**To:** Senate Public Health and Welfare Committee

**From:** Steve Greene on behalf of Findhelp

**Re.** Proponent Testimony Senate Bill 234

**Date:** March 21, 2023

Chairwoman Gossage and members of the Senate Committee on Public Health and Welfare. My name is Steve Greene and I am here to offer proponent testimony on behalf of Findhelp.

Findhelp, is one of the largest closed-loop referral network for social services in the United States with over 20 million users to date nationwide and almost 175,000 users here in Kansas. Findhelp is a Public Benefit Corporation based in Austin, Texas and we are proud to say we have earned the trust of more than 500 clients – from state governments to health and social service organizations, including many that serve here in Kansas such as the Kansas Children's Service League, Aetna, Sunflower Health Plan, Children's Mercy, St. Luke's, Ascension and HCA.

**At Findhelp, our mission is to connect all people in need and the programs that serve them with dignity and ease, and we believe that privacy is a critical part of preserving that dignity.**

Senate Bill (SB) 234 is meant to provide guardrails for how sensitive information is obtained and shared by any state department using a social care network or being provided by a third-party vendor. It is our belief that when a person is seeking assistance whether at a local-food pantry, community action program, or domestic assault shelter, **that person has a right to consent how, when and why that sensitive information is being accessed.**

Let me provide a bit of background on why this issue is so important today. You are all aware of the privacy protections that guide medical information under HIPAA – but many people do not realize that information about social services often exists in a gray area with no federal or state privacy protection.

Most social service providers are small, community based organizations - think of a church which runs a food pantry on Tuesdays and Thursdays - that typically are not "covered entities" under the federal HIPAA law. Thus, they are not guided by the same privacy protections that are required by traditional health care providers. This bill addresses that gray area and ensures legal privacy protections around social services.

In the social care setting, there is often a stigma that comes with needing and accessing social services. It is important that we recognize that this stigma exists and that we respect every person's right to privacy during their time of need. Many people needing these services are newly unemployed, survivors of trauma, or family members helping a relative struggling with substance abuse.

However, some simply do not want widespread access to the fact that they need assistance with food or housing. People expect deeply personal information, which is housed in systems like ours, to only be visible to the people they trust and have consented for the information to be shared.

If people don't trust the system then they are less likely to ask for help and that leads to avoidable outcomes like ending up in the emergency room because you didn't have transportation to your doctor's appointments.

Referrals for social services, which used to be transmitted by word of mouth, are being digitized for the first time. Individuals can still walk into their church or a local non-profit to get help, but now their need for help is potentially accessible by a large number of people and organizations who are part of social service networks using closed loop referral systems.

The digitization of social care referrals provides two opportunities for individual's privacy to be compromised. The first is the ability for individuals or organizations (some of which are for-profit entities) to be able to look up people by name and have access to all their social care referral history. Whether it was a nosy neighbor, an employer or an ex-spouse, one can appreciate why this form of access is highly inappropriate. The second is the situation in which referral information is sent to dozens of service providers. When this happens, the individual seeking services does not know where referrals are being sent and has not provided consent to share their information with this unknown grouping of providers. For these reasons, providing a high level of privacy protection as a default for all social services referrals is a crucially important feature of this bill.

Finally, we think the per-referral consent model of this bill is a best practice that protects privacy and ensures a high level of care coordination. Allowing individuals to consent on every instance of a referral provides them the highest level of transparency about who has access to their information. Likewise, consenting on every referral ensures the referral system delivers the necessary information to the service providers who need it. In our experience working with over 100 health plans and over 180 health systems we have not seen any evidence that a per-referral consent model hinders care coordination. Specifically, our customers have not found our per-referral consent model to be onerous. To the

contrary, we hear from many customers and community-based organizations that choose to join our network that our commitment to privacy is very important to them as they feel strongly about protecting the privacy of the populations they serve. This bill puts care coordination at the forefront while preserving the dignity, privacy, and consent of the person receiving those services.

Finally, in preparing for today's hearing, we have been working with other community partners in leading up to today's hearing. To that end, we may ask the committee to support a subsequent balloon amendment that will address their substantive concerns.

Thank you to the Committee for the opportunity to speak today. I appreciate the hard work of each of the members of this committee and especially Senator Erickson, the sponsor of this critical legislation. I am happy to answer questions at the appropriate time.

