# Guide to DATA-DRIVEN DECISION MAKING



Using Data to Inform Practice and Policy Decisions in Child Welfare Organizations

Guide to Data-Driven Decision Making: Using Data to Inform Practice and Policy Decisions in Child Welfare Organizations
March 2018

This publication was developed by James Bell Associates on behalf of the Children's Bureau, Administration for Children and Families (ACF), U.S. Department of Health and Human Services (HHS), under Contract Number HHSP2332015001331, Order Number HHSP23337001T. The federal Contract Officer's Representative for this contract is Serena Williams, Ph.D. The contents are the sole responsibility of the author and do not necessarily represent the official views or policies of the Children's Bureau, ACF, or HHS.

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For more information about data-driven decision making, please visit the Children's Bureau Web site at www.acf.hhs.gov/cb.





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his guide explains data-driven decision making (DDDM), a process for deciding on a course of action based on data. It describes the requirements of DDDM and the steps for applying DDDM concepts to organizations and service systems.

The guide is designed primarily for child welfare agencies and professionals, but others in human services may also find it useful. It draws on the experiences of state, local, and nonprofit child-serving organizations funded through the Children's Bureau discretionary grant program.1 The guide also follows a fictional organization, Greene County Department of Human Services, as it uses DDDM to improve permanency for children and youth by increasing the number of available foster and adoptive homes (look for the Greene County logo). Finally, case "vignettes" at the end of several chapters illustrate the real-life application of DDDM concepts by current or former Children's Bureau discretionary grantees.

Chapter 1 provides an overview of DDDM. Chapter 2 explains how to formulate questions and develop a plan to test those questions using a theory of change and logic model. Chapters 3–5 cover the steps for implementing DDDM: collecting and analyzing data; communicating results; and refining processes, organizations, or systems. The guide features practical tools that can be adapted and used in various settings. Self-assessment questions are provided to facilitate reflection and help determine readiness to move on to subsequent steps. The appendix includes references, resources, a glossary of terms, and examples of memorandums of understanding, confidentiality agreements, and other materials you can adapt as part of DDDM activities.

For an overview of DDDM, see the accompanying video series.

<sup>&</sup>lt;sup>1</sup> For more information about the program, visit the <u>Children's Bureau Web site</u>.



# 1. Overview of Data-Driven **Decision Making**

DDM is a process for deciding on a course of action based on data. As data systems and technologies have become more accessible and interactive, it has become easier to use data to inform decision making in child welfare and other human services organizations and systems.

### The Process of Data-Driven Decision Making

Through the process of DDDM, data are used to assess, test, and improve a program, activity, or strategy. These activities occur through four iterative stages, which are summarized below and in exhibit 1-1 on the following page.

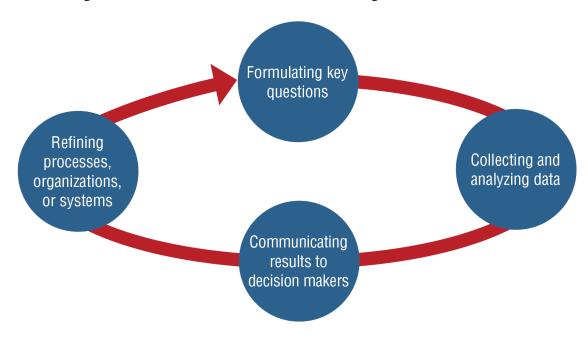
Formulating key questions. The process begins with identifying and clarifying the key questions to be answered for your organization. These questions may address the need to solve a specific problem, learn more about a target population, or improve a program or organizational process.

Collecting and analyzing data. Guided by the key questions, available data are identified and new data are collected as needed. Access to high-quality data is critical.

Communicating results to decision makers. Results are shared with key decision makers within and between levels of the organization or broader service system. Dissemination may take place through various communication channels and formats depending on the information needs of stakeholders.

Refining processes, organizations, or systems. Decision makers use information gathered during the previous stage to assess gaps in services; strengthen the performance of programs, organizations, or systems; and assess the impact of services on outcomes of interest. As more information is collected, the process continues in an iterative manner, with additional evidence producing new insights and subsequent questions for further data collection and analysis.

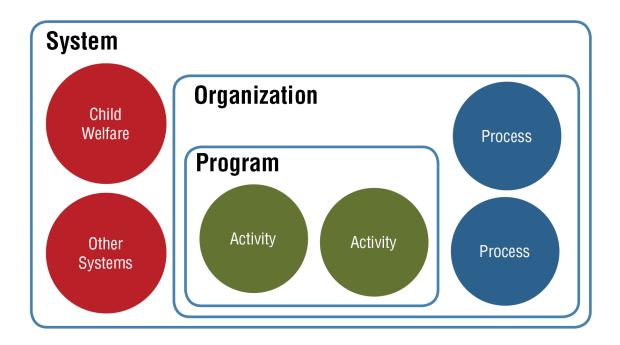
Exhibit 1-1. Stages of the Data-Driven Decision-Making Process



### The Context of Data-Driven Decision Making

DDDM works at the program, organization, or system level (exhibit 1-2). It can be used to improve a single program activity or process, or it can be used to improve the functioning of an entire organization or system.

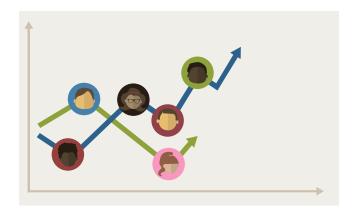
Exhibit 1-2. Data-Driven Decision Making at the Program, Organization, and System Levels



**Program.** The least complex use of DDDM involves a single program activity or process. For example, data could be used to evaluate knowledge gains from staff trainings or the results of efforts to increase the number of family assessments completed by a single department.

**Organization.** The next level of DDDM addresses the overall functioning of an organization. For example, a county that wants to reduce out-of-home placements could integrate Statewide Automated Child Welfare Information System (SACWIS) data with performance data to evaluate the impact of a range of activities on placement rates.

**System.** The highest level of DDDM supports coordinated decisions across organizations and systems. It requires integrated data systems that include information from multiple organizations, often in the interests of effecting collective impact on a common problem or community need. For example, state child welfare, juvenile justice, and mental health systems could develop a trauma-informed service approach for families affected by physical and emotional trauma that includes policy changes and provider strategies across agencies.



### Culture Change and Knowledge Development

DDDM can move an organization toward an evidence-based culture that is focused on the future. It promotes decisions based on data, experimentation, and evidence rather than opinions or intuition. The organization becomes proactive rather than reactive. Rather than simply reporting data for

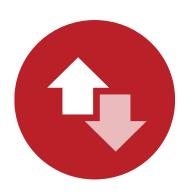
compliance reasons, the organization uses data to drive decisions that improve programs, activities, or strategies. An organizational culture based on DDDM values decisions that can be supported by verifiable data.

The DDDM process transforms data into useable knowledge. Data are raw, unprocessed facts. Through interpretation, provision of relevant context, and identification of correlations, the data can create information that, over time, can be used to test assumptions and solve problems, which in turn results in knowledge that drives decision making. Exhibit 1-3 on the following page provide examples of how child welfare data are transformed into knowledge in the context of case management services designed to improve child behavioral and educational outcomes.

### Exhibit 1-3. Transforming Data into Knowledge

- The child scored X. This is data. Data do not have much meaning without context.
- The child scored X after receiving case management services. This is still data. It provides more context but no interpretation of the data's significance.
- The child scored X before receiving case management services and Y after receiving the services, indicating an improvement in targeted behaviors. This is information. The original data are combined with other data to determine a value in relation to a reference point.
- The child is making progress in her socio-emotional and educational development as evidenced by improvement in targeted behaviors, increased school performance, and successful team meetings with family members. This is knowledge. It combines information from different aspects of the child's life. This knowledge allows the child welfare worker to make decisions about scaling services up or down based on evidence from multiple sources over time. If data are collected for multiple children, services can be evaluated and compared at the organization or system level.

Note: Adapted from Anderson, C. (2015). Creating a data-driven organization. Sebastopol, CA: O'Reilly.



# 2. Formulating Key Questions

The first step in DDDM is to formulate specific key questions. What do you need to know about your clients, capacities, or resources to determine a course of action? For example—

Quantity. How many children entered our child welfare system last year? What proportion of children entering are assessed for mental health needs?

**Distribution.** In which region of our state do we need additional caseworkers?

Duration. How long, on average, do children spend in our system before achieving permanency?

Variance. Which children reunify with their families in less than 6 months? Which children remain in care longer?

To answer these questions, it is imperative to develop a conceptual framework that explains how a program, service, or organizational activity works and to identify relevant and accurate measures of progress and performance. A theory of change and logic model are effective tools for achieving these ends. Although related, they have different goals. A theory of change articulates how and why a proposed service strategy will achieve its long-term goals. The theoretical and logical framework provided by a theory of change is often referred to as the "roadmap" behind a project's goals and implementation. In contrast, a logic model is a visual tool that operationalizes the goals and activities of a program using the evaluation concepts of inputs, activities, outputs, and outcomes. It is accompanied by the data indicators that will be used to measure and track progress.

