

Date of Hearing: April 25, 2023

ASSEMBLY COMMITTEE ON PRIVACY AND CONSUMER PROTECTION

Jesse Gabriel, Chair

AB 1011 (Weber) – As Amended March 16, 2023

As Proposed to be Amended

SUBJECT: Social care: data privacy

SYNOPSIS

This bill would codify the concept of a “closed-loop referral system” (CLRS) and put into place baseline privacy protections for vulnerable individuals’ data that is shared on a CLRS. A closed-loop referral system allows a participating entity, such as a health care provider, social services agency, or nonprofit, to share referral information about a client’s social needs, such as for housing, mental health care, or food assistance, on a computer network. Other entities participating in the CLRS can receive and review the referral information; if one of these entities determines that it can assist the client in meeting one or more of the client’s needs, the entity can update the referral to indicate it is assisting the individual with this issue, thereby “closing the loop” on the referral.

As currently in print, this bill would have established a comprehensive protocol to obtain a person’s informed consent for sharing their information each time a referral was made on a CLRS and each time a participating entity indicated that it might be able to assist the person. This protocol proved controversial; bill opponents argued that the steps required would be burdensome and interfere with the provision of care.

In response, committee amendments propose to amend the bill substantially, while still furthering the author’s goal of protecting individuals’ privacy. As amended, the bill would (i) forbid participating entities from selling information about a person obtained from a CLRS and (ii) require that any such information be used only for the purposes it was collected for, i.e., to provide care to the person. These appear to be baseline standards that ought to be the norm when providing health and other social services; certainly, an individual seeking housing, mental health care, or food does not expect that information about their needs could be sold or used for purposes other than assisting them.

SUMMARY: Defines a closed-loop referral system (CLRS). Prohibits the sale of information about an individual that a participating entity obtains from a CLRS. Requires that such information be used only for the purposes for which it was collected and generated. Specifically, **this bill:**

1) Defines the following terms:

- a) “Closed-loop referral system” or “CLRS” means a technology platform or network that does all of the following:
 - i) Stores the social care information of one or more individuals.

- ii) Enables the sharing of social care information with and between participating entities for the purpose of referring individuals for social care.
 - iii) Provides information to participating entities regarding the progress and outcomes of referrals for social care.
- b) “Social care” means care, services, goods, or supplies related to an individual’s social needs. The term includes, but is not limited to, support and assistance for an individual’s food stability and nutritional needs, housing, transportation, economic stability, employment, education access and quality, childcare and family relationship needs, and environmental and physical safety.
- c) “Social care information” means both of the following regarding an individual:
- i) Any information, in any form, that relates to the need for, payment for, or provision of, social care.
 - ii) An individual’s personal information, as that term is defined under the California Consumer Privacy Act.
- d) “Participating organization” means an entity that meets all of the following requirements:
- i) Provides social care or refers individuals for social care, including, but not limited to, a public agency, nonprofit organization, charitable organization, provider of health care, health care service plan, or CLRS technology vendor.
 - ii) Has the ability to create, receive, or update social care information in a CLRS.
 - iii) Has the ability to create, receive, or update referrals for social care in a CLRS.
- 2) 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.
- 3) Prohibits a participating organization 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.

EXISTING LAW:

- 1) Provides, pursuant to the California Constitution, that all people have inalienable rights, including the right to pursue and obtain privacy. (Cal. Const., art. I, § 1.)
- 2) Establishes the California Consumer Privacy Act (CCPA). (Civ. Code §§ 1798.100-1798.199.100.)
- 3) Defines “personal information” under 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. Personal information includes such information as:

- a) Name, alias, postal address, unique personal identifier, online identifier, IP address, email address, account name, social security number, driver's license number, passport number, or other identifier.
 - b) Commercial information, including records of personal property, products or services purchased, obtained, or considered, or other purchasing or consuming histories or tendencies.
 - c) Biometric information.
 - d) Internet activity information, including browsing history and search history.
 - e) Geolocation data.
 - f) Professional or employment-related information. (Civ. Code § 1798.140(v).)
- 4) Defines "consumer" as a natural person who is a California resident. (Civ. Code § 1798.140(i).)
- 5) Provides a consumer, subject to exemptions and qualifications, various rights, including the following:
- a) The right to know the business or commercial purpose for collecting, selling, or sharing personal information and the categories of persons to whom the business discloses personal information. (Civ. Code § 1798.110.)
 - b) The right to request that a business disclose the specific pieces of information the business has collected about the consumer, and the categories of third parties to whom the personal information was disclosed. (Civ. Code § 1798.110.)
 - c) The right to request deletion of personal information that a business has collected from the consumer. (Civ. Code § 1798.105.)
 - d) The right to opt-out of the sale of the consumer's personal information if the consumer is over 16 years of age. (Sale of the personal information of a consumer below the age of 16 is barred unless the minor opts-in to its sale.) (Civ. Code § 1798.120.)
 - e) The right to equal service and price, despite the consumer's exercise of any of these rights, unless the difference in price is reasonably related to the value of the customer's data. (Civ. Code § 1798.125.)
 - f) The right, at any time, to direct a business that collects sensitive personal information about the consumer to limit its use of the consumer's sensitive personal information to that use which is necessary to perform the services or provide the goods reasonably expected by an average consumer who requests those goods or services, to perform the services. (Civ. Code § 1798.121.(a))

