LAKE COUNTY MENTAL HEALTH COALITION

Data Sharing Project Report

December 11, 2017

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Executive Summary

EXECUTIVE SUMMARY
INTRODUCTION

Lake County, along with the nation and other local communities, is facing a behavioral health[1] crisis that affects individuals, families, friends, neighbors, veterans, employers, schools, hospitals, the criminal justice system, the community, and more.

To address this growing problem and strengthen behavioral health services across the county, Lake County established the Lake County Mental Health Coalition (Coalition) in October 2016. The Coalition is made up of a diverse group of stakeholders investing in Lake County behavioral health, representing County government, hospitals, public health, spiritual/religious care, housing/homeless assistance, law enforcement, justice partners, education, advocacy organizations, community health providers, including behavioral healthcare, and private philanthropic funders. The Coalition established a Charter[2], outlining its aim to prevent and reduce behavioral health illnesses through sharing data and researched-based best practices.

Additionally, case studies have shown that there is a greater chance of success when groups of community-based stakeholders invested in working together on community-level priorities regularly share data and information, coordinate services, and collaboratively organize around outcomes. As a result, the Coalition has initially focused on data sharing and researched-based best practices designed specifically for Lake County to form stronger prevention, build capacity, address gaps, and enhance behavioral health services. To that end, the Coalition commissioned a Data Sharing Project and engaged North Highland to identify data sharing practices and design a future vision for data sharing within Lake County.

The Data Sharing Project included a Current Data Sharing Assessment of Lake County's behavioral health data sharing, a review of existing studies, reports, and programs in the region, as well as identifying available data, missing data, barriers to data sharing, and an analysis of methods to collect transdisciplinary data. Following the Current Data Sharing Assessment, the Data Sharing Project focused on the future vision for data sharing, including identifying the ideal data model, data governance, and action steps to implement.

The Data Sharing Project Report[3] includes this research and the subsequent findings and recommendations, along with "Go First" strategies. The recommendations and Go First strategies are directional in nature and may be implemented as best meets timing and budget considerations. Similar to other comparable community data sharing efforts, the future state vision will take some time to realize, and implementing the Go First strategies will position the Coalition members and stakeholders well to begin sharing data in such a way as to build toward the future state vision.

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[1] Although Coalition documents use the term mental, emotional and behavioral (MEB) health, the term behavioral health is used here and throughout this report to be inclusive of mental health (including MEB as used by the Coalition) and substance abuse conditions and/or treatment and to be proactive and consistent with developing national language pertaining to integrated treatment approaches. Behavioral health may be abbreviated within diagrams throughout the document to "BH." Appendix 7.2 Glossary of Terms contains a listing of terms used throughout this document and Appendix 7.14: Glossary of Acronyms contains a list of the terms used within the report.

[2] Additional information about the Coalition's goals, objectives, and guiding principles is located in *Appendix 7.1 Lake County Mental Health Coalition Charter*.

[3] For the remainder of this report, the term Data Sharing Project will be referring to all tasks, activities and outcomes related to the first phase of the Data Sharing Project. The term data sharing initiative will refer to the overall work of the initiative regardless of the phase of the project. This report is authored by North Highland for the Lake County Mental Health Coalition. The report includes an account of the Data Sharing Project activities, and North Highland's analysis and recommendations that outline how the Coalition and behavioral health community members can advance their data sharing initiative and recognize the benefits of data sharing.

EXECUTIVE SUMMARY
INTRODUCTION

Data Sharing Project Purpose and Report:

The intent of the Data Sharing Project is to support the Lake County behavioral health community's ability to share data for care coordination and the planning and improvement of the behavioral health delivery system. Additionally, the Coalition's goal is to support the Lake County behavioral health system in meeting the behavioral health needs of individuals and families by improving access, responsiveness, and quality of care. The objective is to create an environment in which individuals and families' behavioral health needs are met so they can live the most productive and fulfilling lives they can.

The Data Sharing Project was designed to support the Coalition's goals and objectives and will be implemented in phases. The first phase includes research, a current data sharing assessment, and recommendations that culminate into a future vision, all of which are included in the Data Sharing Report. The second phase entails developing a detailed implementation plan, including a data governance strategy, and implementing data sharing practices.

Data sharing can be difficult, but it is not impossible. To achieve the Coalition's goals and be current with the dynamic local and national landscape, the Lake County behavioral health community needs to begin sharing data. Through research and conversations with comparable communities, it was repeatedly emphasized that these organizations "just got started." They started sharing data incrementally by taking actions like trying out a partnership with another organization, collecting new data, or creating greater awareness of the need to share data.

There have been many incremental activities that support data sharing within Lake County, but never with the direct focus of system-wide data sharing. The ability to get started is influenced by the challenges each organization faces to data sharing as well as technical capabilities and limitations. As each organization has different challenges and capabilities, in order to be able to participate in data sharing, each will need to have individualized paths and starting points. These custom paths do not preclude data sharing activity nor working together towards common goals, rather they enable each organization to contribute at the level they are able to, when they are able to do so.