A theory of change and logic model facilitate the DDDM process in multiple ways:

**Identifying problems and assumptions.** Both tools help stakeholders identify and reach consensus on the issues or root problems DDDM will address. They also bring to light assumptions regarding how programs, organizations, and service systems work, which can be tested and refined as part of ongoing data analysis and evaluation.

Pinpointing strategies and desired outcomes. Along with identifying problems and their underlying assumptions, a theory of change and logic model help stakeholders identify and define the core activities, services, and other features of a program or organization that will be the focus of improvement efforts, along with the desired immediate, intermediate, and long-term outcomes.

**Determining pathways of change.** A theory of change and logic model clarify the expected effects of strategies on subsequent processes and outcomes. Logical gaps or inconsistencies in the direction and strength of these effects can be assessed and adjusted over time.

Laying the groundwork for evaluation. A theory of change and logic model are essential elements of comprehensive, ongoing evaluation. They serve as the basis for formulating research questions and identifying outputs, outcomes, and performance measures that will be recorded and analyzed.

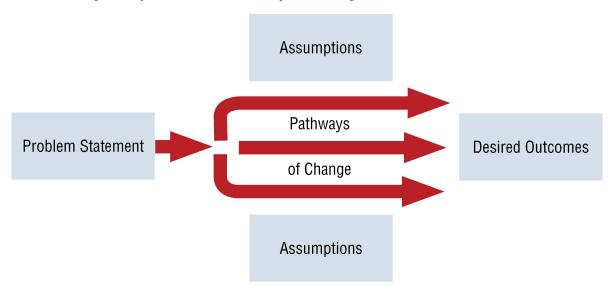
### Theory of Change

A theory of change describes how a course of action will achieve its goals, based on the assumptions of stakeholders such as policy makers, staff, and managers. It includes the following components, as illustrated in exhibit 2-1:

- Problem and assumptions
- Desired outcomes of strategies to address the problem
- Pathways of change between strategies and desired outcomes

Stakeholders should identify assumptions that may require additional evidence to confirm their validity. For example, an assumption underlying the development of a new training program is

Exhibit 2-1. Key Components of a Theory of Change



that the population targeted for training will enroll and attend; this assumption can be tested by collecting and tracking data on enrollment and attendance.

To develop a theory of change, stakeholders should work together to understand the problem, how to address it, and how to measure progress. Development of a theory of change requires a situation analysis, determination of focus and scope, and an outcomes chain (Funnell & Rogers, 2011).

**Situation analysis.** Situation analysis enables program planners to articulate the nature and extent of the problem, identify causes and contributing factors, and consider the direct and indirect consequences of the problem (exhibit 2-2).

Exhibit 2-2. Situation Analysis

Nature and Extent of the Problem	Causes and Contributing Factors	Consequences
What is the problem or issue?	Why does this problem exist?	Why should this be considered a problem?
For whom does this problem exist?	What are its causes?	What are the consequences of this problem for those who are affected by it (directly and indirectly)?
What is the history of this problem?	Are some causes more important or influential than others?	
What projections are there about its future?	What is known about what has and has not been effective in addressing the problem?	

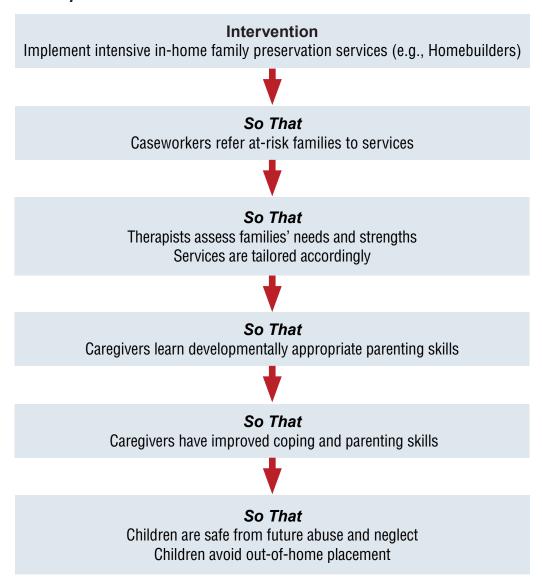
Note: Adapted from Funnell, S. C., & Rogers, P. J. (2011). Purposeful program theory: Effective use of theories of change and logic models. San Francisco, CA: Jossey-Bass.

Focusing and scoping. Stakeholders identify the goals the theory of change will focus on and the goals that are beyond its focus or scope.



**Greene County Department of Human Services** wanted to increase the number of available foster and adoptive homes, with the ultimate long-term goal of increasing permanent placements for children and youth. As part of its theory of change, Greene County outlined an outcomes chain that linked new and expanded recruitment activities with greater inquiries from potential foster parents, which in turn would lead to more families entering and completing the licensing process.

Exhibit 2-3. Sample Outcomes Chain



Outcomes chain. An outcomes chain is a tool for articulating the pathways between activities/ services and expected outcomes, confirming assumptions, and identifying potential gaps. It lists outcomes using a sequence of if-then or so-that statements. Exhibit 2-3 above is an example of an outcomes chain for an intensive in-home family preservation program.

### Logic Model

A logic model translates the theory of change into the "language" of data collection and evaluation. It includes the following components.

**Inputs** are the financial, material, and personnel resources needed to implement a program, along with the population that will be served. Common inputs include funding, office space and equipment, information technology (IT), and trained staff.

Activities are the interventions that will be implemented in response to the problem or need of the target population. Common client-level activities include intake assessments, home visits, and family group decision meetings. Common program-level activities include joint case management, trauma-informed service approaches, and parent partner/mentoring. Internal activities (e.g., staff training) that contribute to the intended outcomes may also be included.

Outputs are the immediate, concrete results of activities, typically expressed in quantifiable terms (e.g., counts or percentages). Examples include number of staff trainings and number of clients completing a parenting class.

Outcomes are the changes expected as a result of the activities. Outcomes may include client outcomes (i.e., child and family outcomes) and program and staff outcomes. Client outcomes are typically categorized in terms of changes in knowledge, skills, or behaviors that lead to longterm positive impacts.

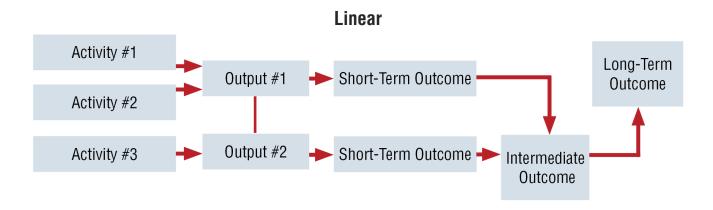
Logic models may be visualized in linear, cyclical, or other formats (exhibit 2-4).

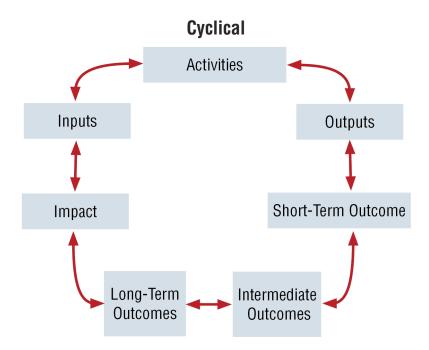
### Choosing Performance Measures or Indicators

Once a coherent logic model is developed, each output and outcome in the model should be paired with an associated performance indicator or measure. The selection of appropriate measures is one of the most important aspects of DDDM, as the usefulness of data for decision making largely depends on the validity of the data and the extent to which they accurately reflect the outputs and outcomes they are meant to represent. As Coster (2013) notes, "The best design and most rigorously executed procedures cannot make up for a poorly chosen measure." Consider the following questions:

- What is the appropriate output or outcome to measure?
- How can the output or outcome be measured?
- Who should or could provide the relevant information?
- When and at what interval should the output or outcome be measured?

Exhibit 2-4. Common Logic Model Formats





When possible, choose measures that are clear and standardized to enable comparisons across time and within and outside your organization or system. Set realistic performance targets or benchmarks by examining trends in the outcomes of interest or reviewing the relevant research literature; targets can also be set later once baseline data are available. State and federal performance monitoring systems (e.g., Adoption and Foster Care Analysis and Reporting System, or AFCARS) can be a source of standardized benchmarks. Examples of benchmarks include "Average time in out-of-home placement will be reduced by 40 percent" and "Eighty percent of families enrolled in parenting education will complete the training."

Exhibit 2-5 offers questions for selecting performance measures. Exhibit 2-6 provides questions for developing a theory of change and logic model.

### Exhibit 2-5. Self-Assessment Questions for Selecting Performance Measures

### What: Specification of the construct

Is there a well-specified explanatory model showing how the intervention links to the outcome of interest?

Have the most relevant dimensions or aspects of the outcome been specified clearly?

### **How: Rationale for selecting the measure**

Does the measurement construct of the instrument match the study's target outcome (as specified by the model)?

Does the instrument address the domains of greatest importance to the study?

Do items in the instrument sample the domain at the desired or appropriate level of specificity?

Are the items well suited to the characteristics of the population?

Does the measurement dimension reflect the type of change expected from the intervention?

Do points on the measurement scale match the degrees of variation expected in the sample?

Are items and scale wording appropriate (i.e., meaningful, understandable) for this population?

Does evidence exist that the measure is sensitive to degrees of change expected in this population?