- 6) Provides that the CCPA applies to any for-profit entity that collects consumers' personal information, does business in California, and meets one or more of the following criteria:
 - a) It had gross annual revenue of over \$25 million in the previous calendar year.
 - b) It buys, receives, or sells the personal information of 100,000 or more California residents, households, or devices annually.
 - c) It derives 50% or more of its annual revenue from selling California residents' personal information. (Civ. Code § 1798.140(d).)
- 7) Establishes under federal law, the Health Information Portability and Accountability Act of 1996 (HIPAA), which sets standards for the privacy of individually identifiable health information and security standards for the protection of electronic protected health information, including, through regulations, that a HIPAA-covered entity may not condition the provision of treatment, payment, enrollment in a health plan, or eligibility for benefits on the provision of an authorization, except under specified circumstances. Provides that if HIPAA's provisions conflict with state law, the provision that is most protective of patient privacy prevails. (42 U.S.C. § 1320d, et seq.; 45 Code Fed. Regs. Part 164.)
- 8) Prohibits, under the state Confidentiality of Medical Information Act (CMIA), a health care provider, a health care service plan, a contractor, a corporation and its subsidiaries and affiliates, or any business that offers software or hardware to consumers, including a mobile application or other related device, as defined, from intentionally sharing, selling, using for marketing, or otherwise using any medical information, as defined, for any purpose not necessary to provide health care services to a patient, except as expressly authorized by the patient, enrollee, or subscriber, as specified, or as otherwise required or authorized by law. States that a violation of these provisions that results in economic loss or personal injury to a patient is a crime. (Civ. Code § 56, et. seq.)

FISCAL EFFECT: As currently in print this bill is keyed fiscal.

COMMENTS:

1) **Background.** This bill would codify the concept of a “closed-loop referral system” (CLRS) and put into place baseline privacy protections for individuals' data that is shared on a CLRS.

A closed-loop referral system generally works as follows. Say, for example, that a domestic violence survivor, having escaped their abuser, goes to a nonprofit housing provider for help in finding a place to live. During the initial intake interview, the housing provider determines that the survivor is also in need of mental health services, legal aid, and food assistance. All of these needs—housing, mental health services, legal aid, and food assistance—fall under the bill's definition of “social care.”

If the housing provider participates in a closed-loop referral system, it can then share information on the CLRS about the survivor, including a description of the survivor's social care needs and the survivor's contact information, among a network of other providers. Under the bill, the information being shared falls under the definition of “social care information”; the housing provider, the CLRS operator, and other participants on the CLRS fall under the definition of “participating entity.”

Other participating entities on the CLRS will receive the survivor's social care information. If one of these entities determines it is able to help the survivor with one of the survivor's social care needs, it can contact the survivor using the information provided on the CLRS. If the survivor accepts the offer of assistance, the participating entity can make this fact known on the CLRS. Doing so "closes the loop" on that portion of the referral and ensures that (i) the referring organization knows one of the survivor's needs is being addressed, and (ii) the referral for addressing that need does not remain open on the network, allowing providers to focus on others' needs.

As explained by the bill's sponsor, Findhelp, a public benefit corporation: "A closed-loop referral system is a technology platform that is used by [individuals in need], and a network of 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."

2) Author's statement. According to the author:

By defining and creating protections for social care privacy specifically, this bill fills in the existing gap in California's privacy laws. The guardrails and regulations created in this AB 1011 provide individuals legal protections over their sensitive social care privacy [information].

3) Why the bill is being amended. As referred to this Committee, the bill would have established a comprehensive set of standards to regulate closed-loop referral systems, including requiring an individual to consent every time their information was shared on a CLRS and every time a participating entity sought to access it. Other social service providers protested that these consent requirements were overly burdensome and would interfere with the provision of care. For example, California 211 Providers Network wrote: "Requiring client consent for each referral instance would have a significant fiscal and capacity impact on 211 providers[.]" Health Center Partners of Southern California contended that repeatedly asking for consent might impair care, writing: "Consent protocols are essential for protecting patient privacy and creating shared understanding for the patient and provider. However, when patients are asked multiple times what appears to be same question they've previously answered, the therapeutic alliance can be negatively impacted and patient-centered becomes process-centered care. Administrative barriers then become access issues that negatively impact patient outcomes."

In response to these concerns, the bill will be amended to remove the controversial consent provisions. As amended, the bill will only provide a definition of "closed-loop referral system" and put into place basic, essential privacy standards for data shared on a CLRS.

