Iowa Department of Human Services

Service System Data & Statistical Information Integration Workgroup Report

December 14, 2012

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Executive Summary

The Service System Data and Statistical Information Integration Workgroup (Data Workgroup) was established by Senate File 525, and was charged to "*develop implementation provisions for an integrated data and statistical information system for mental health, disability services, and substance abuse services. The implementation provisions should incorporate federal data and statistical information requirements.*" The Data Workgroup met five times over a period of eight months and developed the following recommendations to ensure that the data collection and reporting system utilized within the mental health and disability services (MHDS) system is as efficient and effective as possible.

Workgroup Recommendations
1. Entities within the MHDS system will not be required to use the same operational/transactional system.
2. Operational/transactional systems need to have the capability to exchange information. Information that is exchanged needs to be labeled consistently and have the same definition.
3. The central data warehouse should have the capability to match an individual's information from different sources using a unique individual identifier.
4. Privacy and security needs to be maintained consistent with defined roles and responsibilities.
5. The Department should house and manage the data warehouse and be given guidance from key stakeholders.
6. Efforts should be made to integrate the central data warehouse with other electronic data information exchange systems being implemented statewide.
7. An organized, coordinated effort among all MHDS stakeholders should be in place to minimize the cost of operational/transactional systems now and in the future.

Next Steps
The following items were tasks listed in the Data Workgroup charge that went beyond the time and resources allotted; however, workgroup members believe that the recommendations outlined in this report lay out a mechanism to address these tasks in the future:

- Identify federal and state requirements for data collection and output.
- Create a comprehensive list or map of what the integrated system will look like and what it will do.
- Create a list of priorities for developing and rolling out the system.
- Create a recommendations report that includes the specifications for data collection, a timeline and a budget.

Data Workgroup members recommend that these tasks be delegated in an appropriate manner so that the work can be continued. The Department should also examine the changes that could be made by implementing this type of data collection and management system, such as identifying data elements that no longer need to be reported or eliminating some of the irrelevant annual state reports.

It is recommended that the Department establish a budget for how much it will cost to implement this type of data management and data warehouse for the statewide MHDS

system. Furthermore, it is recommended that the Department develops a realistic timeframe to complete these tasks and implement the changes needed to make the centralized data warehouse described in this report operational.

It will also be important for the Department to coordinate the work that has been done in the Data Workgroup with the work detailed in the Outcomes and Performance Measures Committee report. The recommendations from both workgroups should be implemented together so that the statewide data collection and management system is designed in a manner so it supports the assessment of the MHDS system as it was intended by the Outcomes and Performance Measures Committee.

Introduction

The Data Workgroup was established by Senate File (SF) 525, which began the process of redesigning Iowa's MHDS system. This report is based on the activities outlined in SF 525 and SF 2315 that provide guidance for the Data Workgroup.

SF 525 required the workgroup to have representation from the Department of Human Services (Department), the Department of Public Health (DPH) and the Iowa State Association of Counties (ISAC) along with other stakeholders. A complete membership list is included in Appendix B of this report.

The recommendations of the workgroup were founded on ensuring that the data collection and reporting system utilized within the MDHS system is as efficient and effective as possible. With this goal in the forefront, the report provides guidance as the state moves forward with implementing the changes outlined in SF 2315. Workgroup members recognize that this report merely establishes a starting point for successfully implementing an efficient and effective data collection system, and this process will require continued work.

Methodology

The Data Workgroup met five times over a period of eight months. All meetings were open to the public, and all agendas and relevant meeting materials were posted on the MHDS Redesign website prior to meeting (http://www.dhs.state.ia.us/Partners/MHDSRedesign.html).

The group spent much of the first meeting discussing the steps they thought necessary to examine the task at hand. The workgroup determined that it would be necessary for all members to have a basic knowledge of the different data systems that are used in the MHDS system. Workgroup members gave presentations about their respective data systems during the second meeting, and then the last three meetings centered on intense discussions over the factors the members determined would be necessary to address these changes.

Workgroup members have organized their recommendations to address specific changes within the data collection and reporting system to make the system as efficient and effective as possible. Recommendations are listed in the following section and each recommendation is followed by a brief summary of the discussion that led to the decision.