Does evidence exist supporting the ability of the measure to identify meaningful change?

### Who: Determination of the most appropriate source of outcome information

Do the potential providers of outcome information (e.g. professionals, caregivers) match the qualifications criteria of the instrument being considered?

If someone other than a professional will be the respondent, is it probable that the respondent will be able to complete the assessment (i.e., does s/he have the necessary sensory, literacy, cognitive, physical, and communication abilities)?

Can the measure be adapted if needed to accommodate functional limitations of the respondent? Will the identified respondents be available throughout the study period (i.e., for all measurement points)?

### When: Determination of when outcomes should be measured

Does the length of time between assessments match the time period over which this instrument is likely to show effects?

Can the measure be administered as often as required by the study design?

Note: Adapted from Coster, W. J. (2013). Making the best match: Selecting outcome measures for clinical trials and outcome studies. American Journal of Occupational Therapy, 67, 167–170.

### Exhibit 2-6. Self-Assessment Questions for Developing a Theory of Change and Logic Model

### **Theory of Change**

Has the theory of change been completed?

Is it plausible? Are the underlying assumptions reasonable? Have the barriers and facilitators to success been identified?

Is the logic behind the theory supported?

Were all key stakeholders given an opportunity to provide their perspectives on the theory of change?

### **Logic Model**

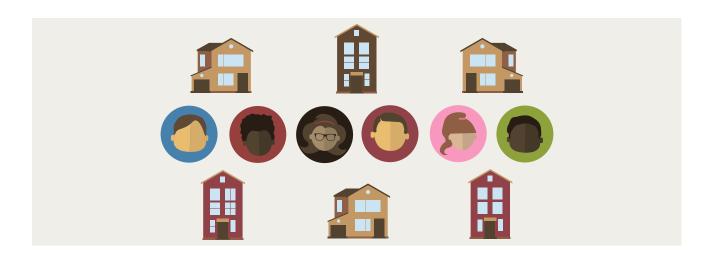
Has the logic model been completed?

Is it plausible? Are the outputs and outcomes feasible to achieve, given the resources? Within what timeframe?

### **Data Selection**

Do the indicators identified in the logic model accurately and reliably inform the performance of the initiative? Can they be relied upon for decision making?

What data sources are available to quantify output and outcome indicators? What tools, instruments, and administrative data sources are available to measure change? Will a tool need to be developed or are standardized tools available? Are they valid and appropriate for the population being served?



### Case Vignette: Developing a Theory of Change and Logic Model

### Dartmouth Trauma Interventions Research Center—Partners for Change

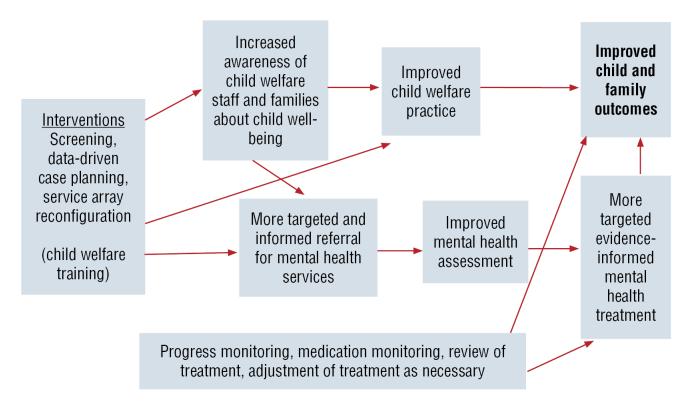
Grantee Cluster: 2012—Initiative to Improve Access to Needs-Driven, Evidence-Based/ Evidence-Informed Mental and Behavioral Health Services in Child Welfare

he Partners for Change project is working with the New Hampshire Department of Children, Youth and Families and its mental health provider partners to create a collaborative trauma-informed child welfare system. The project has successfully implemented universal trauma screenings for all open cases, including 6-month reassessments of symptom and functioning outcomes; trauma-focused, data-driven case planning and referrals based on screening and reassessment data; a service array that includes trauma-focused evidence-based treatment; and ongoing monitoring and analytics through a customized assessment tool integrated with the state child welfare data system.

The Partners for Change team articulated the project's objectives by developing a detailed theory of change and logic models. At the system level, the project's theory of change is that the implementation of strategies to improve screening, assessment, and resource allocation will contribute to improved services for child welfare-involved children. At the *client* level, the theory is that improved interventions and services will lead to better behavioral, health, and well-being outcomes. The theory of change is depicted in exhibit 2-7.

The team expanded on the theory of change by developing treatment- and system-level logic models (see exhibits 2-8 and 2-9 on the following pages). The models introduced evaluation concepts such as inputs (e.g., project stakeholders, funders, data resources), activities (e.g., integrated data systems, collaborative practices), and intended outcomes for children and families. The models also identified contextual factors (e.g., readiness for change) that affect project implementation and facilitate the interpretation of program results for both internal and external users.

Exhibit 2-7. Partners for Change Project: Treatment-Level Theory of Change



The *Partners for Change* team offers several tips for developing a theory of change and logic model:

### **Approach**

- Determine your overarching goals.
- Work backwards to determine what you will need to accomplish your goals.
- Decide who needs to be on your project team.
- Create a working and organizational environment that encourages and supports innovation.

### Training/Buy-In

- Ensure staff understand the importance of actively using data in their work.
- Be specific about the benefits of developing a theory of change and logic model. "Everybody needs to see the value," as one team member stated.

### **Process**

 Recognize that a theory of change and logic model will evolve over time. As one team member noted, "There are a lot of things that you have to learn as you go, and there are a lot of human issues that come into play."

Inputs



Treatment-Level Activities



Treatment-Level Outcomes

#### **Stakeholders**

- Children and families
- DTIRC
- DCYF/district offices
- DJJS/courts
- Clinicians
  - » CMHCs
  - » Private clinics
- Community mental health centers
- Division of Medicaid
- Project advisory board

### **Funding**

- ACF/JBA
- **SAMHSA**
- NH DHHS
- Medicaid

### **Data Resources**

- Bridges (SACWIS)
- Medicaid data
- MCO data
- Chadwick TRST
- **FCARS**
- Postadoption data

### Readiness for Change-Context

- DCYF staff/ leader/ community provider baseline knowledge, attitudes. behaviors, and readiness for change
- Past projects at district offices/ practice

#### Activities

### Training and Support

- Train DCYF leaders/ staff on screening, data-informed case planning, progress monitoring, and medication monitoring
- Train community providers in EBP assessments. prescribing guidelines, and new service array policies
- Train resource parents in trauma

### **Implementation**

- Internal systems/ support set up to assist workers and providers in integrating screening/FU, EBP assessment, and medication monitoring procedures in daily practice
- Hardware and support provided to use online screening/assessment system
- Implement ongoing feedback system between DCYF workers and community providers
- MH providers implement EBPs

### Collaboration

Develop co-training and client-based meetings across DCYF and community practices

### **Ongoing Assessment** of Context

- Caseloads
- Funding of district offices and community-based practices

### Short Term

### Training and Support

- Workers/providers attend and like trainings
- Knowledge and skills of DCYF leaders/ workers increase
- Knowledge and skills of target community providers increase
- Knowledge of resource and adoptive parents increases

### **Implementation**

- DCYF workers and MH providers screen and assess more children for mental health/trauma using evidence-based approaches
- Online screening/ assessment system used by workers and providers
- Non-EBP approaches done less often
- Medications are monitored for all children

### Collaboration

DCYF workers and community providers communicate more frequently

### Context

- Supervisors, workers, and providers committed to maintaining screening, EBP assessment
- Budgets, caseloads, new initiatives organized to maintain screening. EBP assessment, monitoring, and ongoing training of staff and providers

### Long Term

### Staff and Provider Level

- Screening, assessment, and treatment with EBPs become standard practice
- Increase in worker and provider satisfaction

### Child and Family Level

- Increased permanency
- Increased child/family satisfaction
- Child mental health improves
- No red flag psychotropic prescription patterns for children

### Collaboration

- Screening/assessment results documented in/ used for case plans
- Increased levels of collaboration between workers and providers

### Context

- Decreased leader/staff/ provider turnover
- Atmosphere for change at practice/ provider level improves (e.g., leadership, worker commitment to continual improvement)

### **Impact**

- Child well-being improves
- Family well-being improves

### Ongoing Evaluation of Implementation, Costs, and Outcomes

Major Goal: Improve the social-emotional well-being and developmentally appropriate functioning of children and families served by NH DCYF, and optimize DCYF's effectiveness in meeting the individual mental and behavioral needs of the families it serves.

