other valuable consideration.

2) Prohibits a participating entity from using social care information stored in, or transmitted through, a closed-loop referral system for any purpose or purposes other than the purpose or purposes for which that social care information was collected or generated, except as required by federal law or as authorized or required by state law.

COMMENTS

1. Stated intent of the bill

According to the author:

> Many of these social care networks use a new type of technology platform called a closed loop referral system, which allows organizations to seamlessly share information so that people in need are able to receive all the appropriate services available to them, allows social care and social services providers to send and receive referrals to each other and track outcomes of the care people receive.
>
> This highly-personal information deserves a thoughtful and deliberate governance structure that will ensure the privacy of people going through difficult times. Because it is relatively new, there is currently no regulation of privacy in the social care information space specifically.
>
> This bill addresses social care privacy by defining a "closed-loop referral system." Closed loop referral systems have become the place where many social care providers create and transmit data, and therefore are an appropriate place to start regulating privacy in this space. This also allows us to regulate this data without putting undue burdens directly on the social care providers and nonprofits that were exempted from CCPA for a good reason.

2. Ensuring the privacy of clients in closed-loop referral systems

Closed-loop referral systems allow for providers of services to specific populations to connect their clients to various services and goods within a network of fellow providers. As technology enhances this intercommunication between providers, concerns have arisen about the privacy of the sensitive information being exchanged.

The bill seeks to be the first to regulate CLRS, which it defines as a technology platform or network that does all of the following:

- stores the social care information of one or more individuals;
- enables the sharing of social care information with and between participating entities for the purpose of referring individuals for social care; and
- provides information to participating entities regarding the progress and outcomes of referrals for social care.

"Social care" is defined as care, services, goods, or supplies related to an individual's social needs. This includes support and assistance for an individual's food, housing,

transportation, economic stability, employment, education access, childcare and family relationship needs, and environmental and physical safety.

"Participating entities" are those that provide social care or refer individuals for social care and who have the ability to create, receive, or update social care information and referrals in a CLRS. It specifically includes examples of who may qualify as a participating entity: a public agency, nonprofit organization, charitable organization, provider of health care, health care service plan, or CLRS technology vendor.

The bill imposes two main privacy safeguards. The first is a prohibition preventing a participating entity from selling social care information. The CCPA provides a host of privacy rights for consumers and obligations on businesses, but many of the entities involved in these CLRS are not considered "businesses" and therefore are not subject to the CCPA. However, the bill borrows language from the CCPA for what is considered selling, namely: selling, renting, releasing, disclosing, disseminating, making available, transferring, or otherwise communicating social care information stored in or transmitted through a CLRS in exchange for monetary or other valuable consideration.

The second safeguard is that a participating entity is prohibited from using social care information stored in, or transmitted through, a closed-loop referral system for any purpose or purposes other than the purpose or purposes for which that social care information was collected or generated, except as provided.

These safeguards are intended to protect the information and ensure it is only used for the benefit of the individual clients to whom the information pertains. Bolstering the protection is the broad definition of "social care information," which includes any information, in any form, that relates to the need for, payment for, or provision of, social care to the individual, as well as the individual's personal information. The bill again directly borrows from the CCPA by cross-referencing its definition of "personal information."

Some concerns have been raised that the use limitations laid out in the bill are not completely clear and may not provide the level of protection intended. To address these concerns, the author has agreed to amendments that limit the uses to only "social care purposes" to avoid doubt about the universe of purposes that are valid.

Additionally, the bill excepts from this limitation uses that are (1) required by federal or state law and (2) authorized by state law. While the former exception is straightforward, the latter seems to allow for this private information to be used in a variety of ways that seem to undermine the protections of the bill. The author has agreed to an amendment removing that specific exception.

Amendment

Amend Section 61(b) to read: "A participating entity shall not use social care information stored in, or transmitted through, a closed-loop referral system for any purpose or purposes other than the social care purpose or purposes for which that social care information was collected or generated, except as required by federal or state law."

As discussed, there are other privacy laws that may apply to the data collected and shared through these CLRS. In order to ensure that this does not absolve any persons or entities from the obligations of other laws, the author has agreed to add a provision making that clear:

Amendment

Add: "Nothing in this part affects any obligations imposed by other applicable laws."

Writing in support, Findhelp, the sponsor of the bill, makes the case:

> Findhelp believes that privacy in social care is a vital issue to address through legislation. We believe that consumers must be in control of their personal information, and without guardrails around data privacy, many are left vulnerable at the whims of an unregulated industry and rogue vendors. AB 1011 addresses consumer privacy concerns specifically for organizations and consumers who use what is known as a 'closed-loop referral system', or CLRS. A closed-loop referral system is a technology platform that is used by constituents, healthcare entities, public agencies, and community-based organizations to streamline the coordination of care between health care and social care, and to send and receive referrals through a coordinated network.

