Title: Resource directory data sharing

**Prompt:** Given that organizations are using different platforms/technologies in different contexts - but, we share the same goal (to get patients/residents to the services needed/wanted), and maintain a lot of the same resource information - how might we facilitate cooperation in ways that benefit all?

*How many other “homegrown” resource sharing guides exist already. . . )*

Luthern home resource dataset (identified by Waldo)

Food resource map

Community Compass app. . .

Population specific ones - maybe legal aid, Indiana Disability Finder

Another one used by many in IN, Charity Tracker

**STAKEHOLDER NEEDS:**

Need accurate, timely information

What do we mean by information? Specific kinds of information for specific kinds of people. Languages spoken. Kinds of insurance accepted.

Sarah (health provider perspective): hard time keeping up with the proliferating sources of information, what are the updates that we can offer without depending on us to update our own system? I don’t want to have to constantly update my own network. I want changes pushed to me.

Carl: CBOs need funding for capacity. How often is an organization’s exclusive data/locality tied to their funding? Would they lose funding opportunities if their data becomes more available?

Karen: how do we get to the recommendation in a way that’s logged in the EHR? This information needs to be available in different systems.

Ben: System is robust in the urban areas, but rural areas are really struggling. Feedback that 2-1-1 just doesn't have the resources we need. Hoping we see capacity built to address rural areas.

Amy Gilbert: we need capacity for collaboration, and the ability to standardize.

Ellen: Needs to be a high level of trust among organizations.

Clear processes of getting added to resource databases – different inclusion criteria and processes.

Milele Kennedy: Clear policy in place to provide secure services to clients of victims assistance and reentry programs.

Identify one organization with the high level data systems access and security to provide secure and streamlined access to services for clients going through transitional victim, reentry or homeless intervention programs.

Jasmine (IN Primary Care Association): We need data to be integrated into ALL electronic health records. Larger EMRs (Epic, Cerner) are hospital facing, but community health centers who serve primarily low-income Hoosiers, don’t utilize these EMRs and have capacity constraints.

Sriram Somanchi: For someone who wanted to use these data for research, what is the process for getting access?

Sriram Somanchi: How hard is it to integrate the solutions developed back to the providers to evaluate the impact on their practice?

Dean Babcock (dbabcock@marionhealth.org): Metropolitan Indianapolis Addiction Referral Assessment & Plan Project (full [online report](https://drive.google.com/file/d/1kJWWaAjc2OHeMrRriVRsuHAO710I54GD/view)) released in 2020 with survey of service providers, and interviews with consumers. Findings: (1) comprehensive online directory of services that is up to date and pertinent to coordination of care, or that has an online referral and follow-up functionality; (2) Orgs commonly make referrals to those they know and trust, difficult for new providers to get connected; (3) \*\*no universal referral form; (4) transportation; (5) \*\*standard agency profile with payment/price information. \*\* = Workgroups created a universal referral and release of information forms and developed an agency profile template.

**COOPERATIVE STRATEGIES:**

* Open data service register – an authority (funder, accreditor, etc) requires providers to be listed in the register.
	+ Needs methods of monitoring and compliance
* One system that provides resource data to all, as a “utility,”
* Federation through a cooperative network of resource data maintainers, who exchange updates / share common core of data.
* Rebecca Miller (Aunt Bertha)- You can focus the network on priority partners and covered benefits programs while still providing access to the full range of national, state and local programs with self-service.
	+ Vendors should support webhooks and APIs natively
		- No matter what network an entity uses - APIs can support this referral history being aggregated into the HIE network for improved care coordination.
	+ Develop data sharing agreements
		- Some HIEs are wanting to continue to be repository for both health AND social care data, so they are using the AB HIE API endpoint to collect and aggregate social care staff referral history from all AB customers that agree to share this history with the HIE
			* We accomplish this with one opt in agreement signed by each participant

**WHAT MUST BE TRUE TO MAKE THIS SUCCESSFUL?:**

* Standards (existence AND consistent use of them) to enable the exchange of data between disparate systems. See additional resources section below for some links.
* Rebecca Miller (Aunt Bertha) - CBOs should be able to receive referrals in their chosen system of record. They can control how they share data and keep Seeker information private. This leads to significantly greater adoption across the community.
	+ CBOs should be able to access referrals based on care coordination responsibilities. Private referrals should remain private, with the Seeker having the choice to share.

**WHAT QUESTIONS DO WE NEED TO ANSWER TO SUCCEED?**

Who decides?

Who decides who decides?

Where should these conversations happen? What does need to be centralized, and which aspects can be decentralized across a federated network?