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# Protecting Data Privacy in Social Care Coordination

## What is social care?

In recent years, there has been growing interest and bipartisan investment in better addressing the Social Determinants of Health (SDoH) as a strategy for improving overall health and wellbeing. "Social care" is a broad term used to describe services and support provided by publicly and privately funded organizations, including nonprofits, state and local government agencies, religious organizations, businesses, and philanthropy. Social care providers address needs such as hunger and nutrition, safe and secure housing, transportation, economic stability and employment, and child care.

## Why does social care privacy matter?

**Social care data often includes information about the most vulnerable moments in a person's life. Individuals should maintain control of who has access to this personal information.** In an effort to better coordinate the delivery of health and social care, state governments and healthcare systems across the country are beginning to build centralized databases that house information about people's social needs and social care referrals.

**Some states are contracting with technology vendors that default to the same all-in consent model used in healthcare,** where sharing health information is needed to ensure continuity of care and is governed under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). However, using all-in consent in the social care context grants broad data access to networks of service providers without the individual being fully informed about where their personal information is being shared. This compromises the privacy of sensitive information about services accessed during a time of need, such as domestic violence support or substance abuse treatment. Below we illustrate why the all-in consent model used by some technology vendors isn't the appropriate model for social care, which should instead be governed by per-referral consent.

| **All-in Consent** (Health Care) | vs | **Per-referral Consent** (Social Care) |
|---|---|---|
| John's healthcare provider captures John's health records in an electronic health record system. When John consents to putting his records into this system, these **full records are available to healthcare providers** who provide him with care.<br><br>This **all-in consent** is important and necessary for healthcare because if John shows up to an emergency room unconscious, he wants the ER doctor to know about his medical conditions. | | Jane goes through intake at a domestic violence shelter. Jane consents to **only** give her sensitive information to the domestic violence shelter because she received assistance there. Jane also picks up food from a food pantry.<br><br>**In a per-referral consent system,** even if the food pantry is in the same social care network as the shelter, staff at the pantry **would not be able** to see Jane's domestic violence intake information unless she gives **explicit consent** for the domestic violence shelter to share this information with the food pantry. |

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## How can you protect social care data privacy?

**State-level privacy legislation can close loopholes and establish best practices in statute** for protecting data privacy in the growing social care referral networks operating in your state. New Hampshire's legislature recently adopted SB 423, a "**first-in-the-nation privacy protection law** that gives everyone receiving social services assistance the right to consent each time before personal information can be shared with other groups" (*New Hampshire Union Leader*). The legislation requires informed consent be given for each referral to prevent sensitive information from falling into inappropriate hands, and individuals may revoke their consent at any time.

## What are best practices for governing social care data privacy?

1. Require a consumer directed per-referral consent model, in which individuals are asked to opt-in to share their information for each referral. Ensure social care network members' access to referral history is permission-based.

2. Maintain the individual's right to obtain help without conditioning referrals on consent to share personal information.

3. Require that individuals seeking help maintain the right to opt-out of sharing their information at any time, and ensure that revoking network access to personal information is simple for the individual.

4. Allow HIPAA-covered entities to continue following existing pathways for sharing staff-generated referrals with Health Information Exchanges (HIEs) or other covered entities, pursuant to data sharing or network agreements.

5. Establish provisions governing the length of time non-health identifiable information will be maintained in a database.

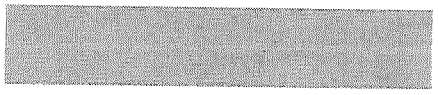
6. Prohibit the sale of personal information without explicit individual consent.

## What is findhelp, and how do we approach privacy?

Findhelp was founded in 2010 to provide an easier way for people in need to find and connect to social care services. We have built and maintain the largest network of free and reduced-cost programs in every ZIP Code across the United States. Seekers (individuals seeking services) come first at findhelp. We support best privacy practices even in the absence of a legal requirement like New Hampshire's law. Seekers can use the findhelp platform anonymously or they can create an account to track their self-referrals. On our referral forms, a consent checkbox needs to be clicked before **each** referral can be sent. Entities viewing referral information must have permission granted by the seeker, and we never sell our data to third parties.

### Want to connect?

Please reach out to Anna Lipton Galbraith (aliptongalbraith@findhelp.com).

# The Accountable Health Communities Health-Related Social Needs Screening Tool

## What's the Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) Screening Tool?

We at the Centers for Medicare & Medicaid Services (CMS) Center for Medicare and Medicaid Innovation (CMMI) made the Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) Screening Tool to use in the AHC Model.[1] We're testing to see if systematically finding and dealing with the health-related social needs of Medicare and Medicaid beneficiaries has any effect on their total health care costs and makes their health outcomes better.