To "just get started," the Lake County behavioral health community should mobilize on the recommendations in this report, specifically the corresponding Go First strategies, to make progress towards the data sharing vision. The recommendations and Go First Strategies are purposefully directional in nature because how these strategies are operationalized can differ across organizations. As each organization joins in systemic data sharing, the data sharing initiative will grow and evolve. This report should serve as a guide for future actions and to inform future phases of the data sharing initiative, including the implementation plan.

EXECUTIVE SUMMARY
FINDINGS

Data Sharing Project Findings[4]:
The following are the key findings from the research conducted for the Data Sharing Project.

Strengths and weaknesses of the Lake County behavioral health community
A review of past and current initiatives surfaced areas of opportunity and positive activities within the Lake County behavioral health community.

- The available reports lack information on or reference to system-wide service performance measurements for the Lake County behavioral health community. Additionally, there is no documentation of the technologies with which data points are collected and shared by service providers. This information is critical for developing a future data sharing model and for system planning and oversight. Members of the Coalition and Lake County behavioral health community will need to establish agreed upon metrics. This report provides a list of metrics as well as information on the data stored across systems and service providers.

- There are many positive activities that are aligned with the goals of the Data Sharing Project and national trends and several of these activities are listed below. The Lake County behavioral health community should leverage the lessons learned and best practices as it moves forward with the Data Sharing Project.
    - Conducting Mental Health First Aid training;
    - Conducting Crisis Intervention Team (CIT) training for emergency response personnel and sworn police officers;
    - Using trauma-informed approaches, such as facility dogs in the Child Advocacy Center;
    - Implementing A Way Out program that is a cross-system collaboration facilitating access to substance abuse treatment;
    - Facilitating a community-wide health and wellness initiative through Live Well Lake County;
    - Mobilizing care coordination best practices through the Mental Health Collaborative;
    - Including organizations and stakeholders that represent the voice of individuals and families with behavioral health needs;
    - Implementing initiatives that work to identify those with the highest needs and are frequent utilizers of cross-system services (e.g. Top 100 jail utilizers initiative);
    - Mobilizing on several justice initiatives (e.g. programs to transition individuals from jail into the community, Data Driven Justice initiatives and SAMSHA's Sequential Intercept Model, updating paper forms and to electronic documentation, including CIT data);
    - Using ServicePoint as a central repository for various initiatives; and
    - Having industry-specific trade organizations provide educational and advocacy support the development of organizations, such as the Alliance for Human Services.

8

[4]Additional information regarding the findings listed in this section is located in *Section 4 Data Sharing Project Findings.*

EXECUTIVE SUMMARY
FINDINGS

Technology Infrastructure and Data Sharing

- Currently, there is not a technology solution within Lake County that can immediately be used to collect and report information across systems for the Lake County behavioral health community. A model needs to be designed to meet the needs of the Lake County behavioral health community and the organizations participating in the data sharing model.

- Data sharing is primarily in the form of telephone calls or facsimiles, which are not conducive to electronic data sharing. The electronic systems that store behavioral health information were not designed to serve as a mechanism to interact with behavioral health data as a whole. As a future technology solution is designed, it should utilize and leverage the strengths of the existing systems.

- Some organizations, including behavioral health providers, use nonelectronic or less robust technologies, such as spreadsheets, for internal reporting purposes. some providers will need to be on a parallel pathway that includes adding capabilities to collect and share data that likely will result in being on a different timeline for participating in data sharing.

Data Governance

- Within the Lake County behavioral health community, there are a few examples of data collection, analysis, and reporting that utilize some form of data governance. However, there is no current cross-system data governance approach for the Lake County behavioral health community.

- As the community comes together to share data, given the standardization needs and organization-specific compliance requirements, data steward workgroups comprised of representatives from participating organizations are needed and will play a significant role in the development of the future data sharing model.

Data Sharing Agreements

- Although there are some cross-sector data sharing agreements within Lake County (e.g. use of ServicePoint[5]), there are no current written data sharing agreements that would support a sustainable, on-going cross-sector data sharing program.

Data Availability

- The types, amount, format, and sharing of the data currently available in the Lake County behavioral health community is not sufficient to provide the desired information consistent with national best practices and prioritized data identified through this project.

- Although there is some data collected that is consistent with best practices for behavioral health communities, there is a need to standardize the collected data as well as significant opportunity to add additional data within all sectors to support the information needs for planning and oversight purposes.[6]

- There is no system-wide aggregated data available for behavioral health system planning and oversight, such as agreed upon metrics for benchmarking, except for the homeless information available through ServicePoint which provides insights into a social determinant of behavioral health.

9

[5]A copy of the agreement is available in Appendix 7.7 Example Data Sharing Agreements

[6] *Appendix 7.10 Data Matrix – Extended List of Data / Measures* provides an extended list of data points/measures that are used by behavioral health communities and the matrix identifies if the data is collected and/or standardized within the Lake County behavioral health community.

EXECUTIVE SUMMARY
FINDINGS

Barriers to Overcome

The research surfaced legal, technical, and operational barriers to sharing data. However, there were no barriers identified that cannot be addressed through technology, processes, education, or advocacy. It is important to note that some of the barriers will require significant thought and agreement between system partners to address.

