Connecting individuals, families, and providers in Massachusetts to community-based behavioral health and social services

Recommendations from an environmental scan of community resource databases

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Behavioral Health: The Unfinished Agenda for Reform
Community Resource Database Action Team

The Brookline Center for Community Mental Health

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I. Executive summary

Health care delivery and payment systems are rapidly evolving in Massachusetts with the goals of controlling health care cost growth, ensuring quality at the point of care, and advancing the health of patient populations. Emphasis has been placed on integrated systems that address patients' physical health, behavioral health, and social services needs. Care coordinators will be challenged to ensure that patients are connected to supports across sectors that haven't traditionally worked together, that services are timely and provided in the most appropriate settings, and that patients receive ongoing, coordinated care to promote positive health outcomes and wellbeing.

At the same time, individuals and families seeking behavioral health and social services in Massachusetts are also experiencing formidable barriers. Often people experience "problem pile up," a need for not just one, but many supports to achieve physical and mental wellness. Moreover, most individuals and families are unaware of what resources exist in their communities, what questions to ask, and which resources best fit their needs.

In June 2016, the Massachusetts Health and Hospital Association began convening a diverse group of stakeholders from across the Commonwealth to advance an initiative entitled *Behavioral Health: The Unfinished Agenda for Reform (BHUAR).* Participants organized into three Action Teams including one dedicated to the exploration of a comprehensive database of community-based services for Massachusetts. The purposes of a comprehensive database would be to enhance access to behavioral health and social services for individuals and families, and to serve as a critical tool for care coordinators in identifying and securing services for their patient populations. Care coordinators may be embedded in accountable care organizations, practices, specialty healthcare practices, behavioral health or disability service organizations, or state or county agencies serving individuals with behavioral healthcare and social service needs.

Shortly after its inception, the BHUAR Action Team began to work in close partnership with The Brookline Center for Community Mental Health. Through its work with high-risk patients, The Brookline Center identified a need for a comprehensive database and secured grant funding from the Blue Cross Blue Shield of Massachusetts Foundation to engage in a comprehensive exploration and planning period. The Action Team and The Brookline Center shared knowledge, explored ideas, met with community-based stakeholders, and partnered on the development of shared deliverables, such as this report. Another critical partner has been the Health Policy Commission (HPC). As mandated by Chapter 224, the HPC engaged in activities to explore how a database might support the integration of physical health care, behavioral health care, and social services. In collaboration with other state agencies, the HPC team conducted field research and stakeholder interviews. The HPC continues to participate in interagency efforts to determine what the Commonwealth's role in this arena might be. The three entities continue to share what they are learning and inform one another's efforts.

This report summarizes the findings from the first phase of the BHUAR Action Team's and The Brookline Center's work; the partners conducted an environmental scan of: 1) databases of community-based social and behavioral health services in Massachusetts; and 2) databases in other states that have the potential to come to Massachusetts. The staff team researched a total of 32 databases, which mostly presented as publicly accessible web-based platforms, though some took other formats (e.g., databases used internally by agencies that provide telephonic referral services). A standard methodology was employed to assess the content and the technical functions of each database to identify critical elements and determine where there may be gaps. The full BHUAR Action Team and The Brookline Center, through a series of stakeholder meetings, live demonstrations of databases, conversations with technical experts in social services databases, and intensive dialogue and group discussion, developed a list of recommendations of features and technology for a comprehensive database of community-based services in Massachusetts. The recommendations are based on already established efforts and identified gaps to better meet the needs of individuals, families, and providers throughout the Commonwealth. They are as follows:

Access: Open and inclusive platform

Public-facing platform

Ensure the database is available and free to everyone, including individuals, families, and providers.

Database linkages
Operate in close collaboration with existing databases and services in Massachusetts, and avoid duplication of efforts. Create a "no wrong door" approach to facilitate the connection of users to needed services.

Cultural and linguistic competency
Ensure availability in multiple languages, accessibility for people with disabilities, and a recovery-orientation.

Usability: Helping users get the information they need

User-friendly interface
Adopt a consumer-friendly platform with attention to readability and a straightforward, intuitive design.

Health and social services literacy
Provide health and wellness information such as definitions of terms, tips on how to navigate services, materials on behavioral health conditions, tools to promote recovery, information on consumer rights, etc.

Search engine capacity
Employ a search function such that users can run queries across multiple domains to identify resources that meet their specific needs and preferences. Include interactive maps with pinned resources.

Crowd-sourced navigation tips
Encourage users to enter fact-based, experiential comments and tips on how to access a particular service, with a mechanism for verification by the database administrator.

Community knowledge/social network
Leverage ways to build connections and share knowledge among users, such as listservs and Q&A forums.

Link to help desk/human support
Collaborate with other databases and services that offer opportunity for users to connect with trained resource specialists. Recognize the key role of the "human element" in helping users ask the right questions, identify services that match needs, and navigate complex systems.

Care coordination and management

User customization, personalization
Include an option for users to set-up password-protected accounts to curate personally relevant resources.

Ability to add on care coordination products
Allow customized, care management tools to interface with the publicly available database, so that providers can leverage the high quality, crowd-sourced data to better manage the health of their patient populations.

Capacity for referrals
Ensure capacity for the database to generate referrals; further explore lessons from pilot programs that employ bi-directional referral systems between health care providers and community-based organizations.

Data maintenance and quality

High-quality, comprehensive, up-to-date data
Dedicate significant staff time to regular data updates, responses to user requests and corrections, the verification of crowd-sourced comments and tips, and the addition of new programs in the community.

Taxonomy
Use open access classification systems to optimize users' abilities to retrieve relevant information through targeted searches and maximize integration of heterogenous data sources.