## Why is the AHC HRSN Screening Tool important?

Growing evidence shows that if we deal with unmet HRSNs like homelessness, hunger, and exposure to violence, we can help undo their harm to health. Just like with clinical assessment tools, providers can use the results from the HRSN Screening Tool to inform patients' treatment plans and make referrals to community services.

## What does the AHC HRSN Screening Tool mean for me?

Screening for HRSNs isn't standard clinical practice yet. We're making the AHC HRSN Screening Tool a standard screening across all the communities in the AHC Model. We're sharing the AHC HRSN Screening Tool for awareness.

## What's in the AHC HRSN Screening Tool?

In a National Academy of Medicine discussion paper,[2] we shared the 10-item HRSN Screening Tool. The Tool can help providers find out patients' needs in these 5 core domains that community services can help with:

- Housing instability
- Food insecurity
- Transportation problems
- Utility help needs

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[1] United States, U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. (2017, September 05). Accountable Health Communities Model. https://innovation.cms.gov/initiatives/ahcm.

[2] Billioux, A., MD, DPhil, Verlander, K., MPH, Anthony, S., DrPH, & Alley, D., PhD. (2017). Standardized Screening for Health-Related Social Needs in Clinical Settings: The Accountable Health Communities Screening Tool. National Academy of Medicine Perspectives, 1-9. https://nam.edu/wp-content/uploads/2017/05/Standardized-Screening-for-Health-Related-Social-Needs-in-Clinical-Settings.pdf.

- Interpersonal safety

In the final version below, we made small revisions to the original 10 questions based on cognitive testing we did since we shared the first version. In the final version we also included questions in 8 supplemental domains that we haven't shared before:

- Financial strain
- Employment
- Family and community support
- Education
- Physical activity
- Substance use
- Mental health
- Disabilities

## Who should use the AHC HRSN Screening Tool?

The questions in the AHC HRSN Screening Tool are meant to be used for individual respondents who answer the questions themselves. A parent or caregiver can answer for an individual, too, if that makes more sense. Clinicians and their staff can easily use this short tool as part of their busy clinical workflows with people of all different ages, backgrounds, and settings.

In the next 5 years, hundreds of participating clinical delivery sites across the 32 AHCs will screen over 7 million Medicare and Medicaid beneficiaries using the 10 core domain questions. The AHCs can also choose to add any of the supplemental domain questions into their standard screening processes.

## Who made the AHC HRSN Screening Tool?

We made this tool with a panel of experts from around the country including:

- Tool developers
- Public health and clinical researchers
- Clinicians
- Population health and health systems executives
- Community-based organization leaders
- Federal partners

We got permission from the original authors of the questions to use, copy, modify, publish, and distribute the questions for the AHC Model and our use only. Based on feedback from the original question authors, CMS has created this table to specify the citation and notification process for each screening question in the AHC HRSN Screening Tool if the questions are used outside of CMS and the AHC Model.

# AHC HRSN Screening Tool Core Questions

If someone chooses the underlined answers, they might have an unmet health-related social need.

## Living Situation

1. **What is your living situation today?**[3]
   - ☐ I have a steady place to live
   - ☐ I have a place to live today, but **I am worried** about losing it in the future
   - ☐ I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)

2. **Think about the place you live. Do you have problems with any of the following?**[4]
   CHOOSE ALL THAT APPLY
   - ☐ Pests such as bugs, ants, or mice
   - ☐ Mold
   - ☐ Lead paint or pipes
   - ☐ Lack of heat
   - ☐ Oven or stove not working
   - ☐ Smoke detectors missing or not working
   - ☐ Water leaks
   - ☐ None of the above

## Food

**Some people have made the following statements about their food situation. Please answer whether the statements were OFTEN, SOMETIMES, or NEVER true for you and your household in the last 12 months.** [5]

3. **Within the past 12 months, you worried that your food would run out before you got money to buy more.**
   - ☐ Often true
   - ☐ Sometimes true
   - ☐ Never true

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[3] National Association of Community Health Centers and partners, National Association of Community Health Centers, Association of Asian Pacific Community Health Organizations, Association OPC, Institute for Alternative Futures. (2017). PRAPARE. http://www.nachc.org/research-and-data/prapare/

[4] Nuruzzaman, N., Broadwin, M., Kourouma, K., & Olson, D. P. (2015). Making the Social Determinants of Health a Routine Part of Medical Care. Journal of Healthcare for the Poor and Underserved, 26(2), 321-327.