Recommendations

1. **Entities within the MHDS system will not be required to use the same operational/transactional system.**

   Workgroup members acknowledge that there are many different entities[1] within the MHDS system that gather, submit and utilize data. These include such entities as providers, counties and future regions, case management agencies, various state agencies, individuals and funders. Many of these entities have already invested time, money and effort into developing data collection and management systems that work for their business purposes and role within the MHDS system. Accordingly so, these entities

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[1] For the purposes of this report, entities are defined as organizations or participants in the MHDS system.

should not have to abandon their prior efforts to create effective data collection systems that work within their business setting for an entirely new data management system.

The workgroup discussed two structural options for ways that data and information could be exchanged through a data management system. In the first type of data system structure, information is decentralized and exchanged between individual entities in the MHDS system. This means that entities who collect data would store the data within their own data system, and then information would be transmitted directly from entity to entity. The second data system structure is one in which information is sent from each entity to a centralized data warehouse and then the information can be accessed by other entities if they have the appropriate authorization and security clearance.

There are benefits and pitfalls within both types of data information system structures. A system in which information is stored peripherally and transmitted directly between entities would improve privacy and confidentiality within the system, since information would not be shared unless it was necessary. However, a major concern with this type of information sharing system is the lack of uniformity and availability of MHDS data across the state. As previously mentioned, entities have spent a lot of time and money developing data collection and management systems that directly support their individual business practices. The data fields contained in these systems most likely collect some similar information about MHDS individuals; however, individualizing these data fields to each entity's needs can complicate communication and information sharing between systems due to differing data platforms and data field structure. This may not achieve the most efficient and effective system possible, and may continue to hinder the facilitation of treatment, service planning, accountability and care coordination for MHDS individuals.

A data collection system in which data from each entity is transmitted and stored in a centralized data warehouse, facilitates treatment and service planning by ensuring that key information about an individual is stored in one place. The downside to this type of system is that much of the information collected and stored about MHDS individuals is confidential and protected by federal and state privacy and information sharing laws. These laws must be observed within in a data collection and reporting system. A system with a centralized data warehouse will require additional oversight and management to ensure that these regulations are being met and to ensure that the privacy and confidentiality of the individual is maintained.

It was recommended that efforts focus on improving the ability of existing data collection, management and reporting systems to share information more effectively. Instead of focusing efforts to redo the entire data management system, it is recommended that information from entities in the MHDS system be sent to a centralized data warehouse.

Several factors were discussed when making this recommendation. The common theme emerging from this discussion was that operational/transactional systems should not place any undue burden on entities within the MHDS system outside the normal course of business. Workgroup members believe that how a business chooses to operate should determine how it handles its IT system. Consequently, an IT system should support the way the business accomplishes its end goal. Data entry and management should be a normal part of doing business and not a separate task or burden. The workgroup

acknowledges that this type of data collection system will require all entities to transmit the information collected to a central data warehouse where it can be stored and accessed by other entities in the MHDS system. A more detailed conceptual framework describing this process is attached as Appendix C and summarized in the second recommendation.

It is believed that some entities would benefit from eventually moving to a statewide data collection and management system. These entities would most likely be organizations that lack the resources or the technological infrastructure to support modern data collection and warehousing practices. Currently, there is no single system statewide that would meet this need. However, as technology and data collection systems continue to improve, change and modernize, it is believed that entities should be able to buy into an emerging system if the opportunity should arise in the future.

2. **Operational/transactional systems need to have the capability to exchange information. Information that is exchanged needs to be labeled consistently and have the same definition.**

Many of the entities within the MHDS system collect similar, if not the same, information from individuals and family members. This leads to duplication of efforts on behalf of the providers and funders, and places increased burden on individuals, family members and providers to furnish the necessary information. Providers and funders collect many different types of information and it will be essential to identify which entity is the best source of this information to make the data collection process more streamlined and effective. The data collection system would be much more effective if it were possible to spread out data collection efforts across entities and then transmit the data to a centralized data warehouse where it can be stored and accessed by other entities. This type of system will allow entities in the MHDS system to maintain its focus on the normal course of business instead of diverting resources away from their normal course of business towards data collection and management. The flow of the information sharing process within this type of data system and data warehouse is illustrated in Figure 4 of Appendix C of this report and is outlined and explained in detail below[2].

Data Landing Zone
   a) Identify entities that have data that is necessary to collect in the MHDS system, such as:
- MHDS
- Central Data Warehouse (DPH)
- Community Services Network (ISAC)
- Regional Administrators
- Central Point of Coordination Administrators (CPCs)
- Other County Data Collection Systems
- State Facilities
- Providers

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[2] This outline is based on the article: Meta Analytix. (2010). *Information Based Design-Next Generation Data Warehouses for Healthcare providers*. Jacksonville, FL: Majarwitz, J & Nair, K.