Inputs



System-Level Activities



**System-Level Outcomes** 

### **Stakeholders**

- Children and families
- DTIRC
- DCYF/district offices
- DJJS/courts
- Clinicians
  - » CMHCs
  - » Private clinics
- Community mental health centers
- Division of Medicaid
- Project advisory board

### **Funding**

- ACF/JBA
- SAMHSA
- NH DHHS

### **Data Resources**

- Bridges (SACWIS)
- Medicaid data
- MCO data
- Chadwick TRST

### Readiness for Change Context (baseline)

- Existing policies, procedures, service linkages, collaboration
- · Past change efforts
- Elements to support systemlevel change

### **Activities**

### Tools, Policies, and Procedures

- Select screening and EBP assessment tools
- Develop policies and procedures for implementing tools
- Develop procedures for data-informed case planning, monitoring, and safe prescribing

### Service Array Reconfiguration

- Analyze current service array
- Codevelop new configuration
- Develop policies and procedures to support new configuration

### **Training and Support**

- Codevelop training with DCYF and communitybased providers; start with test sites → full launch
- Codevelop online system to support screening, case planning
- Finalize training curriculum and implementation support
- Provide training to all stakeholders

### Collaboration

- Meetings/communication: DCYF, Dartmouth, community providers
- Communication with other grantees

### Ongoing Context Assessment

- Other policy changes/ mandates
- Leadership/staff involvement and turn over
- Competing initiatives
- Overall state funding

### **Short Term**

### Policies and Procedures in Place

- Policy for screening (timing, responsible party)
- Policy and/or procedure for referrals and followup screening and assessments
- Treatment procedures, including communication between DCYF and community providers
- Policy and procedure for psychotropic medication monitoring
- Documentation/ reporting and tracking procedures

### Service Array Reconfigured

- Referral systems in place
- Followup systems in place

#### Collaboration

- Trust/partnership increases between DCYF and Dartmouth, and between DCYF and community providers
- Ongoing participation by all partners in meetings, communications, and decisions

### Context

- Leaders remain committed
- Impact of other policy changes/priorities is considered
- Changes in how services are funded/ sustained are considered

### Long Term

### Policies and Procedures Refined and Sustained

- Relevant screening and followup
- Screening tool transitioned to DCYF Bridges (SACWIS/ CCWIS)

### Service Array Reconfigured

- EBP treatment systemwide
- Feedback loops/ tracking mechanisms between DCYF and community providers
- EBPs specified in provider contracts

### **Collaboration**

- Continued partnership between DCYF, Dartmouth, and community providers
- New and/or expanded initiatives

#### Context

- System-level changes sustained and enhanced
- Budget decisions aligned to support ongoing screening, EBP treatment, collaboration

### **Impact**

- Child well-being improves
- Family well-being improves
- Cost-effectiveness of services improves

### Ongoing Evaluation of Implementation, Costs, and Outcomes

**Major Goal:** Improve the social-emotional well-being and developmentally appropriate functioning of children and families served by NH DCYF, and optimize DCYF's effectiveness in meeting the individual mental and behavioral needs of the families it serves.



# 3. Collecting and Analyzing Data

Jour theory of change and logic model, as described in the previous chapter, will form the foundation for your data collection and analysis plan. Begin by assessing your data requirements and considering what data will be meaningful and informative for your organization and its stakeholders. Initial questions may include the following:

- What data will let you know how you are doing?
- What data are most relevant and available?
- What categories of data do you need (e.g., demographic data, service data, performance) data)?
- What indicators will you use to assess progress and change?

### **Data Quality**

The key ingredient to DDDM is high-quality data. The data must be accurate, complete, timely, and actionable.

Accurate. Data collection tools such as surveys should provide accurate and reliable measures of change in knowledge, attitudes, behavior, or other outcomes of interest. When possible, use tools that are grounded in the research literature and have proven validity and reliability.<sup>2</sup>

**Complete.** The data should be complete, well defined, and easily identified.

**Timely.** The data should be accessible and compatible across data systems so multiple users can readily view and use them.

**Actionable.** The data should be actionable so the desired outcomes can be achieved. Establish fidelity metrics to ensure that strategies are implemented as intended and to help identify the need for course corrections to improve implementation.

<sup>&</sup>lt;sup>2</sup> See the glossary for definitions of validity, reliability, and other research and evaluation terms used in this guide.



### Data Infrastructure

Assess your data staffing and systems and determine whether any improvements are necessary to support DDDM. Consider the following.

**Build a data team.** The data team works with managers and frontline staff to identify information needs, interpret data, and answer

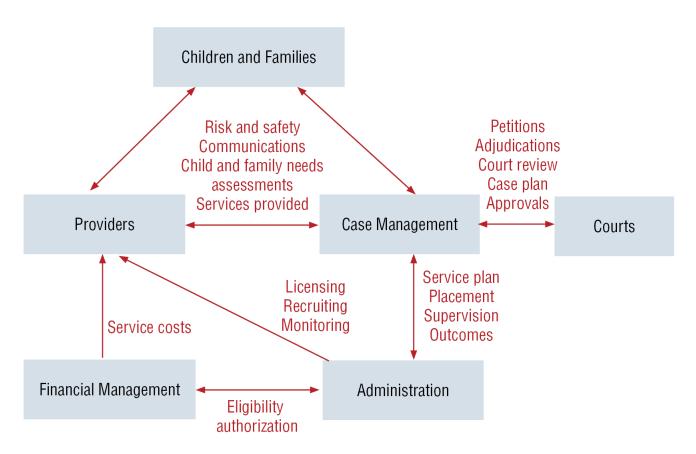
key questions. Hire or designate staff or consultants that match your organization's capacity and needs. Small organizations may only have a data analyst, while large organizations may have a large team. However, any organization can engage in data collection and analysis with appropriate planning, training, and resources. The data team may include—

- A data analyst who collects and enters data, manages databases, completes basic analyses, and conducts monitoring and reporting tasks.
- An IT or computer system specialist who designs, maintains, and modifies the data system.
- An evaluator who has a master's or doctoral degree in a social science, statistics, education, social work, or a related field. This person should be proficient in implementing applied research designs and methodologies, developing logic models and identifying appropriate outputs and outcomes, creating surveys or identifying appropriate standardized assessment instruments, preparing data, and conducting quantitative and qualitative data analysis. Other helpful experience includes community engagement, development and implementation of programs, and cost analysis.
- A frontline staff member or supervisor who can provide important background information to interpret data and place it in its appropriate context. This person can also offer suggestions for making data more understandable and useful, and serve as a liaison between the data team and program staff to foster greater buy-in to the regular use of data. Frontline staff members and supervisors are often "super users" of data who, while not data analysts or IT specialists, have a firm grasp of IT, can perform basic to intermediate data analysis, and are comfortable with interpreting and discussing data output.

Depending on your organization's structure and resources, other data team members may include a **financial specialist** to determine program and organizational costs and work with an evaluator to implement cost studies, and a data visualization specialist to create graphs, charts, reports, and other products that are visually appealing, easy to understand, and useful to child welfare audiences.

Create a data flow chart. The chart should visualize the key stakeholders, data to be collected and shared, and data needed to perform staff roles. For example, frontline staff may need data for each child, while administrative or supervisory staff may need aggregated child data and staff performance data. Exhibit 3-1 provides an example of a data flow chart created for a child welfare organization. The red text indicates types of data, and the blue boxes identify groups of data users. The arrows represent the flow of data being shared between and among those groups.

Exhibit 3-1. Sample Data Flow Chart



Research data systems. Look for a data system that can be joined with other databases, easily accessed by multiple users, and searched using ad hoc data queries. Consider available software packages or cloud-based services that can be used to collect, store, and manage data while meeting federal child welfare information system requirements (if applicable). Also consider systems that have built-in functionality to generate reports, which will increase data accessibility and use by frontline and supervisory staff. Many of these packages and services include mobile data entry and information access, reduce documentation time and data entry error, and provide real-time case updates across staff roles. Cost may be a concern; however, software or services may often be tailored and scaled to fit organizational needs and resources. Some information needs can be met using off-the-shelf products such as Microsoft Excel or Access. See appendix A for resources.



The **Greene County** implementation and data support teams worked together to create a data collection process that included a simple spreadsheet to collect and track data on recruitment activities by type, number of potential resource families who inquired about foster care, and characteristics of these families. This allowed them to continually monitor the relative success of the recruitment activities.

The implementation team reviewed the numbers in monthly meetings and decided to expand the most successful recruitment activities. The implementation team worked with the data support team to develop a dashboard that aggregated their data from their spreadsheets into visual charts. They also modified the data system to enter additional data on families as they moved through the licensing process. These data included the percentage of families who attended informational meetings, completed training, and initiated and completed the process.

**Establish a process to share data.** DDDM is most effective when data are transformed into real-time information that is shared with staff, managers, and leadership to inform decision making and practice. This is discussed in detail in chapter 4.



### **Data Collection**

### **Primary Data**

Primary data are quantitative or qualitative data that are directly observed or collected from a population, staff, or system. Quantitative data are often collected through surveys, standardized instruments, and assessment forms that have been developed by third

parties with specialized clinical training and/or academic experience. These tools can quantify a range of outcomes in mental health, substance use, childhood development, parenting skills, and maltreatment risk. They can also quantify organizational or system-level outcomes such as collaboration efforts among stakeholders or effective leadership. Standardized tools are generally preferred to "home grown" tools, as they have a uniform set of questions and administration procedures, have been normed against one or more populations to determine the normal range of responses, and have been evaluated for statistical validity and reliability.

The drawbacks of using standardized instruments include their narrow applicability to certain populations or programs, the costs often associated with acquiring them, and the specialized training sometimes needed to administer them. Standardized instruments can sometimes be adapted or tailored, and it may be possible to use only the subscales or items that are

most relevant and appropriate for a certain population or program. However, changes could undermine the tool's validity and reliability, so consult the tool's developer before making changes. Resources for identifying and assessing a range of standardized data collection tools can be found in appendix A.