Training and user support
Ensure the database is user-friendly and intuitive, such that individuals and families do not require training to identify the resources they need; offer access to free public training if needed. Offer initial and follow-up trainings and technical assistance to agency care coordinators and care managers, issue notices when updates are introduced, and ensure users have access to 24/7 support.

Analytics

QI and outcomes measurement

Develop capacity to collect and analyze data for: 1) quality improvement (e.g., did the search results yield information the users were looking for); 2) process evaluation (e.g., understanding of users and traffic patterns); and 3) geomapping as a mechanism to shed light on service supply and demand.

During the research phase of the environmental scan, the BHUAR Action Team and The Brookline Center identified a wealth of well-established databases and helplines already in existence in the Commonwealth that are addressing the needs of their user communities, whether defined by service type or geography. Though fragmented, these represent a highly valuable resource of human and intellectual capital. It is strongly recommended that any new efforts prioritize integrating and linking these systems. This will involve both technical solutions (interoperability or metalinks between systems), as well as convening database administrators on a regular basis to share innovative practices, troubleshoot common challenges, and develop referral linkages. It is understood that individuals, families, and providers seek services through a variety of channels, so the system design needs to incorporate a "no wrong door" approach. If individual elements (local databases, help lines) are linked with all the other elements, users will be enabled to identify resources that are most relevant to their needs and in ways (e.g., web-based, telephonic, email) that take into account individual preferences and help seeking styles.

Of note, there are already a handful of databases and services that connect users to individual behavioral health clinicians (e.g., psychiatrists, psychologists, social workers, licensed mental health counselors) in Massachusetts. In addition to concluding that the comprehensive database should exist in close collaboration with these services, the BHUAR Action Team recommends that these services be brought to scale to enhance access to individual behavioral health practitioners in the Commonwealth.

The BHUAR Action Team will share what it has learned and its recommendations on database features and technology widely as a way to encourage new ideas and refine existing recommendations. Given the dynamic nature of both health care reform efforts and technological innovation, the Action Team understands that this is not a static effort. The Action Team and The Brookline Center have already conducted a number of stakeholder interviews and focus groups with care coordinators; this work will continue over the coming months. The purpose of these interviews and focus groups is to test the findings and recommendations from the environmental scan and further engage the end-user community, so that the community drives the technology and not vice versa.

Planning for longer-term sustainability -- including an understanding of upfront and ongoing costs, and identification of funding sources -- is outside the scope of this environmental scan and will be taken up by the Action Team as the final phase of its work. A comprehensive database of community-based services would be a very promising development and an important step forward in improving access to care and enhancing the integration of physical health, behavioral health, and social services. Given the engagement of a large number of stakeholders and policymakers in exploring a comprehensive database for Massachusetts, and the deep bench of local expertise and experience, there is an opportunity of historic proportions to build the next generation of databases of community-based services here in Massachusetts.

II. Background and purpose

Since June 2016, a diverse group of stakeholders from across the Commonwealth has engaged in an initiative called *Behavioral Health: The Unfinished Agenda for Reform (BHUAR)* led by the Massachusetts Health and Hospital Association (MHA). The goal of this initiative is to advance the vision of a strengthened mental health system in the Commonwealth. Out of the group's early efforts came three focus areas: Workforce, Inpatient Capacity and Access, and Community-Based Continuum of Care. As part of the third focus area, an Action Team was created to propose recommendations for a comprehensive database of community-based resources for Massachusetts. This Action Team, chaired by Audrey Shelto of the Blue Cross Blue Shield of Massachusetts Foundation (BCBSMAF), Danna Mauch of the Massachusetts Association for Mental Health (MAMH), and Steve Rosenfeld of the National Alliance for Mental Illness (NAMI) of Massachusetts, comprises various stakeholders working to advance access to behavioral health care in Massachusetts. See Appendix Table 1 for a full list of Action Team participants.

The work of this Action Team consists of four phases:

1. Conducting an inventory of databases of community-based services in Massachusetts and databases across the United States with the potential to scale to Massachusetts; conducting a simultaneous technology environmental scan
2. Conducting stakeholder interviews and focus groups with potential end users of a future database, as well as service providers that would likely be included in the database
3. Defining the scope of the database (e.g., audiences, breadth, depth)
4. Planning for long-term sustainability (e.g., understanding of costs and requirements for development and maintenance)

At the conclusion of this calendar year, the Action Team will draw on the lessons learned through these four phases of work to make recommendations to MHA's broader BHUAR Working Group and the larger community about how to move forward with the development and maintenance of a comprehensive database in 2018 and beyond.

This report summarizes the Action Team's findings from the environmental scan (phase 1 above). The purposes of the environmental scan are: to identify existing databases pertaining to social and behavioral health services in Massachusetts and other states; to understand what elements of these databases seem to be working well, and where there may be gaps; and to formulate early recommendations regarding database features and technology. These findings will inform the subject matter of stakeholder interviews and focus groups (phase 2). Planning for longer-term sustainability is outside the scope of this environmental scan and will be taken up by the Action Team as the final phase of its work.

This environmental scan is a joint effort between the BHUAR Action Team and its valued partner, the Brookline Center for Community Mental Health. The Brookline Center identified a need for a comprehensive database of social services through its *Healthy Lives* program, which provides integrated care to patients with serious mental illness, multiple chronic physical health conditions, and complex social needs. In November 2016, the Brookline Center received a *Special Initiatives* grant from BCBSMAF to engage in a comprehensive exploration and planning period oriented toward a database of social services. A few months later, the BHUAR Action Team launched, and it was quickly decided that the team should include both behavioral health and social services in the scope of its work, as both types of supports are critical to overall health and wellness. Consequently, since its inception the Action Team has worked in close collaboration with the Brookline Center to share knowledge, explore ideas, meet with community-based stakeholders, and partner on the development of shared deliverables, such as this report.