- Iowa Medicaid Enterprise (IME)
- Magellan
- Others (as identified)

b) Develop a unique individual identifier that will allow the data warehouse to match data entered by different entities in the MHDS system to one individual. This process is further detailed in the third recommendation.

c) Identify core and extended data elements that should be collected. This data should be collected from the entity with the most current/accurate data.
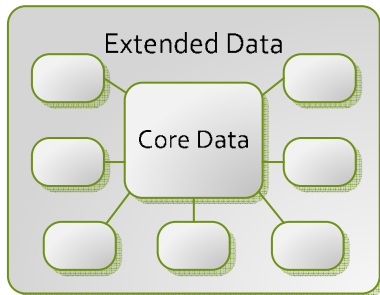

Figure 1: **Core Data and Extended Data Comprising an Integrated Data Model.** *Core data* is the fundamental data that is most essential to know about an individual in the MHDS system. *Extended data* is more specialized data that provides more detailed information about an individual in the MHDS system. Examples are included below.

- Core Data = individual demographics, diagnoses, service eligibility information, etc.
- Extended Data = Detailed service plan, service utilization data, billing information, etc.

d) Determine the format of the data fields collected from entities. Data fields need to be consistent across the MHDS system. Complications with the information linkage and exchange in the current MHDS system stem from the fact that information is not labeled consistently and therefore cannot be easily extracted and exchanged between entities. It is recommended that information in the MHDS data exchange system must be consistent so that the data has the same meaning for each entity.

e) Load data into data warehouse. The workgroup recommends that the information in the MHDS data exchange system be sent to the central data warehouse at minimum on a monthly basis. This will minimize the lag time for reporting information and will ensure that data is reported to the system in a timely manner. Data Workgroup members do acknowledge that this shorter time frame will require entities using the data to have some tolerance for potential changes to data, such as adjustments to claims.

f) Perform data cleansing and standardization as well as validation of data elements for quality assurance. This step should include checking for duplicate data.

Integrated Data Zone
a) Design the integrated data warehouse taking into account the data needed for the primary purposes of the data warehouse. Focus on the data elements that are required for reporting. Leave behind the extra data elements in the data landing zone that have been sourced but do not have requirements held against them.

b) Run reports from this level or continue to the data usability zone.

Data Usability Zone
   a) Identify data marts. A data mart is a subset of the data that is accessed and used to support a specific purpose within the overall system.

   b) Determine how the data will be accessed and by whom. Establish privacy firewalls as necessary. This is further explained in the fourth recommendation.

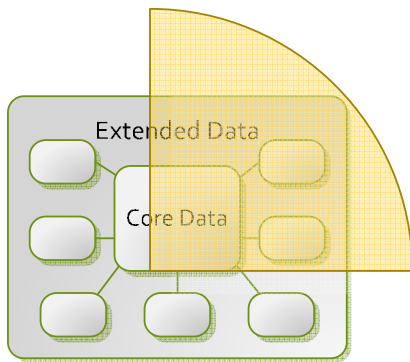   c) Considerations need to be made to performance, availability, security and various other requirements.

Figure 2: A "slice" of the integrated data model that describes a primary business function or data mart (such as service coordination).
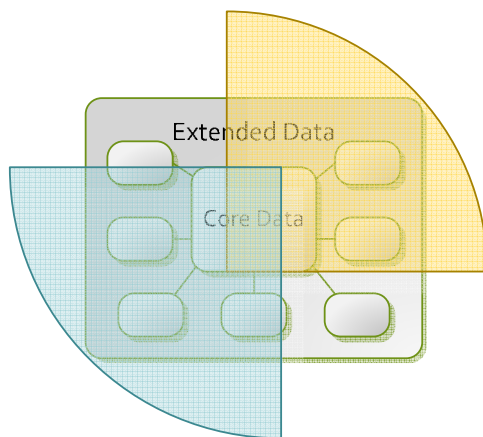

Figure 3: **Data Groupings for Two Business Functions, Showing Their Overlap**
There is the potential that different data marts will overlap in the data warehouse. Handling this overlap is crucial to the sustained success of the data warehouse. The integrated data model needs to keep a singular data model, meaning that there is only one definition for a business entity and attributes are in one and only one place. It is the strict observance of this practice that results in an overall integrated data model. It is important that the business function (or data mart) that is sourced first establishes the common data into an integrated model so that it can be applied towards the second business function, which then only has to add the additional data from sources not yet extracted.