[5] Hager, E. R., Quigg, A. M., Black, M. M., Coleman, S. M., Heeren, T., Rose-Jacobs, R., Frank, D. A. (2010). Development and Validity of a 2-Item Screen to Identify Families at Risk for Food Insecurity. Pediatrics, 126(1), 26-32. doi:10.1542/peds.2009-3146

4. **Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.**
   - ☐ Often true
   - ☐ Sometimes true
   - ☐ Never true

## Transportation

5. **In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?**[6]
   - ☐ Yes
   - ☐ No

## Utilities

6. **In the past 12 months has the electric, gas, oil, or water company threatened to shut off services in your home?**[7]
   - ☐ Yes
   - ☐ No
   - ☐ Already shut off

## Safety

**Because violence and abuse happens to a lot of people and affects their health we are asking the following questions.** [8]

7. **How often does anyone, including family and friends, physically hurt you?**
   - ☐ Never (1)
   - ☐ Rarely (2)
   - ☐ Sometimes (3)
   - ☐ Fairly often (4)
   - ☐ Frequently (5)

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[6] National Association of Community Health Centers and Partners, National Association of Community Health Centers, Association of Asian Pacific Community Health Organizations, Association OPC, Institute for Alternative Futures. (2017). PRAPARE. http://www.nachc.org/research-and-data/prapare/

[7] Cook, J. T., Frank, D. A., Casey, P. H., Rose-Jacobs, R., Black, M. M., Chilton, M., . . . Cutts, D. B. (2008). A Brief Indicator of Household Energy Security: Associations with Food Security, Child Health, and Child Development in US Infants and Toddlers. Pediatrics, 122(4), 867-875. doi:10.1542/peds.2008-0286

[8] Sherin, K. M., Sinacore, J. M., Li, X. Q., Zitter, R. E., & Shakil, A. (1998). HITS: a Short Domestic Violence Screening Tool for Use in a Family Practice Setting. Family Medicine, 30(7), 508-512

8. **How often does anyone, including family and friends, insult or talk down to you?**
   - ☐ Never (1)
   - ☐ Rarely (2)
   - ☐ Sometimes (3)
   - ☐ Fairly often (4)
   - ☐ Frequently (5)

9. **How often does anyone, including family and friends, threaten you with harm?**
   - ☐ Never (1)
   - ☐ Rarely (2)
   - ☐ Sometimes (3)
   - ☐ Fairly often (4)
   - ☐ Frequently (5)

10. **How often does anyone, including family and friends, scream or curse at you?**
    - ☐ Never (1)
    - ☐ Rarely (2)
    - ☐ Sometimes (3)
    - ☐ Fairly often (4)
    - ☐ Frequently (5)

A score of 11 or more when the numerical values for answers to questions 7-10 are added shows that the person might not be safe.

# AHC HRSN Screening Tool Supplemental Questions

## Financial Strain

**11. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:[9]**

- ☐ Very hard
- ☐ Somewhat hard
- ☐ Not hard at all

## Employment

**12. Do you want help finding or keeping work or a job?[10]**

- ☐ Yes, help finding work
- ☐ Yes, help keeping work
- ☐ I do not need or want help

## Family and Community Support

**13. If for any reason you need help with day-to-day activities such as bathing, preparing meals, shopping, managing finances, etc., do you get the help you need?[11]**

- ☐ I don't need any help
- ☐ I get all the help I need
- ☐ I could use a little more help
- ☐ I need a lot more help

**14. How often do you feel lonely or isolated from those around you?[12]**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

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[9] Hall, M. H., Matthews, K. A., Kravitz, H. M., Gold, E. B., Buysse, D. J., Bromberger, J. T., . . . Sowers, M. (2009). Race and Financial Strain are Independent Correlates of Sleep in Midlife Women: The SWAN Sleep Study. Sleep, 32(1), 73-82. doi:10.5665/sleep/32.1.73

[10] Identifying and Recommending Screening Questions for the Accountable Health Communities Model (2016, July) Technical Expert Panel discussion conducted at the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, Baltimore, MD.