Another critical partner in this work has been the Health Policy Commission (HPC). As mandated by Chapter 224, the HPC has engaged in activities to explore how a database might support the integration of physical health care, behavioral health care, and social services. In collaboration with other state agencies, the HPC team conducted field research and stakeholder interviews. The HPC continues to participate in interagency efforts to determine what the

Commonwealth's role in this arena might be. The three entities have worked hard to share what they are learning and inform one another's efforts.

III. Statement of need

Health and social services systems in Massachusetts are complex. With silos that exist between physical health care, behavioral health care, and social services, individuals, families, and providers are often left scrambling trying to identify and obtain needed services. In addition, individuals with behavioral health conditions must also navigate a society that stigmatizes their illnesses and a health care system that has not yet fully implemented behavioral health parity. Due to these barriers and others, many people go untreated. According to a 2015 survey by the Substance Abuse and Mental Health Services Administration (SAMHSA), nearly half of individuals in Massachusetts who self identified as having a mental illness had received no treatment in the prior year.[1] For substance use, treatment rates are far lower: the same survey found that only 8% of individuals in Massachusetts with alcohol dependence or abuse, and 14% of those with illicit drug dependence or abuse, received treatment in the prior year.

Furthermore, many of these individuals lack adequate access to housing, community supports, and other social services that are essential to recovery and maintenance of good health. In fact, studies have shown that social-environmental factors have a substantially greater impact than medical factors on overall health: the Robert Wood Johnson Foundation County Health Ranking and Roadmaps program estimates that only 20% of a person's health is related to clinical care, while the other 80% is attributed to social, environmental, and behavioral factors.[2,3] Addressing these factors (referred to as "social determinants of health" [SDH]), for example through interventions directed at housing, nutrition, community support, income assistance, and early childhood education, has been shown to successfully reduce medical expenditures.[4] The national focus on SDH has sharpened as insurers shift to value-based contracting models, such as accountable care organizations, which aim to simultaneously address costs, quality, and outcomes. As noted by Taylor et al., "Successful movement forward will require careful and persistent attention toward facilitating collaboration and coordination across the social services and health sectors."[5]

An important step toward breaking down silos across behavioral health care, physical health care, and social services that impact health – i.e., moving toward 'whole-person' care – would be to create a statewide community resource database. A publicly accessible database would help individuals, families, and providers identify and connect with agencies and services that can best address their needs. As health care entities in Massachusetts increasingly adopt value-based payment models and move toward integrated care, such a resource becomes increasingly essential.

IV. Methodology

The environmental scan entailed reviewing existing community resource databases (CRDs), collecting information about each database, and analyzing this information to develop preliminary recommendations. Both national and Massachusetts-focused databases were included. These databases mostly presented as publicly accessible web-based platforms, though some took other formats (e.g., databases used internally by agencies that provide telephonic referral services). To collect accurate and consistent information, the BHUAR Action Team and Brookline Center staff filled out a standardized survey for each database, in some cases distributing the survey to the owners of

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[1] Substance Abuse and Mental Health Services Administration. Behavioral Health Barometer: Massachusetts, 2015. HHS Publication No. SMA–16–Baro–2015–MA. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2015. Retrieved from https://www.samhsa.gov/data/sites/default/files/2015_Massachusetts_BHBarometer.pdf

[2] University of Wisconsin Population Health Institute with support from The Robert Wood Johnson Foundation. County Health Rankings 2017. Available at: http://www.countyhealthrankings.org/our-approach/health-outcomes.

[3] Lee, P., & Paxman, D. (1997). Reinventing public health. Annu Rev Public Health, 18, 1-35. doi: 10.1146/annurev.publhealth.18.1.1

[4] "Health Policy Brief: The Relative Contribution of Multiple Determinants to Health Outcomes," Health Affairs, August 21, 2014. Available at: http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf415185

[5] Taylor, L. et al, *Leveraging Social Determinants of Health: What works?*, BCBSMA Foundation, June 2015. Retrieved from https://bluecrossmafoundation.org/sites/default/files/download/publication/Social_Equity_Report_Final.pdf

the database to complete and fact check. For web-based directories, the staff conducted test searches to assess the platform's usability and the content's accuracy. Whenever possible, the team arranged for a live demonstration of the database's key features and options. In total, 32 databases were included. See Appendix Table 2 for a complete list of the databases reviewed, including their platforms (e.g.,web-based, telephonic), geographic area covered, and types of resources included (e.g., social services, mental health services, substance use disorder services).

V. What is a community resource database?

At its most basic, a community resource database (CRD) is a list of services. CRDs come in many forms: paper, a simple Excel spreadsheet, a locally-hosted database for a single agency, or a web-based information system. Paper and intra-agency spreadsheets have been used for decades, but in recent years, technological developments in cloud-based data systems have fueled rapid growth in online directories. In addition, some CRDs are available via smartphone apps, and many offer mobile-friendly websites.

The services catalogued by a CRD may include but are not limited to health care (both physical and behavioral health), housing, transportation, financial assistance, legal assistance, education, and employment. Some focus on a single type of service while others include a broad variety of services. Many began as local resources within a single agency or community and were subsequently scaled to serve multiple geographies or to include additional services. See Appendix Table 3 for a listing of services included in each of the 32 databases. The categories of mental health services were derived from the INTERFACE Referral Service at William James College's "Glossary of Mental Health Services and Approaches to Treatment."[6] (During the research phase of this work, the Massachusetts Division of Insurance released a compendium of standard definitions for mental health services, which provides a common taxonomy for the Commonwealth.)The categories of substance use disorder services were derived from the American Society of Addiction Medicine's continuum of care.[7] Table 3 was quality checked by two staff members of the BHUAR Action Team, and verified with the administrators of individual databases whenever possible.