Additional factors to consider when collecting primary data include—

Minimizing error. Data collection and entry should be based on clear protocols and ongoing training and monitoring. It should also be integrated into everyday work routines. For example, where possible, data should be entered directly into the data system rather than recorded on paper and then entered into the system later.

Establishing a baseline. A baseline documents the status of the system, service, or process at the outset of quality improvement efforts. This provides a point of reference for recording progress and change.

Examples of primary data sources are provided in exhibit 3-2.

### Exhibit 3-2. Examples of Primary Data Sources

### **Primary Data Sources**

Standardized assessment instruments

Surveys

Meeting notes

Case observations

Case studies

Interviews

Focus groups

Chart reviews

### Secondary Data

Secondary data are collected by someone other than the user of those data. In child welfare, secondary data typically come from administrative data systems maintained by local, state, or tribal human service agencies (e.g., Comprehensive Child Welfare Information System [CCWIS], Tribal Automated Child Welfare Information System [TACWIS]). These systems are populated and accessed by a range of users—including caseworkers, supervisors, managers, program administrators, and evaluators—and typically include demographic data, case records, and sensitive information such as maltreatment reports and entries into out-of-home placement. Similar kinds of data are available in information systems maintained by other service sectors, such as mental health, the courts, and school districts. Examples of common secondary data sources, along with links to online information resources, are provided in exhibit 3-3.

### Exhibit 3-3. Examples of Secondary Data Sources

### **Secondary Data Sources**

Comprehensive Child Welfare Information Systems

Adoption and Foster Care Analysis and Reporting System

National Child Abuse and Neglect Data System

National Survey of Child and Adolescent Well-Being

National Youth in Transition Database

National Data Archive on Child Abuse and Neglect

National Survey of Adoptive Parents

National Survey of Children in Nonparental Care

American Community Survey

National Survey of Children's Health

KIDS COUNT

Temporary Assistance for Needy Families Data

Utilization review reports

Court records

State and local mental health records

Medical records

Juvenile justice records

### **Data Sharing**

Data sharing has benefits at both the program and client levels.

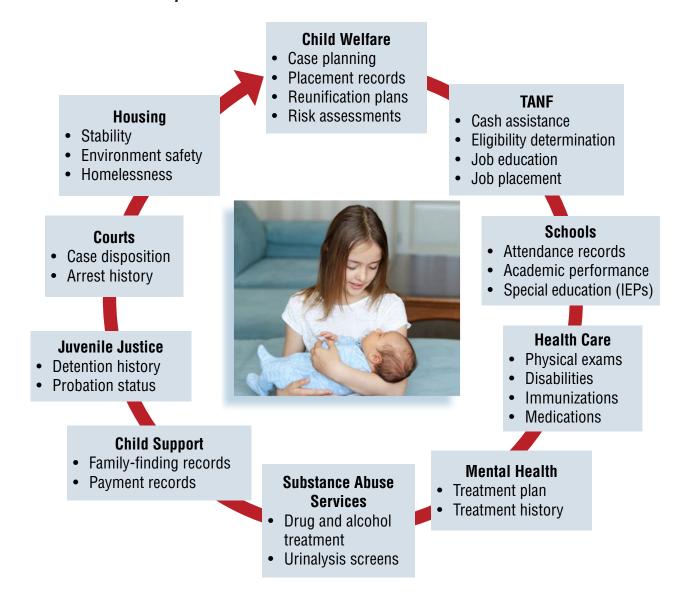
**Program level.** Data sharing helps staff and providers understand clients' needs and contributes to performance measurement, monitoring of client progress and outcomes, and continuous quality improvement (CQI).

Client level. Child welfare-involved children and families have complex needs and must navigate multiple systems (see exhibit 3-4). Data sharing across systems makes things easier for families and supports appropriate, coordinated services and improved outcomes.

### Data Sharing Agreements

Accessing data from administrative and other data sources can be a lengthy process. Time and resources are required to contact the agencies responsible for maintaining the data, and arrangements must typically be negotiated regarding the data that will be shared. Provisions for data sharing between departments and organizations can be documented in existing memorandums of understanding or agreement (MOU/MOA) or tailored data sharing agreements. These agreements, described in more detail on the following page, ensure that information is exchanged in a secure and responsible manner. They address client privacy, confidentiality, data security, and measures for protecting both the clients and the participating organizations. Take

### Exhibit 3-4. Data Requirements in Child Welfare



steps to secure these agreements as soon as possible to ensure that data are available to inform program implementation, outcomes, and ongoing performance.

**MOU/MOA.** An MOU or MOA states the responsibilities and requirements of one or more organizations regarding a policy, program, or initiative. A new or existing MOU/MOA can be expanded to cover information sharing. Key content may include—

- Type(s) of data to be shared (e.g., placement status, substance abuse screens)
- Format in which data will be provided (e.g., aggregated or case level; electronic or paper; intake, screening/assessment, or case history records)
- Respective roles and responsibilities of individuals who will transfer and receive the data
- Frequency of data provision

- Access provisions and restrictions
- Confidentiality requirements

Confidentiality/data security agreement. Unless an MOU/MOA has an extensive section addressing data security, a confidentiality/data security agreement between agencies is also typically developed. This agreement ensures that whoever receives the data handles it in a confidential manner and has the capabilities to keep the data secure. Key content may include—

- Names of the organizations entering the agreement
- Personnel and affiliates who will be responsible for maintaining, securing, accessing, or receiving the data
- Purpose of sharing the data
- Data system and security requirements
- Confidentiality requirements and processes for reporting and addressing breach of confidentiality or data security
- Period of agreement and terms under which agreement can be terminated
- Measures (technology and practices) taken to keep data secure

Client privacy/release of information form. This form advises clients of the circumstances under which their personal information may be shared and obtains their permission to do so. Key content may include—

- Statement of client's rights to privacy and conditions under which information may be shared
- Period during which the authorization will be in effect
- Client's rights to withdraw authorization
- Client signature

See appendix C for examples.

### **Data Analysis**

### Data Cleaning

The data team should clean the data prior to analysis to ensure quality and accuracy. Data cleaning involves identifying and addressing missing and duplicate data, errors, and outliers. The steps include—

- Creating and maintaining a codebook and documenting any changes to the dataset
- Graphing the data
- Running frequency distributions and exploratory descriptive analysis
- Identifying missing data and outliers
- Recoding or transforming variables as needed
- Determining whether the data meet the assumptions for planned inferential analyses. Assumptions may include linearity, normality, independence of observations, homogeneity of variance, etc., depending on the type of analysis.

Data cleaning can be the most time-consuming part of the data analysis process. Adhering to protocols, training, and monitoring for data entry and collection, as discussed earlier, will minimize the time needed for data cleaning. See appendix A for resources.

### Quantitative Analysis

Quantitative analysis refers to a range of mathematical and statistical methods for studying, measuring, and predicting changes in people, programs, organizations, or larger systems; the key ingredient for all quantitative methods is data expressed in numbers. Quantitative methods generally fall into the two broad categories of descriptive analysis and inferential analysis.

**Descriptive analysis.** Descriptive analysis quantifies data in a basic but meaningful way and can often provide much of the necessary information for effective organizational decision making. It can provide insight into an organization's day-to-day functioning by highlighting needed adjustments. For example, you may calculate the number of clients who received a particular service or the number and percentage of staff who completed a training. Descriptive analyses often summarize information in a data dashboard or spreadsheet to facilitate quick interpretation and decision making. The main types of descriptive analysis include—

 Counts (e.g., the total number of children enrolled in a program, services offered, or assessments completed)

- Percentages (e.g., total number of children enrolled in a program compared to all children in the organization's caseload)
- Mean, median, and mode (e.g., a child's mean score on a child welfare assessment, which can then be compared against the mean score for a group of children locally or nationally)

Inferential analysis. Inferential analysis identifies reasons for the patterns you see in the descriptive data. It can provide deeper insights into whether you are achieving your desired outcomes and whether specific interventions may be making a difference. The main types of inferential analysis include—

- Statistical modeling, which tests hypotheses using existing data (e.g., regression, structural equation modeling, multilevel linear modeling)
- Trend analysis, which examines the statistical significance of changes over time (e.g., survival analysis, time-series designs)
- Comparative analysis, which compares two or more similar things (e.g., t-tests, multilevel linear modeling, analysis of variance or ANOVA)

### Qualitative Analysis

Qualitative analysis looks beyond numerical data and puts a human face on findings. It enriches our understanding of how children and families experience child welfare organizations and interventions. Contrary to popular belief, qualitative methods are as rigorous and "scientific"



**Greene County** used descriptive analysis to track efforts to recruit potential foster parents, and inferential analysis to link the number of licensed resource families and their family characteristics with permanency data stored in its child welfare information system.

Members of the implementation team noticed a pattern. A large percentage of families who started the licensing process never completed it. Further investigation showed that the licensing process took over 6 months to complete.