3. Existing models with more stringent privacy protections

Regulating these types of interconnected groups of providers is not unprecedented in California law. For instance, California has clear legal structures around multidisciplinary personnel teams (MPT) that share information in order to serve certain vulnerable populations. As an example, existing law authorizes each county to establish a homeless adult and family multidisciplinary personnel team to facilitate expedited identification, assessment, and linkage of homeless individuals to housing and supportive services within that county and to allow provider agencies to share confidential information for the purpose of coordinating housing and supportive services to ensure continuity of care. (Welf. & Inst. Code § 18999.8.) These teams can include a wide variety of participating entities, including:

- mental health and substance abuse services personnel and practitioners or other trained counseling personnel;
- police officers, probation officers, or other law enforcement agents;
- legal counsel;
- medical personnel with training to provide health services;
- social services workers;
- case managers or case coordinators responsible for referral, linkage, or coordination of care and services provided to adults or families;
- veterans services providers and counselors;
- domestic violence victim service organizations;
- teachers; and
- housing or homeless services provider agencies.

Relevant here, there are explicit guidelines for how personal information about these clients can be shared and strict parameters on what it can be used for. Homeless MPT members can disclose to, and exchange with one another, information and writings that relate to any information that may be designated as confidential under state law if the member believes it is generally relevant to the identification, reduction, or elimination of homelessness or the provision of services. However, requirements are imposed that govern training and retention, protection, and destruction of the information. Every member of a homeless MPT who receives information or records regarding adults and families in their capacity as a member of the team is subject to the same privacy and confidentiality obligations and the same confidentiality penalties as the person disclosing or providing the information or records. Information or records obtained must be maintained in a manner that ensures the maximum protection of privacy and confidentiality rights. Additionally, civil and criminal penalties apply to the inappropriate disclosure of information held by the team members.

This bill takes the first step in placing some guardrails around the information that is being shared within CLRS.

4. Opposition

Writing in opposition, Unite Us writes:

> As currently drafted, AB 1011 imposes unreasonable burdens on individuals seeking care — requiring them to re-tell their story to each provider from which they seek services, even after they have expressly consented to sharing information with their providers. This is not a trauma-informed approach to supporting individuals seeking services, and it contradicts best practices adopted by social care providers. Our focus on advancing care coordination to reduce the burdens on individuals seeking care and improve health outcomes closely aligns with

California's policy goals as well as recent proposed rules by the HHS Office of Civil Rights.

As drafted, this legislation will place burdensome requirements on all "public agencies, nonprofit organizations, charitable organizations, CLRS technology vendors, and other entities that provide social care" in the state. These organizations already must comply with myriad federal and state privacy laws, including HIPAA, CCPA, CPRA, 42 CFR Part 2, FERPA, VAWA, and VOCA. By adding to the burdens these organizations face—many of whom are resource-constrained nonprofits and CBOs—AB 1011 would prevent Californians from accessing the social care services they need.

SUPPORT

Findhelp (sponsor)

OPPOSITION

Infant/Child Enrichment Services
SCHIO
Unite Us

RELATED LEGISLATION

Pending Legislation:

SB 603 (Rubio, 2023) creates a process and standards for the release of recordings of interviews taken by a children's advocacy center in the course of an investigation of a case of abuse. The children's advocacy center or other identified multidisciplinary team member custodian shall ensure that all recordings of child forensic interviews be released only in response to a court order. This bill is currently in the Assembly Public Safety Committee.

AB 1194 (Wendy Carrillo, 2023) provides stronger privacy protections pursuant to the CCPA where the consumer information contains information related to accessing, procuring, or searching for services regarding contraception, pregnancy care, and perinatal care, including abortion services. AB 1194 is in the Senate Appropriations Committee.

Prior Legislation:

SB 1342 (Bates, Ch. 621, Stats. 2022) allowed a county or Area Agency on Aging to establish an aging multidisciplinary team with the goal of facilitating the expedited

identification, assessment, and linkage of older adults to services, and allowed provider agencies and members of the MDT to share confidential information for the purposes of coordinating services. It required a county or agency that establishes an aging MDT to adhere to a number of protocols surrounding the privacy, security, and confidentiality of the information and records shared.

AB 728 (Santiago, Ch. 337, Stats. 2017) created a five-year pilot program in the counties of Los Angeles, Orange, Riverside, San Bernardino, San Diego, Santa Clara, and Ventura that allows those counties to expand the scope of a homeless adult and family multidisciplinary teams to include serving individuals who are at risk of homeless.

AB 210 (Santiago, Ch. 544, Stats. 2017) allowed counties to develop homeless adult and family multidisciplinary teams in order to facilitate identification and assessment of homeless individuals, and link homeless individuals to housing and supportive services, and to allow service providers to share confidential information to ensure continuity of care.

PRIOR VOTES:

Assembly Floor (Ayes 74, Noes 0)
Assembly Appropriations Committee (Ayes 15, Noes 0)
Assembly Privacy and Consumer Protection Committee (Ayes 11, Noes 0)
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