Most CRDs have similar data fields for each service or agency listing, including name of program and organization, address, phone number, web address, and hours of operation. Some databases provide more detailed information to help users access services including language availability and insurances accepted. Databases that help users identify and connect to individual behavioral health clinicians also may include fields such as session format (e.g., individual therapy, group therapy, family counseling), treatment orientation (e.g., psychoanalysis, cognitive behavioral therapy), and expertise (e.g., attention-deficit/hyperactivity disorder, addiction). See Appendix Table 4a for examples of fields included in databases of behavioral health services and Table 4b for examples of fields included in databases of social services. These Tables are meant to be illustrative and are not exhaustive lists of fields.

The function of a CRD is equally straightforward – it is a tool for connecting people to the services it lists. This clear purpose informs the key questions that can be used to evaluate a CRD: Is it easy to navigate and intuitive? Is it accessible to diverse users? Is the information accurate and useful? The next section of this report summarizes the key findings and recommendations from the environmental scan, guided by these and other evaluative questions.

VI. Early recommendations regarding features and technology

As a result of the scan, the BHUAR Action Team and the Brookline Center developed a shared list of recommendations regarding features and technology that seem most critical in enhancing the functionality of a database. A description of each recommendation follows; some include articulation of their relevance to the Commonwealth, illustrative examples, as well as challenges and how they might be addressed. See Appendix Table 5 for a complete list of recommendations on features and technology for a comprehensive database.

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[6] "Glossary of Mental Health Services and Approaches to Treatment. INTERFACE Referral Service at William James College. Availablet at: https://interface.williamjames.edu/guide/glossary-mental-health-services-and-approaches-treatment

[7] "What is the ASAM Criteria? Reflecting a Continuum of Care." American Society of Addiction Medicine. Available at: https://www.asam.org/resources/the-asam-criteria/about

A. Access: Open and inclusive platform

Public-facing platform

It is highly recommended that the database be available to everyone, including individuals, families, and providers. In order to enhance access to behavioral health and social services, it makes sense for the data to be available to as many users as possible. Likewise, it is important that the database be available to the public at no cost to avoid financial barriers. Providers might find it useful to have the ability to add on customized care coordination products (see *Care coordination and management*), but these would draw from data in the publicly available database.

Database linkages

During the research phase of the environmental scan, the BHUAR Action Team and The Brookline Center identified a number of databases already in existence in the Commonwealth that are addressing the needs of their user communities, whether defined by service type or geography. Examples include, but are not limited to, the Massachusetts Substance Use Helpline, which consistently received positive reviews from Action Team members, and Behavioral Health Connect (Southcoast Health), which was developed through a very thoughtful and inclusive process involving many regional stakeholders. Many of the services/databases that connect users to individual behavioral health clinicians also fall into this category. They are, in no particular order: INTERFACE Referral Service at William James College, Massachusetts Psychological Association's Find a Psychologist, the National Association of Social Work (NASW) Massachusetts Chapter's Social Work Therapy Referral Service (SWTRS), and the UMass Child Trauma Training Center's Centralized Referral System (LINK-KID). These services all provide personalized, telephonic services for users and have developed extensive knowledge of and relationships with individual clinicians in their databases. Similarly, services/databases like National Alliance on Mental Illness (NAMI) Massachusetts COMPASS offer users the opportunity to connect with peers and family members to better understand the right questions to ask and what services might be most helpful.

It is strongly recommended that a database of comprehensive, community-based resources exist in close collaboration with existing databases and services in Massachusetts. One way to do this is to feature logos and links to other databases and services on the main search page of the proposed, comprehensive database. In this way, the comprehensive database will be a door to many services/databases, so that users can obtain information about resources that are most relevant to their needs and in ways (e.g., web-based, telephonic, email) that take into account individual preferences and help seeking styles. Another idea is to regularly convene various database administrators throughout Massachusetts in a learning community of sorts. Participants can share innovative practices and troubleshoot around common challenges. By developing stronger relationships and greater familiarity with one another's work, database administrators can also agree to refer users to one another as appropriate. As individuals, families, and providers seeking services will do so through a variety of channels, the intent is to create a "no wrong door" approach to facilitate and expedite the connection of users to the services they need.

Cultural and linguistic competency

Given the linguistic and cultural diversity of Massachusetts residents and evidence that racial and ethnic minority populations are more likely to delay or forego seeking behavioral health treatment,[8] it is critical that the database meet the needs of a diverse user population.

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[8] R.C. Kessler et al., "Comorbidity of DSM-III-R Major Depressive Disorder in the General Population: Results from the U.S. National Comorbidity Survey,"*British Journal of Psychiatry Supplement* 30 (1996): 17–30;

L.K. Sussman, L.N. Robins, and F. Earls, "Treatment-Seeking for Depression by Black and White Americans," *Social Science and Medicine* 24, no. 3 (1987): 187–196; and

A.Y. Zhang, L.R. Snowden, and S. Sue, "Differences between Asian and White Americans' Help Seeking and Utilization Patterns in the Los Angeles Area," *Journal of Community Psychology* 26, no. 4 (1998): 317–326.