Staff conducted brief phone surveys with recently licensed foster families, in which participants expressed challenges completing the necessary paperwork and scheduling appointments with licensing staff. Licensing staff agreed that the paperwork process was inefficient, and they confirmed that an influx of families had created delays.

as quantitative methods—the primary difference is in the types of research questions they are designed to answer. Qualitative data are often gathered through interviews, focus groups, observations, or case studies. Child welfare organizations may record participant testimonials, for example, or supplement reports with direct quotes.

Software programs such as Atlas.ti, NVivo, and Wordle can be used to identify patterns and themes. For example, Wordle creates "word clouds" that display words or phrases that appear frequently in a set of qualitative data; the larger the font, the more often a given word or phrase appears in the dataset.3

Exhibit 3-5 highlights common methods in quantitative and qualitative analysis. Some traditionally quantitative tools (e.g., surveys and questionnaires) may include qualitative elements (e.g., open-ended survey questions).

Exhibit 3-5. Common Quantitative and Qualitative Research Methods

Quantitative: Focus on Results (What? When?)	Qualitative: Focus on Experience and Meaning (How? Why?)
Surveys/questionnaires	Open-ended survey questions and semi-structured interviews
Standardized assessment instruments and tests	Focus groups
Analysis of existing administrative data	Case studies
Case record review (e.g., data on program attendance and service receipt)	Document review (e.g., case notes)
Structured observation (e.g., numeric rating scales)	Observation (e.g., detailed field notes or journal entries)

### **Building Staff Capacity to Collect and Use Data**

For organizations to become more data driven, staff must understand the need for data and learn how to gather and use it in their daily work. Consider whether staff at all levels "buy into" the need for data collection and DDDM efforts, and the extent to which they are willing to participate. Frontline staff in particular may view collecting and using data as a barrier to forming relationships with clients or delivering services.

Leadership should begin building staff buy-in as early as possible by demonstrating how data can enhance their job performance, improve participant outcomes, and increase the overall quality of their work experience. Involve staff in the planning stages of the DDDM process, engage them in ongoing discussions about findings, and invite them to share their knowledge and experience to address challenges. The following steps can help staff engage with data.

<sup>&</sup>lt;sup>3</sup> Visit the Wordle Web site for examples of word clouds.



**Expand capacity through education and** training. Provide onsite trainings or send staff to seminars to help them build skills collecting and applying data to their work. Continue offering such opportunities even after staff learn the basics, either as standalone trainings or as part of other training or supervisory activities.

### Embrace technology to simplify workloads.

Use technology to streamline and automate the

DDDM process while helping staff maintain greater control over work quality and consistency. Available tools include remote access to data systems through laptops or tablets, data dashboards with client- and program-level data, and algorithms that automatically score screening and assessment instruments.

Use short, simple tools. Select surveys, questionnaires, and tests that are short and easy to administer. Developing your own tools may save time, but standardized tools ensure validity and reliability.

Leverage secondary data sources. Make it easy for the organization to access and analyze data from existing sources, such as child welfare information systems or relevant databases. Ensure that staff extract, clean, and analyze secondary data so they can be used in conjunction with primary data you gather directly.

Enlist the help of others. If your organization is near a college or university, seek out graduate students or recent graduates looking to hone their research skills. If you have an active volunteer base, explore whether your volunteers have experience designing Web sites or databases, or involve them in basic activities like mailing paper surveys.

Share data regularly. Sharing data with frontline staff as they are produced offers more opportunities for workers to understand and apply new information to their day-to-day work. It also reinforces data sharing as a bidirectional process in which feedback from frontline staff contributes to program and organizational improvements and generates new questions for follow-up analysis.

Exhibit 3-6 presents self-assessment questions you can use to build capacity for collecting and using data.

### Exhibit 3-6. Self-Assessment Questions for Data Collection and Analysis

### **Data Quality**

Do the primary data collection measures accurately assess the needed constructs? Are they valid? Are they reliable?

Are the primary data sources complete, well defined, and easily identified?

Do the secondary data sources accurately assess the needed constructs? Are they valid? Are they reliable?

Are the secondary data complete, well defined, and easily identified?

Are key stakeholders getting the data they need to make data-driven decisions in a timely manner? Are programs, processes, or activities being delivered in the way they were intended? What fidelity data are being collected?

### **Data Systems**

What are the staffing needs for the data team? What is the current capacity, and who still needs to be contracted or hired?

Has a data flow chart been created to identify how different types of data will be collected and distributed among key stakeholders?

Are new data system solutions available to help meet data system needs? Do they meet CCWIS requirements?

How will the data system be modified to accommodate changes in the data flow?

How could the data system be improved to help key stakeholders make data-driven decisions?

### **Data Collection**

What are the main questions/information needs that need to be addressed through data collection? What are the primary data collection methods? How do they need to change to adapt to data system changes?

Who will be collecting primary data? When and where will that collection occur?

What form of data will be most informative to key stakeholders? Quantitative? Qualitative? Both? How can errors in data collection and data entry be minimized?

Are data sharing agreements in place for all shared primary and secondary data sources?

### **Data Analysis**

How will secondary data sources be linked with primary data sources (if collected) prior to analysis? How will the data be cleaned prior to analysis?

What type of analysis is needed for different staff roles?

Does the data analysis answer key questions that improve decision making? Could the data be analyzed more productively?

### **Staff Capacity**

How will staff be trained in any new processes or procedures related to the data system, data collection, or reporting?

What strategies are being used to ensure staff buy in?

Do stakeholders know how to apply the results of the data analysis?

How will new processes or procedures be incorporated into the organization or system and sustained?



# Case Vignette: Designing Information Systems for Effective Project Implementation

San Francisco Human Services Agency—Families Moving Forward

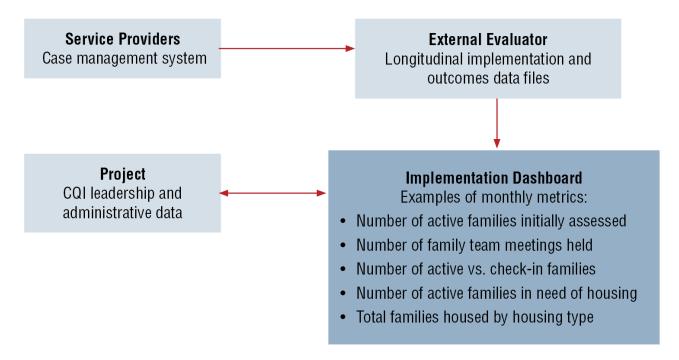
Grantee Cluster: 2012—Partnerships to Demonstrate the Effectiveness of Supportive Housing for Families in the Child Welfare System

The Families Moving Forward project fosters cross-system collaboration and coordination to house and support homeless families with children who are at risk of out-of-home placement or were recently removed from the home. The project team needed to quickly and effectively identify families who could benefit most from the program, provide them with services, and closely monitor their progress through various service systems, including child welfare, housing, and mental health. The team ensured successful implementation by creating the data elements and systems necessary to identify a target population, establish baseline outcomes, set improvement targets, track implementation fidelity and family progress, and ultimately measure impact. The information was used to adjust and improve the project's service model.

Analyzing data flow and information needs. During the project's planning year, the team used administrative data to target a population that fit the intervention's theory of change and to begin identifying gaps in services. Project leadership then convened a CQI team consisting of staff from all partner agencies providing child welfare and housing services as well as internal and external evaluators. The CQI team, which meets monthly, developed a data flow chart to track and analyze the movement of information within and outside the agency (see exhibit 3-7).

**Structuring the data to inform decision making.** Once the project's data infrastructure needs were assessed, the project team identified new ways to track families as they moved through the program. For example, to help families find permanent housing, the team needed to know not only whether a family had found housing but also how the search process

Exhibit 3-7. Families Moving Forward Project: Data Flow Chart



unfolded in San Francisco's tight housing market. Tracking key events and dates (e.g., voucher application, voucher receipt, lease, move-in) identified bottlenecks. The project's external evaluator designed a database to combine case management data, child welfare administrative data, and data from other sources to measure long-term impact.

Project tips. Creating a robust and modular data collection and analysis system is critical to implementation. The project team offers the following tips:

- Think strategically during implementation planning. Consider what kinds of quantitative and qualitative information might be needed at different stages of implementation, including selecting the target population, monitoring eligibility, providing early and ongoing services, and measuring impact.
- Design a flexible data collection system that tracks events over time to facilitate longitudinal analysis.
- Create a multidisciplinary CQI team that includes members with programmatic knowledge and data and analytic skills. Families Moving Forward relies on team members who ask questions about implementation, find information sources to answer those questions, and harness the team's capabilities to improve the system.



# **Case Vignette: Using Data Analysis to Inform Program Improvement**

**Connecticut Department of Children and Families Collaborative on Effective Practices for Trauma (CONCEPT)** 

Grantee Cluster: 2011—Integrating Trauma-Informed and Trauma-Focused Practice in Child Protective Service

he CONCEPT project seeks to create a data-driven, trauma-informed child welfare system to identify and respond to the needs of children who have experienced physical and/or psychological trauma. The team conducted descriptive and inferential analyses for two key project activities: workforce development and evidence-based practices.