4) Committee amendments—replacing controversial consent provisions with essential privacy protections. Committee amendments would delete the existing provisions of the bill and replace it with the following provisions, which are reflected in the **SUMMARY** above:

Civil Code ###. *(a) For purposes of this section, all of the following definitions apply:*

(1) "Closed-loop Referral System" or "CLRS" means a technology platform or network that does all of the following

(A) Stores the social care information of one or more individuals.

(B) Enables the sharing of social care information with and between participating entities for the purpose of referring individuals for social care.

(C) Provides information to participating entities regarding the progress and outcomes of referrals for social care.

(2) “Participating entity” means an entity that:

(A) Provides social care or refers individuals for social care, including, but not limited to, a public agency, nonprofit organization, charitable organization, provider of health care, health care service plan, or CLRS technology vendor.

(B) Has the ability to create, receive, or update social care information in a CLRS.

(C) Has the ability to create, receive, or update referrals for social care in a CLRS.

(3) “Social care” means care, services, goods, or supplies related to an individual’s social needs. “Social care” includes, but is not limited to, support and assistance for an individual’s food stability and nutritional needs, housing, transportation, economic stability, employment, education access and quality, childcare and family relationship needs, and environmental and physical safety.

(4) “Social care information” means both of the following regarding an individual:

(A) Any information, in any form, that relates to the need for, payment for, or provision of, social care to the individual.

(B) The individual’s personal information, as that term is defined in subdivision (v) of Section 1798.140 of the Civil Code.

(b) A participating entity shall not sell, rent, release, disclose, disseminate, make available, transfer, or otherwise communicate 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.

(c) 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 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.

Subdivision (b) bars a participating organization from selling or otherwise sharing an individual’s social care information for money if the information was stored or transmitted through a CLRS. Subdivision (c) imposes a “data minimization” requirement: an individual’s social care information stored or transmitted through a CLRS can only be used for the purpose of meeting the individual’s social care needs, except as otherwise authorized or required by law.

Barring sale of social care information and requiring data minimization with respect to social care information appear to be reasonable baseline standards for data shared through a CLRS.

Putting these standards into law alleviates any fear a vulnerable individual might have that highly-sensitive information about their needs might fall into others' hands. Such protections are necessary because there is no way of knowing, before an individual's social care information is shared, what privacy laws might apply to a participating entity in a CLRS that receives the information.

One opposition argument calls for a response. Unite Us, which describes itself as "the nation's leading software company bringing sectors together to improve the health and well-being of communities," criticizes this measure as "a platform-specific bill that rejects the individual rights-based approach taken by the CCPA and CPRA[,] i.e., the California Consumer Privacy Act.

Declining to adopt a CCPA-style consent model for sale of data is a deliberate policy choice in this bill. **A person seeking social care from a participating organization in a CLRS should be able to expect that the information they are sharing will not be sold and will only be used to refer them for, and provide them with, social care.** A person seeking social care is not in the position of, say, a person who opens a Google account in order to use Gmail and Google Docs. The former is likely in a highly vulnerable state. They do not expect, nor should they, that the information they are providing about themselves and their needs could be sold or used for purposes other than providing them with necessary care. They are exceedingly unlikely to know that in order to safeguard the privacy of the information they have shared, they may have to contact various entities to request that their data not be sold, that it be deleted, and so forth. By contrast, the new Google user is almost certainly aware that Google is going to collect, use, and sell the data it collects from their use of Gmail and Google Docs; if they are a Californian, there is a good chance they will also know that they have CCPA privacy rights they can exercise to restrict Google's use of their data. The two situations are not comparable.

It is critical to understand that closed-loop referral systems are operating in California right now. Absent this bill, participating organizations not subject to other privacy laws (such as the Confidentiality of Medical Information Act (CMIA) or the CCPA) are free to do as they wish with social care information they receive on closed-loop referral systems. This is particularly true of smaller and/or nonprofit technology vendors that may not fall under the CCPA definition of "business." The selling of sensitive information about Californians' vulnerabilities obtained on a CLRS might be occurring right now, and it all may be perfectly legal.

5) Related legislation. The author may wish to consider whether there is overlap between this bill and the following measures enacted to address provision of social services to homeless individuals.

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

AB 728 (Santiago, Chap. 337, Stats. 2019) built on AB 210 by establishing, until January 1, 2025, MDT pilot programs in Los Angeles, Orange, Riverside, San Bernardino, San Diego, Santa Clara, and Ventura Counties.

REGISTERED SUPPORT / OPPOSITION:

Support

Findhelp, a Public Benefit Corporation (sponsor)

Opposition

211 San Diego

California 211 Providers Network

Health Center Partners of Southern California

San Diego Regional Task Force on Homelessness

Unite Us

United Way of Ventura County

United Ways of California

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