Many of the national, consumer-facing databases reviewed during the scan offered support in multiple languages. For instance, Network of Care has human-translated documents and videos in 14 languages, and the site can also be translated into 100 languages through Google. Aunt Bertha is fully compliant with Web Content Accessibility Guidelines (WCAG) through level 2AA, meaning that it meets the highest standards of website accessibility for people with disabilities. Specifically, it is navigable by keyboard, understandable by screen reader, and visible to those with low-contrast vision and color blindness, and it contains no elements that might detract from the experiences of users who are deaf or hard of hearing.

Another important requirement is that the database reflect in its presentation and content a recovery orientation. Language can be a very powerful tool in either reinforcing negative stereotypes or promoting strengths-based health and wellness. “The use of language is critical to ensuring a recovery-oriented and person-centered approach. It is important that people are seen first as people and not seen as their illness.”[9] There are numerous recovery-orientated language guides that support the development of materials that are empowering and inspire hope.

B. Usability: Helping users get the information they need

User-friendly interface

“User-friendly” translates to straightforward, intuitive design that aids the user in identifying needs and pinpointing a good resource fit. Southcoast Health’s Behavioral Health Connect is a terrific example. On the main search page, there is an easy-to-use search tool on the left side and a map of Southeastern Massachusetts on the right. The advanced search tools offers just enough options to help users identify resources with some specificity, but not so many that the tool is overwhelming. A search generates a list of results that are also pinned on the regional map. The landing pages for individual services and resources are well designed. They contain an abundance of helpful data, and are laid out such that there is a lot of white space, the information is highly organized, and the language used is clear and concise. The systems that users are trying to navigate are complicated enough themselves; an easy-to-use database platform goes a long way in helping users understand, identify, and connect with the services they need.

Health and social services literacy tools

Providing accurate, easy to understand, public information about health and wellness improves overall health and social services literacy. Examples of different types of health and social services literacy information include definitions of terms, tips on navigating various systems and services, explanations of consumer rights, and descriptions of what to expect when seeking specific services. The INTERFACE Referral Service, for example, offers several guides to help users identify the type of provider, treatment, or resource they may need. The MA Substance Use Helpline provides a definition for every item listed in the dropdown menu of services; users can educate themselves as they search and make sure the terms they select actually correspond to the services they seek.

Network of Care also utilizes health and social services literacy tools to educate users about diagnostic terms, prevalence of conditions, efficacy of common treatments, and more. These resource records are reviewed by medical professionals for accuracy and are clearly and concisely written for a general audience. Within articles and the “symptom checker” search engine, symptoms (like fatigue, lightheadedness, postpartum depression) and other terms one may not be familiar with are hyperlinked to another page on the site that defines the terms in plain language.

Search engine capacity

An effective search engine helps users identify the resources they need from the universe of information included in the comprehensive database. This assumes that users already know what types of services would be the best fit for their needs. Many individuals, families, and even providers might not have a full understanding of the resources

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[9] Taken from Mental Health America, Person-Centered Language on September 5, 2017: http://www.mentalhealthamerica.net/person-centered-language

available to them in community; in other words, "We don't know what we don't know." HelpSteps, a database developed and maintained by The Online Advocate team at Boston Children's Hospital, has adopted an innovative way to address this problem. HelpSteps offers users the opportunity to complete a guided questionnaire on topics including comfort in speaking English, number of children, current living situation, household income, hazards in home (e.g., leaking roof, faulty electrical wiring), concern about food running out, domestic violence, etc. After completion of the survey, HelpSteps offers users a list of services that might be helpful to them. Users have the option to add additional types of services to their search, but this list gives them a starting point. Another database that has the capacity for guided searches is the Massachusetts Substance Use Helpline. Users complete a short, twelve question form and the answers are used to populate the search engine with the correct search terms.

Most databases allow users to directly search for services. The Massachusetts Behavioral Health Partnership's Find a Behavioral Health Provider has a sophisticated search function that includes free text boxes, drop down menus, and checkboxes. Users can search by multiple domains including geography, provider type, provider gender, language, and special interest (e.g., adolescent behavioral disorders, child trauma, transgender issues, etc.). In this way, users can identify resources with a fairly high level of specificity to their individual preferences and needs.

Many times searches yield a long list of candidate agencies, and it can be difficult to know which ones to prioritize. Most often, data is sorted by geography and much time must be taken to review multiple results to determine consumer eligibility, resource availability, and how to actually enroll or obtain services. Another common challenge across many databases is that users often find, after calling, that many resource listings do not actually provide the services they need. When agencies provide a wide variety of services, it is easy to produce an incorrect search result by searching for two terms that may both appear in the resource record, but not together as part of one service (e.g. an agency that provides both residential services and services for adolescents does not necessarily have an adolescent residential program). To address this issue, it's important to employ a taxonomy -- how data is indexed so that it can be logically retrieved -- that is most supportive of the user community (see Taxonomy below).

The next stage of community resource database development will require finding the correct mix of both technological and human solutions in order to help consumers identify needs and prioritize searches. State of art search technology with machine learning, free text searches (like Google), and flexible multi-faceted taxonomies offer a way forward to make the search process more targeted and efficient. In reviewing the capabilities of databases available in the marketplace, selection criteria will include robust taxonomies, analytic capabilities, and linkage structures to facilitate interface with staffed information and referral solutions in the Commonwealth.

Crowd-sourced navigation tips

A few resource directories, such as Network of Care and One Degree, allow users to leave fact-based comments about a particular service and/or tips to facilitate access. Tips could include what documentation to bring to an appointment, what hours or days are best to visit, times when navigators fluent in a language other than English are onsite, or even what entrance of a public building to use. These comments draw from the knowledge base of users of a comprehensive database, and offer information that is both highly useful and potentially time saving. Comments and tips can additionally contribute to the accuracy and comprehensiveness of the information listed in a database.