3. **The central data warehouse should have the capability to match an individual's information from different sources using a unique individual identifier.**

    Meeting required privacy standards is important. Entities within the current MHDS system use individual identifiers and many of the entities in the MHDS system have developed an individual identifier to use within their IT system varying from a Medicaid State ID number to a Social Security number. MHDS is required by Iowa Code §225C.6A to use an individual identifier made up of *"…the last four digits of an individual's social security number, the first three letters of the individual's last name, the individual's date of birth, and the individual's gender in an order determined by the department."* The level of specificity in the Iowa Code creates several challenges when trying to identify MHDS individuals. Some pieces of information required in the code can change and the information is insufficient to accurately link unique individuals to other systems. This creates a system with potential for multiple entries in the data warehouse for the same individual simply because of changing pieces of information over time or lack of ability to match.

    It is recommended that Iowa Code §225C.6A be amended to make it more generic. Making the code more generic would allow the Department to implement a unique individual identifier that is identifiable across all data systems. This will greatly reduce duplication of entries in the data warehouse and will allow persons managing the data to use individual characteristics as a way to query information related to the unique individual identifier.

    Because there is not an effective unique individual identifier, the current MHDS data reporting system does not have an efficient way to match individual information from one entity with information from another entity. Many times the information must be re-identified and matched to an individual (using personal information) before it is combined with information from another entity. This process is labor intensive and uses valuable time and resources within the MHDS system and is prone to error.

    It is recommended that in addition to using a more effective unique individual identifier, the centralized data warehouse have a more effective method of matching individual data in a way that maintains privacy. The workgroup examined the efforts surrounding the Iowa Health Information Network (IHIN) as a model for the MHDS system. IHIN will use a two-phase match process to match individual information; this allows individuals to be matched as their data is entered into the data collection system and it allows for large-scale data matching across systems. During the IHIN data matching process, individuals are initially matched across primary data fields. For the IHIN, the primary data fields are: family name, given name, date of birth and gender. If the information entered into the system meets a certain match threshold percentage, the system will identify the information as a match with an already existing individual. If the information entered does not meet this threshold, the system then utilizes the secondary data fields as a way to make a more precise match. The secondary data fields are: Social Security number, Medicare number,

driver's license number, postal code, phone numbers, email address, place of birth, mother's maiden name, death date (if relevant) and multiple birth order (if relevant). If the system is still not able to match this information with an already existing individual, the information is then entered as a new individual who is receiving services.

The workgroup recommends that a similar, yet slightly modified, process be operationalized within the MHDS centralized data warehouse system. It is recommended that an individual's full name and date of birth be used as primary data fields that all entities within the MHDS system should be required to collect from its individuals. The majority of entities within the MHDS system already collect this information so requiring this should not produce any undue burden. It is further recommended that the secondary data fields consist of the client Social Security number, Medicaid state ID, phone number, postal code and email address. Entities within the MHDS system are not consistent with whether or not they currently require this information to be collected from each individual. In keeping consistent with the recommendation that the data collection system should not interrupt normal business practices, it is recommended that entities should not be required to add these secondary data fields in their already existing data systems if the information is not already collected.

Workgroup members note that the type of centralized data repository described in this report assumes that all data is reported at the individual level. However, not all fiscal information reported in the current MHDS system is reported on an individual basis. These services include such things as: crisis services, consultation, mental health education, jail diversion, sheriff costs for transportation and mental health services provided in jail. Currently, some entities report the data relevant to these services in their IT systems and tie all of the financial information to a "dummy" individual. This allows their systems to track the overall service expenses but does not allow this expense to be reported by individual. It is acknowledged that financial reporting may not be the primary purpose of this type of data warehouse; however, it is understood that there will be some loss of information regarding these types of services, if data is reported in the recommended manner.

4. **Privacy and security needs to be maintained consistent with defined roles and responsibilities.**

The workgroup recommends that information collected in the MHDS system be stored so other entities are able to access certain pieces of the information from a central warehouse instead of having to collect it themselves. This warehouse will hold a large amount of personal individual information and workgroup members recognize that not every person who has access to the data warehouse will need to access all of the information collected.