[11] Kaiser Permanente. (2012, June). Medicare Total Health Assessment Questionnaire. Retrieved from https://mydoctor.kaiserpermanente.org/ncal/Images/Medicare%20Total%20Health%20Assessment%20Questionnaire_tcm75-487922.pdf

[12] Anderson, G. Oscar and Colette E. Thayer. Loneliness and Social Connections: A National Survey of Adults 45 and Older. Washington, DC: AARP Research, September 2018. https://doi.org/10.26419/res.00246.001

## Education

**15. Do you speak a language other than English at home?[13]**

- ☐ Yes
- ☐ No

**16. Do you want help with school or training? For example, starting or completing job training or getting a high school diploma, GED or equivalent.[14]**

- ☐ Yes
- ☐ No

## Physical Activity

**17. In the last 30 days, other than the activities you did for work, on average, how many days per week did you engage in moderate exercise (like walking fast, running, jogging, dancing, swimming, biking, or other similar activities)?[15]**

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7

**18. On average, how many minutes did you usually spend exercising at this level on one of those days?[16]**

- ☐ 0
- ☐ 10
- ☐ 20
- ☐ 30
- ☐ 40
- ☐ 50
- ☐ 60

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[13] United States, US Census Bureau. (2017). American Community Survey. Retrieved from https://www.census.gov/programs-surveys/acs/

[14] Identifying and Recommending Screening Questions for the Accountable Health Communities Model (2016, July) Technical Expert Panel discussion conducted at the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, Baltimore, MD.

[15] Coleman, K. J., Ngor, E., Reynolds, K., Quinn, V. P., Koebnick, C., Young, D. R., . . . Sallis, R. E. (2012). Initial Validation of an Exercise "Vital Sign" in Electronic Medical Records. Medicine and Science in Sport and Exercise, 44(11), 2071-2076. doi:10.1249/MSS.0b013e3182630ec1

[16] Ibid

☐ 90
☐ 120
☐ 150 or greater

Follow these 2 steps to decide if the person has a physical activity need:

1. Calculate ["number of days" selected] x ["number of minutes" selected] = [number of minutes of exercise per week]
2. Apply the right age threshold:
   - Under 6 years old: You can't find the physical activity need for people under 6.
   - Age 6 to 17: Less than an average of 60 minutes a day shows an HRSN.
   - Age 18 or older: Less than 150 minutes a week shows an HRSN.

## Substance Use

**The next questions relate to your experience with alcohol, cigarettes, and other drugs. Some of the substances are prescribed by a doctor (like pain medications), but only count those if you have taken them for reasons or in doses other than prescribed. One question is about illicit or illegal drug use, but we only ask in order to identify community services that may be available to help you.** [17]

**19. How many times in the past 12 months have you had 5 or more drinks in a day (males) or 4 or more drinks in a day (females)? One drink is 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of 80-proof spirits.**

☐ Never
☐ Once or Twice
☐ Monthly
☐ Weekly
☐ Daily or Almost Daily

**20. How many times in the past 12 months have you used tobacco products (like cigarettes, cigars, snuff, chew, electronic cigarettes)?**

☐ Never
☐ Once or Twice
☐ Monthly
☐ Weekly
☐ Daily or Almost Daily

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[17] United States, U.S. Department of Health and Human Services, National Institutes of Health. (n.d.). Helping Patients Who Drink Too Much: A Clinician's Guide (2005 ed., pp. 1-34).

**21. How many times in the past year have you used prescription drugs for non-medical reasons?**

- ☐ Never
- ☐ Once or Twice
- ☐ Monthly
- ☐ Weekly
- ☐ Daily or Almost Daily

**22. How many times in the past year have you used illegal drugs?**

- ☐ Never
- ☐ Once or Twice
- ☐ Monthly
- ☐ Weekly
- ☐ Daily or Almost Daily

## Mental Health

**23. Over the past 2 weeks, how often have you been bothered by any of the following problems?[18]**

**a. Little interest or pleasure in doing things?**

- ☐ Not at all (0)
- ☐ Several days (1)
- ☐ More than half the days (2)
- ☐ Nearly every day (3)

**b. Feeling down, depressed, or hopeless?**

- ☐ Not at all (0)
- ☐ Several days (1)
- ☐ More than half the days (2)
- ☐ Nearly every day (3)

If you get 3 or more when you add the answers to questions 23a and 23b the person may have a mental health need.

[18] Kroenke, K., Spitzer, R. L., & Williams, J. B. (2003). The Patient Health Questionnaire-2: validity of a two-item depression screener. Medical Care, 41(11), 1284-1292.

**24. Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his or her mind is troubled all the time. Do you feel this kind of stress these days?[19]**

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

## Disabilities

**25. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?[20] (5 years old or older)**

- ☐ Yes
- ☐ No

**26. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?[21] (15 years old or older)**

- ☐ Yes
- ☐ No

[19] Elo, A.L., Leppänen, A., & Jahkola, A. (2003). Validity of a Single-Item Measure of Stress Symptoms. Scandinavian Journal of Work, 29(6), 444-451.
[20] United States, U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (n.d.). (2011). Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. Retrieved from https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status
[21] Ibid.