A few of the community resource databases also provide ways for users to add star ratings; this approach is standard in other consumer-based applications like Yelp and TripAdvisor. While the ability for users to leave fact-based comments and tips was widely embraced, a star rating function was much more controversial. Many stakeholders expressed reservations with star rating systems as the information presented is so subjective. As such, it is not recommended that a database include a rating feature at this time. Instead, the potential for this feature should remain under consideration by agencies, users, and policymakers for subsequent database iterations or updates.

Community of knowledge/social network

Most resource directories have not explored the possibility of building social networks among their users. There is a wealth of knowledge, experience, and wisdom across the individuals who are searching for resources. It is recommended that a database leverage innovative ways of building connections between users, and in doing so, foster a community of behavioral health and social services knowledge. One way to achieve this is to develop a Question & Answer Forum, whereby an individual can post a question and other users can submit answers. Amazon.com, for instance, posts "Consumer questions and answers" for each product it sells. Another model is Trip Advisor's Travel Board. Users can learn from other travelers to get insider tips. On Trip Advisor's Massachusetts Travel Forum, topics include "cheapest way from Logan Airport to Copley," "best/worst seats for concert at TD Garden, and "Mass Pike cashless tolls and rental car." Database administrators, in turn, can cull through questions and topics posted on these types of forums to develop "Frequently Asked Question" resources for users. The goal is to create a community of support, learning, and sharing across users facing similar challenges. The strategy draws on a database's greatest asset -- the real world, practical knowledge and experience of its user community.

Help desk/human support

There are limits to what technology can do. Machine searches work best when hunting simple, highly structured resources (like food pantries) that all provide similar services and differ primarily in one or two variables like location and hours. When searching for highly complex resources, like psychotherapists or legal aid, help desks staffed by trained resource specialists are likely to be the most effective. It would be extraordinarily challenging to develop a computer model that could emulate the work of an experienced help desk specialist who, for instance, matches individuals to clinicians by taking into consideration preferences and criteria such as gender, age, insurance coverage, discipline, location, available hours, and therapeutic orientation.

This is the value that the INTERFACE Referral Service (William James College), Social Work Therapy Referral Service (NASW Massachusetts), Find a Psychologist (Massachusetts Psychological Association) and LINK-KID (UMass Child Trauma Training Center) offer to their users. All of these services maintain internal databases that are not public facing. Users of these services speak to trained resource specialists who complete a comprehensive intake. Referrals are then made, and clinicians are alerted at a minimum; in the case of INTERFACE, clinicians are consulted before a referral is even made. This extra effort ensures a better match and less frustration for the user.

National Alliance on Mental Illness (NAMI) of Massachusetts's COMPASS is another example of a service that offers intensive human support. COMPASS is staffed exclusively by peers and family members, who have been trained and are experienced in asking "the right questions" to help identify what types of behavioral health and social services might be of greatest support to callers. Staff report that it's not unusual for callers to ask for help securing a particular service, when in fact, they would be better served by other types of support. Over time, the nature of calls to COMPASS has intensified; NAMI reports more callers with complex behavioral health and social needs who often need support identifying and connecting to services across multiple state and/or community-based agencies.

All of these help desks offer much more intensive and individualized services than offered by a traditional community resource database. The importance of this human element cannot be underestimated given the challenges associated with navigating these extremely complex systems, particularly in the context of individuals and families struggling with unmet behavioral health and social services needs. As such, it is strongly recommended that human supports exist in close collaboration with a comprehensive, database of community-based services (see Database linkages above). It's clear that this extra level of support can make all of the difference in helping people access services that are the best fit for their needs, and in a timely and efficient manner.

C. Care coordination and management

User customization/personalization

Another important functionality of a database is the option for users to set up their own personalized, password protected account. In this way, users can curate personally relevant resources. These may include organizations, specific services or programs, and/or health and social services literacy materials. Often, platforms allow users to organize these resources into lists so that can be easily retrieved at later dates.

One Degree, for instance, allows users to bookmark both organizations and specific services, and organize these resources into collections. Network of Care allows users to set-up Personalized Health Records (PHR) for themselves, family members, and others they care for. Users can upload information from medical records, store information about organizations and services identified through searches of the directory, and save articles of interest. All information in the PHR is stored on a secure, Verisign-encrypted server that is designed for HIPPA compliance. Users can choose to allow others -- such as family members, trusted caregivers, and lawyers -- to access all or parts of their PHR. The goal is to create a private and secure place to store all of one's medical files and resources of interest, so that they can be conveniently accessed via the web and shared as appropriate to promote enhanced care management.

Ability to add on care management products

Some of the databases also allow for integrated care management modules. In this way, care managers and coordinators are able to draw from all of the information in the publicly available database, and leverage this data to better care for their patients with customized, care management tools. The care management modules include the capacity to track individual patients, view workflows, manage patient panels, and create and share treatment plans. Aunt Bertha, Health Leads, and Healthify, for instance, all offer integrated care management solutions. In addition to the functionalities listed above, their platforms also include features such as reminders and some outcome recording. Network of Care offers a Personal Health Record (PHR) with options for sharing with or reporting to clinical or care management staff.

An assessment of the various care management modules is outside the scope of this environmental scan; these are distinct applications with large numbers of competing solutions currently in the market. However, it is clear that the ability of care management products to interface with the publicly available database is a critical. With the rise of Accountable Care Organizations (ACOs) and Community Partners (CPs) across Massachusetts, this functionality will be critical to their abilities to manage the health of entire patient populations, particularly those at greatest risk for complex social, physical, and behavioral health conditions. Likewise, if care managers and coordinators across the different ACOs and CPs are leveraging the publicly available database, this will also help keep the data as accurate and comprehensive as possible (i.e., by requesting that edits be made to incorrect or out-of-date listings, adding comments and tips to help other users navigate services, etc.) and organize a substantial community of knowledge.

