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**The Office of the National Coordinator for Health Information Technology (ONC)
Health Information Technology Advisory Committee (HITAC) Virtual Hearing**

Testimony of:

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Thank you to the Office of the National Coordinator for Health IT for the opportunity to provide testimony, and thank you to the distinguished co-chairs and members of the committee for your leadership and relentless efforts to support the health and wellness of all people. I am humbled to contribute to the national dialogue to advance health equity, and I welcome the responsibility to deliver to you key learnings and the voice of the families and communities we serve.

My name is Jaffer Traish and our company is called findhelp, (formerly Aunt Bertha). I was fortunate to have two parents - and while they both grew up in poverty - they fought to help others, one through health research and the other through social work - offering an unapologetic perspective on community centered service.

To people and organizations that help others, findhelp is the modern safety-net that brings dignity and speed to the process of getting help – because

our open community organization network helps all people know *what* social services they are eligible for and if an organization is able to pay for the service on their behalf, all while protecting the privacy of the individual.

Our Mission is to connect all people in need and the programs that serve them - with dignity and ease. Health Equity by Design is a core part of our mission, and health equity drives key product principles for the technology and network we build. I will focus the following testimony on health equity as it relates to social care.

Today is the first time we are sharing the following sober statistics on the record:

- Each *week*, more than 350,000 people looking for help (such as food, housing, transportation and healthcare) connect to service programs in our network.
- Each *month*, more than 150,000 electronic social care referrals are sent across our network.
- Overall, more than 9.5 Million people and growing have used the network to find help.

Through digitizing the nationwide supply of non-profits and reduced cost social services, we are *democratizing* how people can find and apply for services. 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 large organizations navigating for people in need (*including 7 of this committee members' organizations*).

When we think about health equity and the aims of inclusion, equitable outcomes, access and affordability - we think back to 1964 when the Economic Opportunity Act by President Johnson paved the way for Neighborhood Health Centers to open, including the first two - in Mound Bayou Mississippi, and Columbia Point in Boston. Now, there are nearly 1,400 FQHCs serving more than 30 million people with medical, social and behavioral needs. We must remember that health equity cannot be achieved without working to eliminate poverty and root cause disparities.

I will focus my testimony on two core principles of equity in social care that we are building into our technology, and one core principle of working with government.

1. Consumer-Directed Privacy and Per-referral Consent
2. Equal access to an inclusive and holistic network of programs
3. Government partnership through capacity building, standards and interoperability certification, and innovation demonstrations

On Privacy: Many people are aware of the privacy protections that guide appropriate handling and storage of medical information under HIPAA. The industry is regulated, there are penalties for misuse of data, and what is considered protected health information is generally clear.

Social care information, however, can be created, shared, and used entirely outside of HIPAA regulation – and it can cross sectors, originate in covered spaces, and in the absence of guidance, some technology companies are taking advantage of the lack of a sound policy framework and legal repercussions related to this data sharing.

We must remember – there is often a stigma that comes with needing social services, and with whom we share sensitive information. When a person is ready to receive help, we must respect this sensitivity to not lose trust with our patients, constituents, or students, and not lose them in the care journey.

Many people needing these services are newly unemployed, survivors of trauma, ex-offenders trying to re-enter society, or parents helping their struggling teenagers.

People expect this deeply personal information, which is housed in a closed-loop referral systems like ours, to only be visible to the organizations and people they choose, transparently.

Thus, we have made it our mission to offer the most appropriate safeguards and have built a very important and necessary consumer directed privacy approach into our technology in the following ways:

1. We support self-navigated referrals, where the person can self-refer, with complete privacy. This is specifically useful for the circumstances an individual is not yet ready to share.
2. We do not automatically show these referrals to customers, because they are private. Customers and CBOs may request access to the private history, and the person has the option to grant this access. This is very similar to

- how as a medical patient, if you self-pay for a procedure, that information is NOT permitted to be shared with your insurance company or affiliates.
3. We track a consent on each instance of a referral - this way, we know who the appropriate parties are to that referral - the community organization, the person, and the helper. This allows our technology to bring transparency to the person in need.
 4. The person in need can add or remove organizations' access to the private referral history at any time. Relationships change, people move, and this transparency is essential.
 5. We respect cross-sector care coordination agreements when in place, and we have built the technology for a longitudinal referral history to be viewed across organizations.

The potentially harmful alternative we have seen out in the market is a one-time, all-in consent model that provides open access and lookup of a person to any organization in the network. Imagine if you signed one consent form to have your information put into a database so you could receive a food referral - but with that one action, more than 120 non-profit organizations in your community, many of which are not covered entities can now see your financial, social, and medical information in its entirety.

This is not a hypothetical example - the exact language of that consent reads: "CIE and its partner agencies may share your personal, financial, and health information...Information disclosed pursuant to this Authorization may be re-disclosed and no longer protected under privacy laws." In the words of one healthcare professional who read this: "Holy mackerel".