Laws and regulations at both the federal and state level are very clear on requirements for privacy and security standards. The majority of federal regulation in

this area stems from the Health Insurance Portability and Accountability Act (HIPAA) (45 CFR § 160; 45 CFR § 164), with additional restrictions on substance abuse information sharing from the federal government (42 CFR § 2.11). The majority of state level regulation regarding the sharing of mental health information is found in Iowa Code Ch. 228. The different regulations governing the privacy and confidentiality of individual information make the process of maintaining privacy and confidentiality very complex; however, the workgroup expressed very clearly that they expect any statewide data warehouse to meet the requirements outlined in these laws.

At the federal level, HIPAA "…protects all *individually identifiable health information"* held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral. This has been termed "protected health information" and includes any information, including demographic data that relates to:

- The individual's past, present or future physical or mental health or condition;
- The provision of health care to the individual; or
- The past, present, or future payment for the provision of health care to the client, and that identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual.

A major purpose of HIPAA is to define and limit the circumstances in which an individual's protected heath information may be used or disclosed by covered entities. A covered entity may not use or disclose protected health information, except either: (1) as the Privacy Rule from the U.S. Department of Health and Human Services permits or requires; or (2) as the individual who is the subject of the information (or the individual's personal representative) authorizes in writing. Information that has been deidentified does not have any restrictions on the disclosure or use of this information."

Information relating to substance abuse treatment has additional restrictions when shared within a Health Information Organization (HIO), much like a statewide data warehouse. Identifying information may only be made available to an HIO for exchange if a patient signs a consent form authorizing the program to disclose the information to the HIO or if a Qualified Service Organization Agreement (QSOA) is in place between the program and the HIO. Patient consent is also required for information stored in the HIO to be transmitted to another participating provider. These restrictions on disclosure apply to any information disclosed that would identify the person, either directly or indirectly, as having a current or past drug or alcohol problem or as being a patient in a program. An HIO may release demographic information without patient consent only if the demographic information does not reveal any information that would identify the person. These restrictions on HIOs apply to organizations or information exchanges that:

- Provide the infrastructure to exchange patients' health records among entities participating in the HIO network and facilitate the exchange of patients' electronic health information;
- Serve as a data warehouse that holds or stores patient records supplied by entities participating in the HIO network and then makes them available for exchange in response to participants' requests for such records;
- Provide a record locator service for HIO participants and match patients to their health records from different locations; or
- Review and respond to requests for patient records from HIO participating providers.[3]

For mental health treatment, current Iowa state law is much more restrictive than HIPAA. Iowa Code Ch. 228 is very clear that it is necessary to have written authority from an individual to release identifiable information regarding mental health treatment, even for the purposes of clinical treatment. There are no restrictions to sharing aggregated deidentified information but express permission from the individual is needed to share information for the purposes of treatment with another provider.

2012 Iowa Acts, SF 2318: An Act Relating to the Iowa Health Information Network states:

> "Unless otherwise provided in this division, when using the Iowa health information network or a private health information network maintained in this state that compiles with the privacy and security requirements of this chapter for the purposes of patient treatment, a health care professional or a hospital is exempt from any other state law this is more restrictive than the Health Insurance Portability and Accountability Act that would otherwise prevent or hinder the exchange of patient information by the patient's health care professional or hospital."

This provision directly relates to information sharing within the IHIN network; however, the workgroup believes that this is relevant to information sharing within the MHDS system as well. If the provision quoted above can be applied to the MHDS system, it seems to help facilitate exchange of information between providers but not with community planners or regions. The workgroup stressed the importance of making this information available to entities in the MHDS system that administer and coordinate treatment for individuals within the system, and recommend that the provisions in Iowa Code Ch. 228 be expanded to include these entities if it is necessary to do so.

A major part of ensuring that privacy and confidentiality regulations are being met will be to establish appropriate privacy screens by restricting access to information in accordance with the roles that entities play in an individual's care. An important

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[3] Frequently Asked Questions: Applying the Substance Abuse Confidentiality Regulations to Health Information Exchange (HIE). Prepared by the Legal Action Center for the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

factor will be further defining the roles that each entity will play in gathering and submitting information. For example, the information that a provider will need to access about an individual on a regular basis may be somewhat different from information that a region or MHDS will need to access about an individual on a regular basis. Clearly defining the roles that the different entities will play may have will play a major role in enabling the establishment of privacy screens. These privacy screens can be established by programming restrictions on which entities can access information in the data system or by establishing data marts comprised of relevant types of treatment information. It is recommended to use the privacy and security rules that have been implemented for governing the IHIN as a guide for this process.