Future capacity for referral management

Some community resource databases have the capacity to generate a referral. This is usually in the form of a printed information sheet, an email, or a text to the individual seeking services, and, in some cases, an email notification to the service provider. Some databases have functionality to track the success of referrals, that is, whether or not the client received services from the provider agency. However, this information is often collected by patient self-report, which is subject to adverse selection and recall bias. Interactive, two-way communication between community resource directories and community agencies would help to enhance the efficiency of the referral process and understanding of outcomes; at the present time, this type of data exchange is in the early stages of development.

One example of a database that employs a referral function is Aunt Bertha. Aunt Bertha allows users to "tell a friend about a program" via email or text. Users simply complete a short form with a customized message; Aunt Bertha will send the message to the "friend" along with a link to the program or organizational listing.

An innovative example of two-way communication for referral management and care coordination is the Massachusetts State Innovation Model (SIM) e-Referral Program. Through a 2013 SIM testing award, the Massachusetts Department of Public Health was able to create an open-source, bi-directional referral system between medical providers and community-based organizations.[10] As a result of this e-Referral Program, clinical sites were able to send referrals from their EMRs to community-based agencies, and who could then act on referrals and send feedback reports. In this way, the e-Referral Program was able to "close the loop" on referrals, enhancing communication between medical and social services providers, and allowing for evaluation of services received. The Commonwealth aligned the e-Referral Program with the Prevention and Wellness Trust Fund (PWTF) established by Chapter 224 of the Acts to 2012, requiring all nine community-based partnerships to establish at least one bi-directional electronic referral partnership. Most PWTF partnerships expressed interest in adding more linkages than required.[11] The experience and lessons learned from these efforts will be important to further more widespread adoption of interactive two-way communication for referral management across the Commonwealth.

D. Data maintenance and quality

Dedicated staff for data acquisition and maintenance

Perhaps one of the most important aspects of a database is the ability to maintain high quality data that is regularly updated. A database can have all the other key pieces of a good tool but if the data is not up-to-date and accurate, none of the other features can be used effectively. In other words, a database is only as good as the data within it.

In order to ensure that a database has the highest quality data, there needs to first be significant staff time dedicated to the process of acquiring data and vetting it. A variety of techniques are used to acquire data initially. One Degee, Health Leads, and Purple Binder all collect paper or electronic directories from local providers when entering a new community, as well as collect online data from publically available sources such as websites and Form 990s. Staff then review the information, verify it with the agencies if possible, and sort the information using their individualized taxonomy. Many effective databases also include the ability to for users to edit pages or suggest edits. At Network of Care and One Degree, staff review user suggestions within 48 hours and post changes as they are verified.

Another potential route to good data is the adoption of an open 'data commons' standard. The Open Referral project is a leader in this arena. Their team has developed a common 'machine language' that any technology can be programmed to understand, which allows any resource database to talk -- or share data in real time -- with any other resource database. People using different community resource databases, regardless of technology or organizational type, can all see and use the same information. Interoperability allows for economies of scale, as the arduous task of acquisition and curation is shared across systems.[12] There is already considerable momentum toward this both in Massachusetts and nationally. The technological hurdles (relating to data classification and taxonomy) are not substantial, but achieving an open standard will require the leadership of policymakers, consumers, and agencies.

After the initial acquisition and vetting of data, there needs to be staff dedicated to data maintenance. Maintaining complete and accurate information is extremely difficult because the service landscape is dynamic. Agencies change over time: programs come and go depending on funding; hours and availability of services often vary from month to month. The success of a referral depends upon these dynamic variables. A data set obtained from annual or

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[10] L. Nasuti L (Office of Statistics and Evaluation, Massachusetts Department of Public Health). "Formalizing Community-Clinical Relationships: e-Referral Program." Presentation to the Public Health Council, March 9, 2015.

[11] Massachusetts Department of Public Health. "Update on the MA SIM e-Referral Program." Presentation to the SIM Stakeholder Meeting, March 16, 2015.

[12] Our Video: Open Referral in Three Minutes. Available at: https://openreferral.org/our-video-open-referral-in-three-minutes/

semiannual queries or interviews quickly becomes obsolete. Further, many small, local agencies do not have a web presence and therefore will not be included in databases that rely on web-scraping strategies. Thus, databases that have dedicated staff that continuously update data, respond to user requests and corrections, and add new resources as they become aware of them are some of the most effective in this area.

Taxonomy

The key to operating and using a database is the ability to sort data. Taxonomy is how data is classified to optimize the ability to index and retrieve information. There are a variety of systems for organizing lists of services into a database. Some databases create their own taxonomy to fit to their needs, such as One Degree. Another that is commonly used is the AIRS (Alliance of Information and Referral Systems) taxonomy, one of the oldest and largest taxonomies. It is used by 211 and Network of Care in many states. This offers a standard list of services that can be used to catalog a wide range of human services. (There are 9,000 items in the list. Like a library catalog, the list is hierarchical with five levels of classification (e.g. Income Security-Employment-Employment Acquisition-Job Banks). Given its size and complexity, most of the community resource databases have created simplified versions of this.

Taxonomy proves to be a critical factor in users' experience. The way that services and agencies are sorted and classified determines what results are generated from user queries. The taxonomy has to be optimized in a way that helps users retrieve information from database searches that is most relevant to meeting their specific needs.

Training and User Support

An ideal database should be user-friendly and easy to navigate. It should be straightforward and intuitive such that users do not require training to identify the resources and supports they need. However, it is recommended that individuals and families have access to free training if needed. Users will inherently have varying levels of health and technological literacy. Training can help break down barriers and help ensure the database is not underutilized.