**NEXT STEPS / OWNERS**

**ADDITIONAL RESOURCES:**

**Standards for SDoH:**

* ONC collection of resources: <https://www.healthit.gov/topic/health-it-health-care-settings/social-determinants-health>
* Gravity project: <http://www.hl7.org/gravity/>
* Open Referral data standards documentation: <http://docs.openreferral.org/en/latest/>

**Resource sharing chat\_4302021**

**09:27:21 From sarah Stelzner to Everyone : it is me sarah I am on phone and on video due to tech issues and not in any breakout.**

**09:40:54 From Greg Bloom to Everyone : People can select to Raise Hand under the Reactions button, to indicate that you haven’t yet introduced**

**09:48:08 From Amy Gilbert to Everyone : Karen - we are very much thinking about the same thing right now. Excited for today's conversation!**

**09:49:39 From Greg Bloom to Everyone : Given that organizations are using different platforms/technologies in different contexts - but, we share the same goal (to get patients/residents to the services needed/wanted), and maintain a lot of the same resource information - how might we facilitate cooperation in ways that benefit all?**

**09:50:41 From Greg Bloom to Everyone : https://docs.google.com/document/d/1ItEevzXcfRKwrxLYkEH1Ko28udatiHa2lkid7tjGBeU/edit#**

**09:54:04 From Amy Gilbert to Everyone : There are a number of population-specific resource directories as well - eg. Indiana Disability Finder, etc.**

**09:54:33 From Kayla Bledsoe to Everyone : There are also the ones for mental health, so really so so many**

**09:56:06 From Carl McKinley to Everyone : How often is an organization’s exclusive data/locality tied to their funding? Would they loose funding opportunities if their data becomes more available?**

**10:01:07 From Amy Gilbert to Everyone : It would be helpful for everyone to identify their unique perspective - eg, provider, etc.**

**10:01:40 From Amy Gilbert to Everyone : - when writing onto the document or speaking. Some of us wear multiple hats, multiple perspectives.**

**10:01:48 From Jasmine Page to Everyone : on that same vein....we need something available in the EMR**

**10:02:31 From Jasmine Page to Everyone : not all EMRs have functionality to be integrated with Aunt Bertha. We have to consider the limitations of staff at smaller practices who don't have capacity to track or embed data into the health record**

**10:04:49 From Kayla Bledsoe to Everyone : 211s have collaborations with Aunt Bertha in other states, so I know that's an example of how its worked/is working now, I'm sure Rebecca could speak more to that**

**10:08:49 From Rebecca Miller to Everyone : Absolutely Kayla, great point, and Aunt Bertha and United Way / 211 have worked together in several states to strengthen community health and wellness**

**In some regions, the 211 community search is powered by Aunt Bertha as well. Data Partnerships such as with 211 San Bernardino are supportive of the community, as we bring data together to surface the strongest, most accurate network with breadth and depth. https://company.auntbertha.com/blog/2020/04/22/aunt-bertha-and-united-way-team-up-to-launch-connectatx-org/**

**10:08:57 From Kelsey Stinson to Everyone : From CBO perspective- what's the process of getting added to the resource databases? I believe Vision Link-Connect211 has to meet AIRS accreditation- not sure about Aunt Bertha. How to we centralize and remove barriers for CBOs to join the resource directories?**

**10:10:22 From Rebecca Miller to Everyone : Kelsey, good point, and this aligns with the Aunt Bertha perspective too. It is free and easy for CBOs to claim their listing for free and reduced cost direct services.**

**10:11:16 From Amy Gilbert to Everyone : To expand on what I said previously, IN211 is longer regionalized, and we're very actively working to improve the database itself with the full force of our resources behind us. Dr. Sullivan mentioned that IN211 has been a part of FSSA for a year, but to be clear - that transition was just finalized. We're just now starting to run full tilt with quality improvement, and we invite/request honest and regular feedback about gaps and inaccuracies.**

**10:11:50 From Kayla Bledsoe to Everyone : From CBO perspective-I would agree that utilizing Aunt Bertha has been really easy for our team to keep resources up to date, but fully integrating to use it for our intake forms does take some time/transition but still easy, just takes some training with the team which Aunt Bertha provides for free**

**10:12:00 From Sarah Wiehe to Everyone : also along the lines of access but from another perspective (a 'provider' of a less formal role like block captain or pastor) = a need is how can I easily access this information too? and what is the burden to update this information on the community-based organization (or individual) end? and balancing that with a need to maintain valid data (what if the directory information conflicts)?**

**10:12:41 From Rebecca Miller to Everyone : Sarah, to your good point earlier about supporting patient’s language translation needs, we at Aunt Bertha make it easy to filter programs by programs that communicate in Spanish for instance: https://support.auntbertha.com/hc/en-us/articles/360029769472-Supported-Languages**

**10:13:29 From Sarah Wiehe to Everyone : thank you, Rebecca!**

**10:15:50 From Matthew Aalsma to Everyone : Great job adding to google doc!!! Keep it up. . .**

**10:16:01 From Rebecca Miller to Everyone : We at Aunt Bertha have a target to update programs every 6 months. Additionally, Programs listed on the platform can claim their programs and update the information in real time! https://support.auntbertha.com/hc/en-us/articles/218578707-Updating-Programs**