**Workforce development.** Workforce development was examined through successive steps:

- Project staff conducted statewide staff trainings on trauma-informed care.
- Training attendance records, workshop evaluations, and qualitative feedback were entered into a Web-based system.
- Participants completed a survey before and after training and 3 months later. The survey measured changes in knowledge and attitudes related to trauma, available trauma resources, trauma screening procedures, and application of the training content to daily work activities.
- Descriptive analyses by training type and cohort were completed to inform potential modifications to the training program. For example, if training attendance or survey scores remained low at a particular site, additional trainings or technical assistance were provided.

 A repeated measure design was used to analyze the combined survey results across training types and cohort. Initial results indicate significant and sustained improvements in knowledge and attitudes regarding trauma.

Evidence-based practices. Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) and the Child and Family Traumatic Stress Intervention (CFTSI) were studied through a similar process:

- As clinicians were trained in and implemented TF-CBT and CFTSI, they collected and reported data on the number and characteristics of clients, provider ratings of fidelity to the treatment models, and results of standardized child and family assessments.
- A repeated measure design using provider ratings of child and family outcomes collected pre- and post-intervention was used to study the relationship between treatment dosage, fidelity, and outcomes.
- Benchmarking was used to create a comparison group based on results of previous randomized controlled trials published in the academic literature. The team compared changes in clinical outcomes, treatment completion rates, and effect sizes in the comparison group with families receiving TF-CBT and CFTSI.
- Propensity score matching using administrative data was implemented to create a comparison group of children with similar case characteristics and trauma exposure who did not receive TF-CBT. Differences in well-being and functional outcomes between the intervention and matched comparison groups were analyzed over time.



# 4. Communicating Results to Decision Makers

After you have analyzed your data, the next step in the DDDM process is conveying results to key decision makers. The way data are presented can impact people's reactions and the actions they take as a result. It is therefore critical to convey the data in a way that is both understandable and useable.

#### **Identifying the Audience**

First, identify the audience so you can determine how to interpret, communicate, and present your findings. Consider key stakeholders such as managers, supervisors, or funders who may rely on the information presented to make decisions (Patton, 2008). Also consider others who might have an interest in the data, assuming there is permission to share the findings beyond the initial stakeholders. Here is an overview of common audiences in the field, along with their interests, information needs, and presentation preferences.

Funders, agency administrators, and governing boards. Program funders, agency administrators, and governing boards typically want a high-level overview of key findings, with access to in-depth analyses by request. They generally want time to react to the "gist" of the results and an opportunity to provide input regarding the content and format of future public presentations. Reports for this audience should be concise and visually engaging. Begin with an executive summary highlighting the purpose, methods, and results, followed by key recommendations. Include details about the methodology and analyses in an appendix. Oral presentations should highlight key results and include graphics that are easy to interpret.

**Middle managers and potential program adopters in other agencies.** People in these roles often want more detailed findings to help them manage daily operations or make decisions about program additions or changes. Emphasize results that may have implications on procedures, culture, staff expectations and performance, and client outcomes. Middle managers and potential program adopters also want information that may impact program costs with respect to training, supplies, logistics, and personnel.

**Supervisors and frontline workers.** These stakeholders want to know how the findings may impact their day-to-day casework, workflow, interactions with program participants, and the way

they share tasks with their colleagues. These audiences will especially benefit from concrete examples and recommendations that can be put into immediate practice.

The checklist in exhibit 4-1 can help you identify typical audiences and roles in the DDDM process.

Exhibit 4-1. Evaluation Consumer Checklist

Evnected Role

	Exherien unie				
Individuals, Groups, or Agencies	Make Policy	Make Operational Decisions	Provide Input	React	For Interest Only
Funding agencies/sponsors					
Governing boards					
Agency managers/administrators					
Program staff					
Program participants					
Other agencies					
General public/community members					
Community/opinion leaders					
Program opponents					
Potential program adopters					
Professional colleagues					
Professional associations					
Dissemination networks					

Note: Adapted from Worthen, B. R., Sanders, J. R., & Fitzpatrick, J. L. (1997). Program evaluation: Alternative approaches and practical guidelines. White Plains, NY: Longman Publishers.

# **Communicating Information Frequently**

For maximum impact, present information frequently and in formats that maximize the quality and usability of your findings. Regular progress reports and updates are important, even before final results are ready. Base the format on the information needs, capacity, and availability of the target audience. For example, a 100-page report with detailed program findings may not be helpful to state legislators or departmental heads, but a one-page summary with infographics highlighting key successes may offer just the right amount of information to inform their decision making. Following are common formats for communicating information.

Periodic updates and progress reports. Evaluators should actively engage with program staff through the reporting process, whether in recurring meetings or through periodic performance reports. Program data can also be provided in electronic formats, such as weekly or monthly email updates or newsletters.

**Data dashboards.** It is increasingly common to make data available using "dashboards" that visually display selected performance and outcome indicators at the aggregate level. Dashboards typically present multiple indicators on a single screen or in a spreadsheet arranged to examine trends over time. The dashboard's content can vary depending on the user and purpose. For example—

- Executive dashboards monitor performance indicators.
- Analytical dashboards promote data discovery or look for patterns and trends.
- Supervisory dashboards highlight frontline staff members' activities and performance.

The case vignette at the end of this chapter includes an example of a data dashboard developed by the District of Columbia Child and Family Service Agency.

> Greene County learned that its process for licensing foster families was taking longer than it should. The agency uncovered numerous obstacles that made the licensing process inefficient and burdensome to foster families.

The implementation team presented its findings to an executive team, which appointed a workgroup that included foster family advocates, agency licensing staff, and policy staff. The workgroup reviewed the paperwork requirements for licensing and made recommendations that led to a simplified, more streamlined process. Workgroup members also created a part-time position to help with appointment scheduling, followup, and paperwork. This freed up licensing staff to work more directly with families.



#### **Presenting Results**

Communicate results as clearly, accurately, and objectively as possible. Frame findings in terms of their strength (e.g., the rigor of the evidence supporting the claims) and importance (the significance of the claims). Include specific recommendations to maximize the report's usefulness, but clearly separate them from the report's findings and interpretations.

#### Communicating Unwelcome Findings

Professional ethics require organizations to present findings as fully and accurately as possible, even negative ones. This may include findings that question a program's effectiveness or findings that show no impact. The following guidelines can be helpful when communicating negative results.

**Share the good news first.** It is often easier to start a difficult conversation on a positive note, so begin by presenting program strengths or promising outcomes before switching to less desirable results.

Avoid surprises. Share potentially negative findings early so stakeholders are not blindsided by a final report or public release of unexpected results.

Talk it through. Many people find it easier to accept bad news presented verbally. Sharing negative findings in person or by phone, however, does not mean you can leave them out of reports and other documents.

Highlight lessons learned. Remind your audience that negative or unexpected findings can be as informative as positive ones. Present findings in the context of program development and improvement rather than as final judgment of a program or its staff.

Provide time to process. Finally, allow stakeholders time to digest, explain, and react to negative findings. Their perspectives may provide different interpretations of the results that can be included in subsequent reporting.

#### **Making Recommendations**

Many audiences expect program and policy recommendations based on the results of the DDDM process. Consider the following guidelines when crafting recommendations:

- Ensure recommendations are clearly supported by the data analyses and results.
- Organize recommendations by potential timeline (e.g., short-term steps, long-term steps).
- Present multiple options.
- Ask stakeholders to consider the risks and benefits of implementing and not implementing the recommendations.
- Focus on actions that stakeholders have the power and resources to implement.
- Be aware of political and cultural contexts. Some recommendations may not be feasible
  or acceptable given the political realities in which programs operate or the cultural norms
  and expectations of people who work for or are served by an organization.

In **Greene County**, the DDDM process incorporated multiple people at multiple levels to facilitate collaborative learning and action.

Frontline staff reviewed and updated the spreadsheets and charts used to create their data dashboard to determine the agency's most effective recruitment activities. Managers used the dashboard to help staff stay on track and to allocate resources appropriately. They provided training on recruitment strategies as needed and hired additional staff.

Greene County's executive team met monthly to review the findings accumulating through the data dashboard and to support the organization's capacity to recruit additional foster and adoptive families and track permanency rates. Over time, the rates of licensure completion began to increase while time to complete the licensing process grew shorter.

Greene County staff continued to collect and monitor data to determine which changes were effective and to reflect on new strategies to increase licensing and permanency rates even further. Additionally, they revisited their theory of change and updated it to reflect the findings from the DDDM process.

#### **Disseminating Findings**

To inform effective decision making and program improvement, make sure you get the right data to the right people (see exhibit 4-2). When everyone at an organization has access to factbased information, problems can be solved at multiple levels.

# Exhibit 4-2. Self-Assessment Questions for Communicating Results to Key **Decision Makers**

#### Reporting

Who are your key audiences? What results will most inform their understanding and decision making? How will the information be used?

What are the most important messages to convey?

What conclusions can be drawn from the results?

Based on the findings, what recommendations should be made?



# **Case Vignette: Reporting and Communicating Findings Using Data Dashboards**

District of Columbia Child and Family Service Agency—System Transformation to **Impact Outcomes for Children in Foster Care** 

Grantee Cluster: 2012—Initiative to Improve Access to Needs-Driven, Evidence-Based/Evidence-Informed Mental and Behavioral Health Services in Child Welfare

the System Transformation to Impact Outcomes for Children in Foster Care project is working to create a data-driven, trauma-informed child welfare system in the District of Columbia. The initiative includes the development of a comprehensive data system that supports real-time decision making.