5. **The Department should house and manage the data warehouse and be given guidance from key stakeholders.**

By establishing a centralized data warehouse, the workgroup realizes that it will be necessary to monitor usage and access. The workgroup recommends that the management and oversight of this data warehouse be implemented hand-in-hand with the design and development of the warehouse to allow for a collaborative process that provides ongoing decision-making, guidance and troubleshooting. The workgroup reached consensus on the factors that will determine how the data warehouse should be monitored:

- Where should the warehouse reside?
- Who should be responsible for it?
- How should it be governed?

It is recommended that the data warehouse reside within the Department and that they be given guidance by key stakeholders in the management of the warehouse. The workgroup members further recommended that an advisory committee be established to provide the Department with guidance on both policy and technical aspects of the system.

Workgroup members recommend that the e-Health Executive Committee and Advisory Council for the IHIN network be used as a model for the advisory committee. The advisory committee should be comprised of a set of stakeholders within the MHDS system. This includes representation from constituents who contribute data, consumer advocate groups, individuals with technical expertise, and legal advisors to ensure that the data warehouse continues to meet privacy laws and any other legal concerns that may arise in the future. These stakeholders can be combined into one committee or can be divided into two groups: one pertaining to technical issues and one related to policy and governing decisions. The workgroup envisions that this advisory committee should work closely with the Department in all aspects of the data warehouse. This includes guidance pertaining to technical issues, data management and utilization, in addition to guidance regarding policy decisions related to the data warehouse.

6. **Efforts should be made to integrate the central data repository with other electronic data information exchange systems being implemented statewide.**

   In Iowa, the e-Health Executive Committee and Advisory Council, overseen by DPH, is building the IHIN with the purpose of making clinical information available between data systems. Membership includes representatives from Wellmark, the University of Iowa, Mercy Hospitals and a legislatively established board. The IHIN will use direct secure messaging (DSM) as a way to directly transmit patient data between enrolled providers. This means that the data within this system is not centrally warehoused; rather, it is stored peripherally in the data system from which it originated. The current focus of the IHIN is on ambulatory health care, but the workgroup members believe that the system has not been designed in a way that would exclude the inclusion of data from the MHDS system.

   Data Workgroup members stress the importance of potentially integrating the two systems in the future as a way to get an overall informational picture for all individuals served in the state. There are several areas where traditional ambulatory healthcare and the MHDS system interact and workgroup members are seeing the integration of these two networks as a way to facilitate interaction between these systems and improve care coordination for individuals served. For example, it will be beneficial to emergency room providers to be able to query a database for information about an individual who visits the emergency room when experiencing a mental health crisis to see if they are already receiving MHDS services. This will assist in providing more effective treatment and will also assist in getting the individual to appropriate follow up services. The workgroup is interested in monitoring the development of the IHIN network and exploring the opportunity for these two systems to work together.

7. **An organized, coordinated effort among all MHDS stakeholders should be in place to minimize the cost of operational/transactional systems now and in the future.**

   Data Workgroup members realize the importance of having an efficient and effective data collection system. However, they also recognize and emphasize that the purpose of redesign was to improve access to a similar array of MHDS services across the state. Workgroup members do not want to lose this focus and recommend that all stakeholders involved in the MHDS system should work to ensure that the costs associated with operational and transactional data systems be minimized to maintain system focus on providing services to individuals. Many factors that minimize the cost of operational and transactional systems have already been discussed in this report. Streamlining data collection efforts and minimizing duplication of data save both time and resources, and consistent data labeling throughout the data warehouse system will assist in this process.

Next Steps

The Data Workgroup accomplished much work throughout the course of their meetings; yet, there is still much work to be done. The following items were tasks listed in the workgroup's charge that went beyond the time and resources allotted; however, members believe that the recommendations already outlined in this report have laid out a mechanism to address these tasks in the future:

- Identify federal and state requirements for data collection and output.
- Create a comprehensive list or map of what the integrated system will look like and what it will do.
- Create a list of priorities for developing and rolling out the system.
- Create a recommendations report that includes the specifications for data collection, a timeline and a budget.

It is recommended that these tasks be delegated in an appropriate manner so that the work can be continued. The Department should also examine the changes that could be made by implementing this type of system. These changes include new efficiencies in the system, such as identifying data elements that no longer need to be reported or eliminating some of the irrelevant annual state reports, since data submitted and reported on a monthly basis would make these reports unnecessary.