**10:16:16 From Dean Babcock to Matthew Aalsma(Direct Message) : Agencies told us in the RAP project they need to stay abreast of current services, new agencies, and those that are no longer in service. Also if an agency created a new service line how do folks know that. There is a need for payment accepted information, and information down to an intervention level in some circumstances ie MAT, Trauma, etc. Also people need to search by population and population characteristics ie Spanish speaking, adolescent, senior, women, pregnant women etc**

**10:19:03 From Greg Bloom to Everyone : https://docs.openreferral.org**

**10:19:04 From sarah Stelzner to Everyone : i love that idea and dream of the day that EMRs do the same thing**

**10:19:17 From Greg Bloom to Everyone : https://docs.google.com/presentation/d/12DejtrhZdYcX9Wm069WmAqjM6Rf1opcEeg2cyvmz1nI/edit?usp=sharing**

**10:19:49 From Waldo Mikels-Carrasco to Everyone : The Open Referral specification is analogous to the change that occurred when EMRs were forced to adopted interoperable data standards to exchange patient information across proprietary EMS vendors.**

**10:20:11 From Matthew Aalsma to Everyone : Good example Waldo. . .**

**10:21:01 From sarah Stelzner to Everyone : but EMRs still dont share information easily or completely**

**10:22:05 From Sriram Somanchi to Everyone : This is wonderful, Greg, to see integration and combining the data from multiple data sources. For someone who wanted to use these data for research, what is the process for getting access?**

**10:22:11 From Amy Gilbert to Everyone : I do want to be transparent about the fact that IN211/ICC and Aunt Bertha had a great conversation in October, and are currently scheduling another meeting. I don't think this conference is the place for a hard sell, we're here to collaborate and learn.**

**10:22:54 From Waldo Mikels-Carrasco to Everyone : @Sarah,, but at least we have a base set of standard document standards (ADTs, CDAs, lab reports, etc.) that we can collaboratively operate from, that doesn't exist in the social service sector.**

**10:23:40 From Rebecca Miller to Everyone : We agree Amy! Looking forward to collaborating and learning together too.**

**10:23:43 From Matthew Aalsma to Everyone : We are also going to save the chat. . .**

**10:34:56 From Amy Gilbert to Everyone : @Peter - I couldn't agree more!**

**10:39:22 From Matthew Aalsma to Everyone : This breakout can go until 1055 and take 5 minute break. Emily confirmed!**

**10:40:50 From Kayla Bledsoe to Everyone : I have to go, but it was great to be part of this conversation! Thank you all!**

**10:42:17 From Amy Gilbert to Everyone : I know this conversation is focused on registry data, but when coupled with closed loop referral capacity there are some incentives built in such as simple, customizable reporting capacity (related to referrals, demographics of population served, etc.)**

**10:43:48 From sarah Stelzner to Everyone : there seems to be many young people in graduate programs about practical use of big data as well as learning health systems research. how about an Americorp version of placing these young graduates in community based organizations?**

**10:45:39 From sarah Stelzner to Everyone : @waldo but what is the timeline for actual sharing of information in EMR?**

**10:45:57 From Carl McKinley to Everyone : Are we talking about providing a resource for patients/clients or a resource for CBOs?**

**10:48:00 From Sarah Wiehe to Everyone : the yes, and... :)**

**10:48:55 From Sarah Wiehe to Everyone : my question to the group is then how do we start in terms of next steps?**

**10:49:07 From Waldo Mikels-Carrasco to Everyone : @Sarah, it is happening in some regions already, and initiatives like Gravity are helping codify some of the screening data (in ICD10). Next needs to be the resource data.**

**10:49:24 From Amy Gilbert to Everyone : @ Ben - my perspective is both.**

**10:49:37 From Peter Embí - Regenstrief Institute to Everyone : To document what I just stated: One other consideration to the question of “centralization” vs. “federation” is to determine what “must” be centralized for things to function as desired and what is “okay” to do in a federated way (even if centralization would be ideal)**

**10:51:46 From Peter Embí - Regenstrief Institute to Everyone : To Sarah’s point - many have already been convening for the pilots (like via Monon collaborative) and we have groups like that and IPIC to leverage to keep the discussion going and movement happening. Seems to me that’s a key take away from this workshop.**

**10:52:55 From Rebecca Miller to Everyone : We convene statewide collaboratives as well for 20 entities we are currently supporting with their social care strategy**

**10:55:30 From Rebecca Miller to Everyone : We would be happy to join the Monon collaborative or IPIC to facilitate next steps**

**10:56:04 From Rebecca Miller to Everyone : remiller@auntbertha.com**

**10:57:23 From Emily Hardwick to Everyone : Hi everyone! Take a few minutes for a break. Get outside to enjoy some fresh air! We will start promptly at 11:00am.**