

Findhelp Testimony

Submitted to the House Consumer Affairs Committee

May 25, 2022

Chairman Marshall and members of the Committee:

Thank you to the Committee for the opportunity to submit this testimony. For the record my name is Erine (pronounced Aaron) Gray and I am the CEO of findhelp.org (formerly called "**Aunt Bertha**"), the largest closed-loop referral network for social services in the United States with over 10 million users. We are a Public Benefit Corporation based in Austin, Texas and we are proud to say we have earned the trust of more than 400 clients – from state governments to health and social service organizations, including many that do business here in Pennsylvania. As the nation's leading social care network, I am very proud that our company was recently named "Best in KLAS" as the top performer in the Social Determinants of Health Network category by KLAS Research, the "Consumer Reports" of health IT.

Findhelp created and maintains a database of free and reduced cost social programs provided by nonprofits and government agencies across the country. We've created an online search and referral so programs are easy to find, and referrals to programs are easy to make and track. The pandemic has increased the need for social services to unprecedented levels. Since March 2020, Pennsylvanians have used our platform to seek help over 1.5 million times. Findhelp connects Pennsylvanians to over 16,064 available programs and 1,927 in-network CBO programs.

We also employ several community engagement managers in Pennsylvania to assist non-profits in using the free services we provide to them as a part of our mission as a Public Benefit Corporation.

As noted in the below heatmap of Findhelp searches, Pennsylvanians across the commonwealth are searching for social services. From food pantries to assistance paying utility bills, we live in a time of great need.



The Pennsylvanians accessing these free and reduced cost programs deserve the dignity of privacy. Many people are aware of the privacy protections that guide medical information under HIPAA – but many do not realize that federal privacy protections for an individual’s interactions with social services are unclear and ambiguous.

Most social service providers are small, community-based organizations. They provide needed social services but they typically are not “covered entities” under the federal HIPAA law. Thus, they are not guided by the same privacy protections and policies that are required of traditional health care providers.

More importantly, there is often a stigma that comes with needing social services. It is important that we all recognize that this stigma exists and that we respect the right to privacy for people seeking social services.

Social services exist to help people during their time of need, in some of our most vulnerable moments. Many people needing these services are newly unemployed, survivors of trauma, ex-offenders trying to make their way back into society, or parents helping their struggling teenagers. People expect this deeply personal information, which is housed in closed-loop referral systems like ours, to only be visible to the people they trust — people they know.

Pennsylvania has the opportunity to become a leader in privacy for social services. Rep. Rob Mercuri's HB 2202 is an important bill that tackles the critical issue of data privacy as it relates to big tech. We appreciate Rep Mercuri's interest and work on this issue and his time discussing our thoughts on this bill which resulted in our submitting testimony for this hearing. With our work in other states, we have been able to see similar data privacy bills move in other legislatures and have advocated successfully for the inclusion of language that would protect the data of those seeking help online. Many other states around the country are grappling with the issue of how to coordinate care without abandoning the rights of individual privacy.

As you continue the critical conversation around privacy in social services, please remember the importance of consent. We believe good policy requires the need to consent on each instance of referral, and to ensure that any organization receives the consent of the individual before their sensitive and personal referral information is looked at. With technology, a "per-referral consent" is a way to appropriately limit access to parties that shouldn't have access.

If individuals want to share their records with people they trust, perhaps a social worker at a local nonprofit, they can do that in a per-referral consent model. Any legislation that addresses privacy in social services is ultimately about access and ensuring that the right people have access to the right information at the right time.

In contrast, with an "open-access consent model", any user with a valid login and password to a centralized database — even someone in another town that you've never met, or never talked to, can look you up and see your information if you've received social services in Pennsylvania. In some cases, like healthcare, that model works. If I show up to an emergency room unconscious, I want the ER doctor to know about my medical conditions. But to govern access to deeply personal social services information the same way? It's a lot riskier as this database contains information about people's most vulnerable moments. While an open-access consent model may allow for convenience — we strongly believe that people won't seek the help they need if they fear their information will be seen by the wrong people. A requirement of a "per-referral consent" is the right way to go.

Protecting the privacy of those seeking social services in Pennsylvania is of the utmost importance. Findhelp strongly urges you to prioritize the privacy of those utilizing social services as you finalize privacy legislation.

Over the course of your consideration of this important legislation, I will make my team available to members of the General Assembly to further discuss the issues we have raised and suggest legislative language that has been implemented in other states around data privacy and social services. We stand ready to partner in helping the Commonwealth to become a leader in data privacy in the social service space and better address the social determinants of health in Pennsylvania by providing assistance to those seeking and providing help.

Thank you for your consideration of my thoughts.

Appendix

Exhibit 1: Findhelp search history in Pennsylvania



Exhibit 2: Types of searches in Pennsylvania on Findhelp

① Most Common Search Terms | All Dates

TERM	DOMAIN	SEARCHES
food pantry	food	56,161
help pay for housing	housing	52,021
help find housing	housing	43,994
help pay for utilities	housing	40,476
food delivery	food	32,677
emergency food	food	26,490
transportation for healthcare	transit	19,124
temporary shelter	housing	18,928
financial assistance	money	18,632
transportation	transit	17,180
food pantries & emergency food	food	16,071
help pay for food	food	14,138
housing vouchers	housing	14,096
meals	food	12,744
help pay for internet or phone	housing	11,835