The workgroup recommends that the Department establish a budget for how much it will cost to implement this type of data management and data warehouse for the statewide MHDS system. One limitation to the changes recommended is the cost that will be necessary to implement these changes. The data warehouse will require an upfront investment to get the system in place and then will require monetary and personnel resources to maintain the system in the long run. Furthermore, the workgroup recommends that the Department considers a realistic timeframe to complete these tasks and implement the changes needed to make the centralized data warehouse described in this report operational. The Department needs to be able to provide technical assistance to entities as they move through the process of establishing this type of centralized data warehouse.

It will also be important for the Department to coordinate the work that has been done in the Data Workgroup with the work detailed in the Outcomes and Performance Measures Committee report. The recommendations from both workgroups should be implemented together so that the statewide data collection and management system is designed in a manner so it supports the assessment of the MHDS system as it was intended by the Outcomes and Performance Measures Committee.

Appendix A
Service System Data & Statistical
Information Integration Workgroup Charge

Service System Data & Statistical Information Integration Workgroup Charge

Mission
To develop an integrated data and statistical information system for mental health, disability, and substance abuse services

Goals
- The Workgroup should make recommendations for establishing the specifications of electronic, integrated service and funding data, demographic, diagnostic, and statistical information system for all persons receiving publically funded mental health and disability services.
- The new system will:
  - Build on what currently exists.
  - Exchange data within existing systems.
  - Not cause undue burden on consumers or providers.
  - Not collect more data than what is used and use data that is collected.
  - Create a process to ensure data integrity.
  - Be forward thinking and flexible.
  - Determine who will report and define compliance measures.
  - Demonstrate that the public investment made is resulting in positive change.

Tasks
For an effective data and statistical information system to be realized, several tasks will need to be completed.
- Review current data collection tools, resources, reports, and types of data collected from current departments and providers.
- Conduct a gap analysis.
- Research other states' data collection and integration systems and best practices.
- Identify federal and state requirements for data collection and output.
- Identify "points of pain."
- Balance need for standardization with flexibility with how to accomplish the outcome.
- Determine how data will be communicated.
- Consider HIPAA requirements when determining data collected and outcome and performance measures.
- Establish maintenance management.
- Create a comprehensive list or map of what the integrated system will look like and what it will do.
- Create a list of priorities for developing and rolling out the system.
- Work with other groups to develop a set of guidelines for data collection and output.
- Create a recommendations report that includes the specifications for data collection, a timeline, and a budget.

Appendix B
Workgroup Membership List

# Service System Data and Statistical Information Integration Workgroup Members

Chair- Shults, Rick	Department of Human Services- Division of Mental Health and Disability Services	Division Administrator
Co-Chair- Harlow, Robin	Iowa State Association of Counties (ISAC)	Technology Manager
Co-Chair- Stone, Kathy	Iowa Department of Public Health	Division Director
Dowell, Karen	Black Hawk County	Funding Coordinator
Duhn, Sue	Dickinson County	Privacy Officer
Eaton, Jill	Marshall County	Central Point of Coordination Administrator
Gabbert, Kevin	Iowa Department of Public Health IDPH)	Executive Officer 2 - Access to Recovery
Graves, Kris		Mental Health Consumer
Grush, John	Boone County	Central Point of Coordination Administrator
Holmes, Jody	Iowa Medicaid Enterprise (IME)	CORE Unit Manager/HIT Project Director
Jansen, Andrea	Iowa State Association of Counties (ISAC)	Program Support Coordinator
Kaestner, Cindy	Abbe Center for Community Mental Health	Vice President/Executive Director
Maguire, Lonnie	Shelby, Harrison & Monona Counties	Central Point of Coordination Administrator
Moore, Ashley	Iowa State Association of Counties (ISAC)	Program Support Analyst
Novak, Sue	Linn County	Budget Manager Director
Petersen, Dennis	Magellan of Iowa	Operations Director
Preuss, Eric	Iowa Department of Public Health (DPH)	Executive Officer 2 - Iowa Plan
Sample, Joseph	Iowa Department on Aging	Aging and Disability Resource Center Director
Seehase, Susan	Exceptional Persons	Services Director
Walters-Crammond, Karen	Polk County Health Services	Program Planner for Budget

Appendix C
Data Warehouse Conceptual Framework and Outline

Data Warehouse – Planning Broadly & Executing Modularly

Warehouse Environment Overview[4]