To overcome significant barriers, the future data sharing model will need to:
- Address organizations' reporting, data governance, and resource concerns;
- Alleviate the community's challenges of engaging organizations to participate in light of conflicting priorities;
- Support the Lake County behavioral health community in balancing and emphasizing the value of data sharing with the costs of participating; and
- Enable the flexibility to adapt to new strategies as they arise and address changes outside the control of organizations and the Lake County behavioral health community, such as Medicaid or Managed Care Organizations' (MCO) initiatives.

Several laws are cited as barriers which were designed to protect personal identifiable information (PII) and patient health information (PHI) and which present limitations to sharing participant-level data. Legal or policy restrictions to sharing aggregated data would be unique to each organization based on organization-imposed restrictions. These restrictions and the resulting privacy practices at each organization can be influenced by strict laws, such as the Mental Health and Development Disabilities Confidentiality Act (740 ILCS 110) which focuses on the confidentiality of data rather than promoting data sharing. This barrier may be overcome with a significant and concerted effort to amend the additional restrictions beyond HIPAA and further support data sharing or policies/practices.

Health and Human Services

The Lake County behavioral health community should become more engaged in and aligned with national and local initiatives that have parallel objectives and that support the Coalition's vision, goals, and guiding principles. Although there are a few examples within the Lake County behavioral health community of embracing and mobilizing on the changes being realized nationally and forthcoming in the state of Illinois, the Lake County behavioral health community as a collective is not aware of or collectively embracing these opportunities. When compared to other communities nationally and locally, the Lake County behavioral health community has an opportunity to enhance its care delivery continuum and clinical and operational practices. Example improvement activities include implementing health homes, using data and technology to identify those with highest needs for care management, and engaging value-based payment models.

EXECUTIVE SUMMARY
FINDINGS

Information Needed and Desired for a Future Data Sharing Model

- There was a general agreement among stakeholders that the information collected and reported on through a data sharing model should reflect the complexity of the entire cross-system behavioral health collaboration effort. This included data from each of the three sectors: healthcare, justice, and community organizations.
- There were three key themes[7] about needed and desired information that repeatedly surfaced during interviews and discussions. The themes were related to being able to answer the following three questions:
  o Who is in need of or seeking behavioral health care and what services do they need?
  o Are the service needs of those accessing behavioral care being met?
  o Are the services provided impacting outcomes and making a difference for the individuals and families served?
- There was general agreement that any approach for the data sharing project should prioritize data needed to answer the three theme questions. The first two theme questions were seen as the most logical place to start seeking answers and to keep the third question in mind throughout the development of the model to then address it in later stages.
- There are several aspects of data sharing that support answering the three theme questions that also need to be included in a future data sharing model.
  o Aggregate level information can help answer some of the questions posed, but participant level information can provide for more robust analysis.
  o For the first and third theme questions, identifiable participant level information needs to be shared to measure the true need and trends overtime. To link participant information from different systems requires a process by which like participants are matched and deidentified as appropriate.
  o To answer the second question, aggregate level information can be used to assess total service demand on the system. However, access to back-end data, such as time stamps for specific information can help assess the timeliness of services.
  o Reporting capabilities must be in place within the model to extract and display the data.
- Stakeholders agreed that any activity relating to obtaining information would need to include:
  o Sequencing of what information is shared
  o Sequencing of what entities would provide what information
  o Phasing of what technology is used to collect data that would be converted to usable information
- There were virtually no standardized system-level performance metrics published or agreed upon to evaluate the performance of the Lake County behavioral health delivery system (e.g. timeliness of services) and these would need to be established to evaluate system-wide trends over time.

[7] Additional information about the themes and questions is available in *Appendix 7.12 Systemic Questions to Prioritize – Workshop 1* and *Appendix 7.13 System Questions to Prioritize Systemic Questions to Prioritize – Workshop 2*.

EXECUTIVE SUMMARY
DATA SHARING PROJECT VISION AND RECOMMENDATIONS

As a result of connecting all elements of the Data Sharing Project,[8] a Data Sharing Vision was developed with eight recommendations[9] and corresponding sub-recommendations to recognize a future data sharing model for the Lake County behavioral health community.

These recommendations address the short-term and long-term needs of the Coalition in obtaining the necessary information for planning and oversight of the behavioral system, as well as eventually assisting in care coordination and improving care.

The recommendations are directional in nature as they need to be flexible to adapt to changing needs and resources while serving as a guide to move the Lake County behavioral health community forward towards a patient-centered vision. A compass is included throughout the report to emphasize the directional nature of these recommendations.

Arriving at the Data Sharing Vision will take time and be the product of incremental changes. Included in the report are suggested activities, or "Go First Strategies," for the Coalition to mobilize on to "just get started" on each of the eight recommendations.

[8] For the approach, research, and findings that led to the development of the Recommendations, see sections *2. Approach*, *3. Research*, and *4. Data Sharing Project Findings* within the report respectively.
[9] Additional information on each recommendation can be found in *Section 5. Data Sharing Project Recommendations*.