It is further recommended that every organization using the database, particularly if it is in a case management or care coordination role, complete training for every staff user. One Degree, for example, trains every user of its database when an agency first adopts it and personalizes the training for the specific providers and services.

Ideally, training should cover all the features of the database, how it can interface with care coordination platforms already in existence, how users can be active participants in upkeep of the information, and how the database can be leveraged to make a client's experience simpler. There should be an initial training and subsequent trainings after users have had a chance to use the tool. There should also be follow up training if new features are introduced and there should be 24/7 support for users who have questions about use of the database.

Analytics

The benefit of a comprehensive, freely available database extends beyond the connection of people to services. There is still much to learn about how to address social and behavioral health needs across different geographies and with diverse populations. Gaps exist in knowledge related to interventions and existing literature needs to be strengthened by studies that use more rigorous research methodologies to document impact. A universal database could potentially provide a wealth of data about the social service and behavioral health delivery landscape and the relationship of constituents' needs to the availability of existing resources -- the analysis of which would help inform planning, population health management, and thoughtful allocation of scarce dollars to improve care for all citizens. An application of this is called "geo mapping," whereby data on demand versus the availability of services is overlaid on a map of the Commonwealth to identify areas of the state with the highest unmet needs.

Most databases have some substantial capacity for analysis of users and traffic. This can include aggregated data about user characteristics, types of referrals searched for (i.e., search term frequencies), and, if reported by the user, the success of these referrals (e.g., appointment made, appointment kept). Few of the databases collect personal health information about users. To the best of our knowledge, none of the databases perform follow-up studies to determine if the referral actually resolved the presenting behavioral health or social services related problem or need.

Some databases, like Aunt Bertha, offer analytic reports to participating service providers listed in the database, including number of queries related to the organization's area of service, number of views of the agency's page/information, and number of referrals. Additionally, databases with care management capabilities also allow for analysis related to individual user-groups/workforces. Analytics may include caseloads, wait times, numbers of referrals, and other individualized outcome measures.

One piece of data that is missing in the analytics of most databases is the efficacy and outcomes of searches. There is almost always no information gathered on what happened once a person was referred to a service making it difficult to glean the effectiveness of a service, whether the database effectively described the service and its eligibility criteria, what the experience was like at a certain service provider, or if the results of a search were relevant to a consumer. If a database could gather this type of information, it could use the information to make searches more efficient and effective at connecting consumers to resources that are helpful.

VII. Special consideration: Access to individual behavioral health clinicians

At the outset of this initiative, one issue that the BHUAR Action Team grappled with was whether or not individual behavioral health clinicians should be included in the scope of the comprehensive database of community-based services. As mentioned above, the environmental scan revealed that there are already a number of entities that connect individuals, families, and other providers to solo behavioral health practitioners in Massachusetts. In no particular order, the organizations and services that were explored in greatest depth include: INTERFACE Referral Service at William James College, Massachusetts Psychological Association's Find a Psychologist, the National Association of Social Work (NASW) Massachusetts Chapter's Social Work Therapy Referral Service (SWTRS), and the UMass Child Trauma Training Center's Centralized Referral System (LINK-KID).

Each of these services completes a detailed and time intensive intake for each individual seeking care. Trained staff ask questions about insurance coverage, individual demographics (e.g., age, gender, language), history of behavioral health concerns, treatment preferences, and appointment availability (e.g., evenings, weekends). This information is then used to "match" an individual to one or more clinicians in the organization's database. Over time, staff have developed good relationships with the clinicians in their database and often have a strong working knowledge of different practitioners' specialities and approaches to care. Some staff will even reach out to clinicians in advance to consult on an individual's intake information, make a shared decision about whether the therapeutic relationship might be a good match, and to confirm provider availability. Weeks after individuals receive their clinician matches, some entities will follow-up to check in and see how things are going. If the individual does not think the clinician is a good fit for his/her needs or preferences, staff will continue working with that individual until a successful match is made.

As a number of these services already exist in the Commonwealth and are very experienced, the BHUAR Action Team concluded that these services should exist in close collaboration with the comprehensive database, and have prominent links on the main search page. While beyond the scope of this project, it is additionally recommended that private or public funders invest in these services and bring them to scale to enhance access to solo behavioral health clinicians in the Commonwealth.

VIII. Next steps

It is of tremendous importance to the BHUAR Action Team and The Brookline Center that we use the information gathered in this scan and the momentum garnered in order to move towards adopting a database for the Commonwealth of Massachusetts. It has become evident through this process that there is both a need and a demand for a database that would connect individuals, families, and providers to behavioral health and social services. Following the distribution of this environmental scan, the Action Team will conduct select stakeholder interviews to fill in any gaps in knowledge that we may have missed in this scan. Through these stakeholder interviews, we will test our findings and use the opportunity to engage the end-user community to ensure that the community drives the technology and not vice versa.

The Action Team has already begun to engage in some preliminary brainstorming around sustainability, including better understanding upfront and ongoing costs as well as potential sources of funding. The Action Team would also like to see the formation of an advisory committee that will use the recommendations from this scan to guide further planning and implementation of a community resource database.

Community resource databases are a very promising development and an important step forward in integrating health care and social services. There is potential to meaningfully enhance access to behavioral healthcare and social services for individuals and families, as well as provide a critical tool to care managers and coordinators engaged in healthcare delivery reform efforts. Given the engagement of a large number of advocates and policymakers in exploring a comprehensive database and the deep bench of local clinical and technical expertise, we believe there is an opportunity of historic proportions to build the next generation of databases of community-based services here in Massachusetts.