While an open-access consent model may allow for convenience — we strongly believe that the lack of clear safeguards to protect consumers' HIPAA-adjacent data will have a chilling effect on equitable access, trust, and use of social services through closed-loop referral management systems and networks.

Through technology, we also support anonymous search and connections to programs. Some vendors require submission of all of your demographic and identifying data just to perform a search.

New Hampshire, Connecticut, Rhode Island and others are leading the way on this issue by drafting and considering legislation in a bi-partisan manner to

ensure proper and sound privacy controls when sensitive information is shared with social service agencies.

Our organization has helped millions of people using a model that includes informed consent at each instance of referral. It has not hindered care coordination and most importantly it enables a technology solution that respects the right to privacy of the individual. Equity through Privacy.

On Access and Holistic Network: Put simply, people deserve to know their options for receiving help. The full opportunity of programs that may serve me. For example - in my neighborhood, there are 22 organizations that offer emergency food. By offering this holistic network, I can find an organization that speaks my preferred language, or an organization that understands veteran trauma.

We take a health equity by design approach to the network because we've chosen to be accountable to the network quality through human curation. Here are some of the intentional program network addition projects we've undertaken recently: Dental Care programs in states without covered adult preventative care. Native American Resources. Indian Health Service Programs. Free Severe Mental Illness Resources. Centers for Independent Living Programs. Re-entry Programs. 3,000 COVID-19 specific support programs. Immigration Legal Services in partnership with Stanford. And many more.

By investing in a holistic network, we aim to be as inclusive as possible in the program types and services people can find. Through our technology, our customers and partners can also create focused or preferred networks within the open network, maintaining the best of both worlds.

We recently reviewed our data to assess if health systems (of which we work with more than 160 formally), are helping people connect to programs serving all of one's needs. It is likely not surprising to some on this committee that 94% of the referrals were limited to housing, food and medical care. Goods, Legal, Education, Work, Transit, and other services were only 6%. Regardless of this possible industry bias, we know that many people receive help outside of the healthcare ecosystem. Schools, libraries, kiosks in New York City – by offering a holistic network and not one catering to industry incentive, we are bringing equity to the process of finding help.

On Government Partnership: We believe in and support the government's influence in modernizing the social safety net. We also believe the government can be mindful of health equity in the vehicles used to disburse funds, create certifications, establish standards, and prevent monopolistic behavior.

One of the most equitable approaches to communities is to apply funding to capacity building of effective non-profit organizations. By providing funds to the source of the service delivery, we remove significant industry bias, eligibility bias, and maximize the resource value going into the hands of those in need. Through our technology, we offer needs based data to philanthropy to aid in their funding direction.

We also applaud the efforts to expand USCDI, whereby public specifications can be used to encourage, regulate or certify technology that complies with interoperability. We are live in our technology with interoperable referrals not only from source systems, but with CBO systems as well.

We support CMMI Demonstrations, State Section 1115 Waivers and State Plan Amendments that explore improvement in healthcare outcomes through value based or contracted CBO networks. We support these contracted networks in states like Massachusetts and California with our technology today.

We believe in the future, there may be a role for ONC to certify FHIR based and/or interoperable vendors that can demonstrate accurate state and federal reporting for state funded or federally funded initiatives. Our technology was the first to be certified for the Accountable Health Communities Grant model.

However, we must be mindful of the lessons of the past. In 2015, when Dr. Paul Tang chaired the health IT policy committee, the committee noted the following: "Some advanced health models are responding to interoperable challenges by granting community organizations with access to a single platform, rather than realizing true interoperability across different systems".

This point could not be more salient today, where we've seen some states attempt to mandate one network or platform to be used by thousands of organizations, instead of leveling the field for innovation through standards and reporting requirements. This has allowed some technology vendors to go as far as to have exclusivity in their contracts with community organizations. This is state sponsored monopolization that will not advance the goals of health equity.

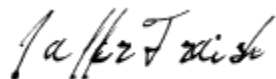
As CMS and ONC become more involved in promoting social determinants efforts, there is an opportunity for the departments to share guidance letters and education. We must be careful to not inadvertently fund technology or a monopolistic approach that fails to offer a health equity by design approach to serving all people.

In closing – we are all seekers at some points in our lives. Giving up our privacy should not be a contingency of getting help. Being privileged to have a healthcare entry point to a social worker should not be a contingency of getting help. And government can ensure that vendors are not forcing exclusivity on communities' use of technology, further siloing data and adoption.

We will continue to invest in health equity by design and will continue to offer findhelp.org to the nation.

With great respect and appreciation for the committee's time and attention.

Jaffer Traish

A handwritten signature in black ink that reads "Jaffer Traish". The signature is written in a cursive style with a large initial "J" and a long, sweeping underline.