Figure 4: Depicts the logical architecture of the major functions and data flow through the data warehouse environment proposed by the Data Workgroup.
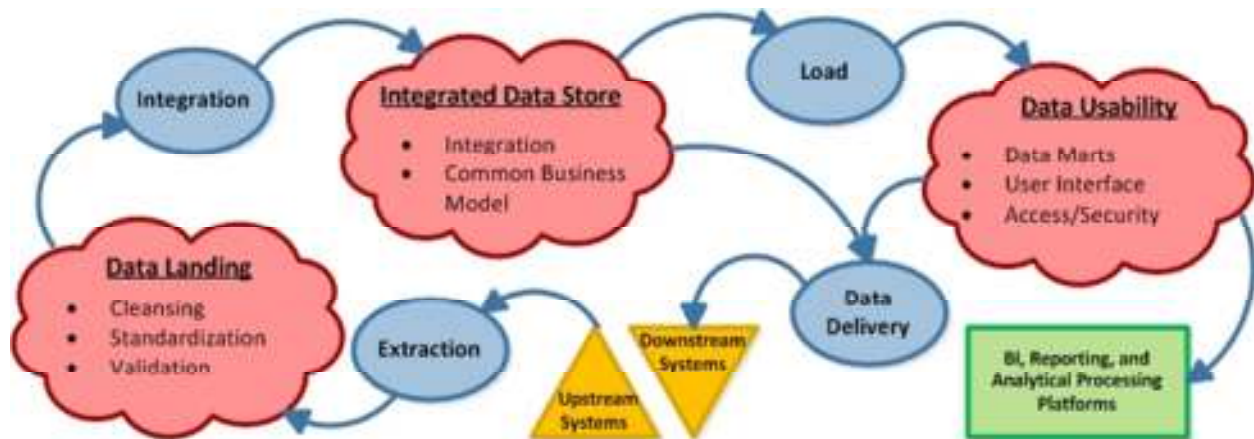
The "cloud" shaped zones *(or major stores of data)* - Common to each zone the *staging area* is used to collect data and perform work in progress. The *publishing area* is used to make data available for later use. In order to reliably connect the cloud shaped zones together, it is important that there is a well-established protocol for what data can be used later on and when this usage can occur. Separation of staging and publishing establishes this definition. Each of the three cloud shaped zones is defined below:

- Data Landing Zone - Point where data from external sources interfaces with the warehouse environment. This is also the place where data cleansing and standardization can be performed as well as validation of data elements for quality assurance.
- Integrated Data Zone - Point where the data from various sources are integrated into a common model that is organized around the overall system data model instead of the data model of each source entity. *Creating a well formed integrated data model is the single most important piece of the data warehouse environment because this will serve as the foundation for how easy or hard it will be to perform the later decision support and analytical functions.*

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[4] This conceptual framework is based on the article: Meta Analytix. (2010). *Information Based Design-Next Generation Data Warehouses for Healthcare providers*. Jacksonville, FL: Majarwitz, J & Nair, K.

- Data Usability Zone - Point of interface with end users. The data is available for access by entities with security permission in order to fulfill decision support and analytical functions. Data can also be extracted for delivery to external entities such as regulatory bodies, business partners, funders, providers, etc.

The Oval Shaped Zones *(or flow of data)* - Represent the extract, transform and load (ETL) processes that are responsible for moving data from one point to another and converting the data into the desired structure. *It is important to distinguish between duplication of data and replication of data.*

- Extraction - Addresses sourcing data from upstream systems, with *major emphasis on acquiring the necessary source system data and incorporating it into the Data Landing Zone.* This can also entail processing to clean up, validate and standardize data elements.
- Integration - Addresses significant transformation to combine the data from separate source systems into a common, integrated data model. *This is typically the most complex and performance sensitive processing within the data warehouse environment.*
- Loading – Addresses the movement of the data from the integrated data source to the data usability zone.
- Delivery - Addresses being able to provide data extracts to downstream targets.

The Integrated Data Model
Being able to plan to work globally and execute modularly is tied to these basic two observations regarding the integrated data model:

1) You do not need to have all of the data in the data warehouse for some of the data to be of use for decision support and analytics. Taking advantage of this observation allows for a project to be executed modularly.
2) As additional data is sourced in the data warehouse environment, it will relate to existing data already in the environment. Taking advantage of this observation results in a better data model, providing consistent quality, high performance and low cost. This requires one to plan globally.