A key component of the data system is an integrated dashboard called the Well-Being Profile (see exhibit 4-3). The profile summarizes data from several standardized assessment instruments, including the Child and Adolescent Functional Assessment Scale, the Preschool and Early Childhood Functional Assessment Scale, and the Caregivers Strengths and Barriers Assessment. Case planning and service data in the profile allow supervisors and case workers to identify patterns in needs and outcomes, which furthers their understanding of service effectiveness.

**Developing a data dashboard.** Efforts to develop the Well-Being Profile began in 2012 with an analysis of existing screening, assessment, and monitoring practices. The project team needed a tool for determining what services children and families were receiving and whether they were being implemented as planned. For 2 years, the team worked with the District's Department of Behavioral Health, other service partners, federal agencies, and the agency's IT department to design, build, and test the profile.

**Communicating and applying findings.** The Well-Being Profile consolidates data on children and parents across domains into a snapshot of their functioning and progress. The profile facilitates DDDM across several levels:

- Caseworkers view and track child and family information, and the profile prompts them to complete screenings, assessments, and case plans. The profile helps caseworkers interpret assessments and make service recommendations.
- Supervisors track indicators associated with families' progress, such as service eligibility and completion rates. The profile contributes to joint case plan development and progress monitoring across the agency.
- An executive team monitors aggregate performance indicators related to child welfare and behavioral health across the service continuum.

Feedback on the profile from managers, frontline workers, and service providers has been positive. They now see assessment as a way to inform service decisions rather than a matter of compliance. As one project team member noted, "When we showed people the concept of [the profile], it changed the conversation. [Supervisors] weren't asking, 'Why aren't you doing this [assessment] every 90 days?' They were saying, 'Wait a minute; this child scored really badly in school, but I don't see services related to school in the service plan.' That's what we wanted to see we wanted to change the conversation."

# Exhibit 4-3. System Transformation to Impact Outcomes for Children in Foster Care Project: Well-Being Profile Data Dashboard

#### **Child View**



# **Caregiver View**





# 5. Refining Processes, Organizations, or **Systems**

he last step in the DDDM process is using information to facilitate changes both big and small—to activities, programs, organizations, and entire systems. At this stage in the cycle, the primary stakeholders are ready to use the knowledge generated through DDDM to improve the way the entity functions and to strengthen outcomes for children and families.



#### **Making Data-Driven Decisions**

DDDM is not complete until the information it generates leads to action. Ideally, decision makers use the information conveyed by the data to adjust the "levers" of an organization or system. First, you must use communication, collaboration, and critical thinking to encourage them to move these levers.

#### **Communication**

Do not just give staff access to reports and analyses; make sure they know how to use the information. Provide regular opportunities such as workgroups and learning collaboratives to discuss how they can apply the information in practice. Communication should occur within and across staffing levels and departments, with information flowing both up and down the organizational chart.

Consider holding regular meetings to address and discuss results from the data collection and reporting process. Meetings can occur all at once or in succession based on the audience. For example, the executive team could meet first to discuss findings, before individual directors meet with their frontline staff. Feedback from these smaller gatherings can then be communicated back to the executive team via meeting minutes or other communication channels.

#### Collaboration

Regular data reviews can show how results vary over time, but they cannot explain why certain outcomes occur or determine if the results are positive or negative. Create interdisciplinary teams that provide the context needed to understand and interpret the findings and the daily realities that may impede or boost results. Embracing multiple perspectives enhances the DDDM process and can increase staff motivation, accountability, and teamwork.

#### Critical Thinking

The decisions made by child welfare organizations can have a direct and significant impact on the lives of children and families. Ideally, the DDDM process informs these decisions by pinpointing specific goals and providing related feedback. Keep the following recommendations in mind.

View information from the client's perspective. Think about the way most cases flow through the child welfare system (e.g., intake, assessment, treatment, placement, discharge). Try to get data to flow accordingly and in a way that minimizes burden on clients.

Assess strengths, not just weaknesses. The first instinct when examining data is to focus on problem areas; however, much can be learned from looking at what is currently working. Get the backstory for indicators that are meeting or exceeding performance targets or benchmarks. This information can offer insight into how other indicators can be improved.

Don't overlook the work environment. An organization's physical space can impact data collection, entry, and processing. For example, clients may choose to withhold sensitive information if their intakes are conducted in areas with limited privacy. Similarly, directly inputting data into an iPad or laptop while meeting with families can reduce errors in data entry. It is also helpful to think through where data analysis should occur if you want analysts located at multiple sites or in a centralized location.

Be aware of bias. Consider individual and group dynamics, and the multiple types of bias that may exist, when conveying information to inform the decision-making process. For example, cognitive biases result from differences in the way individuals process information, while motivational biases result from selecting or ignoring information based on individual preferences and motives. Social biases, by contrast, are triggered by social pressure or context (Fiske & Taylor, 2013).

Model DDDM through leadership. One of the major barriers to effective DDDM is an organizational culture that relies too heavily on the instincts of its leaders instead of facts pulled from concrete data. Consider identifying champions to lead DDDM efforts at the executive level and to model data use strategies among peers and those who report to them.

Don't forget the stakes at hand. Remember that decisions made in child welfare settings affect children and families, many of whom face difficult circumstances. Actions should be informed by data, but they should also reflect empathy and understanding

#### Repeating the Cycle

Once the DDDM cycle is complete, it can be revisited from the beginning, creating an ongoing loop of data-driven improvements (see exhibit 5-1). Improvements can be made to one program or component of an organization at a time; when appropriate, the process can be repeated at the systems level across multiple organizations or service providers. As an organization's analytical capacities mature, DDDM leads to a cultural shift in which testing hypotheses becomes the norm, and actions are taken based on evidence and observed outcomes. This cultural shift can be sustained through internal policies and procedures that mandate the use of data in routine decision making.

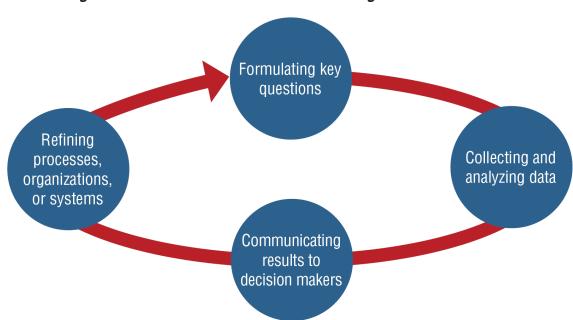


Exhibit 5-1. Stages of the Data-Driven Decision-Making Process

## Revisiting the Theory of Change and Logic Model

Your organization's theory of change and logic model should be regarded as dynamic tools that facilitate ongoing project management, monitoring, and CQI. Be sure to revisit both to determine whether refinements to the program or organization have necessitated any changes (see exhibit 5-2). Ask yourself—

- Are new services, activities, and policies being developed and implemented as intended?
- Are changes in knowledge, beliefs, attitudes, behaviors, or status occurring as a result of the program?

# Exhibit 5-2. Self-Assessment Questions for Refining Processes, Organizations, or Systems

#### **Making Data-Driven Decisions**

How have we applied findings to our ongoing work?

Based on the findings, what, if any, changes should be made to our program design, implementation, or other processes?

Does our theory of change and/or logic model need to be modified?

What systems are in place to ensure data translate to continuous program refinements?

Has DDDM become part of our organization's culture? If not, how can we support this cultural shift?

If expected changes did not occur, the theory of change and logic model can help identify the reasons why and determine needed adjustments. Consider, for example, whether results were not achieved due to-

- Poor or inadequate theory of change
- Poor or inadequate implementation
- Insufficient or inappropriate data

Finally, when program modifications are required, the theory of change pathways can help predict potential effects. Don't forget to ask how the modifications will affect the organization's implementation objectives and outcomes and the linkages between them.

#### Conclusion

DDDM moves human service organizations away from opinions, anecdotes, and "turf" issues toward hard facts and actionable information. The results are improved program strategies and better outcomes for children and families.

Through DDDM, internal and external stakeholders at all levels gain appreciation for data collection and analysis and learn how to use findings effectively. That leads to a richer understanding of programs, organizations, and systems and a greater potential for positive change.

To learn more about DDDM, see appendix A.



# **Case Vignette: Using Continuous Quality Improvement**

University of Maryland—National Quality Improvement Center on Tailored Services, Placement Stability, and Permanency for Lesbian, Gay, Bisexual, Transgender, Questioning, and Two-Spirit Children and Youth in Foster Care (QIC-LGBTQ2S)

'he purpose of the QIC-LGBTQ2S is to identify and collaborate with local implementation sites to develop, integrate, and sustain best practices and programs that improve outcomes related to permanence, stability, safety, and well-being for children and youth in foster care with diverse sexual orientations, gender identities, and gender expressions.

The QIC-LGBTQ2S leads a quality learning collaborative (QLC) for the sites that provides technical assistance and serves as an evaluation hub to identify best practices. The project is led by the Institute for Innovation and Implementation at the University of Maryland School of Social Work in partnership with the Human Service Collaborative, Judge Baker Children's Center, and Youth M.O.V.E. National.

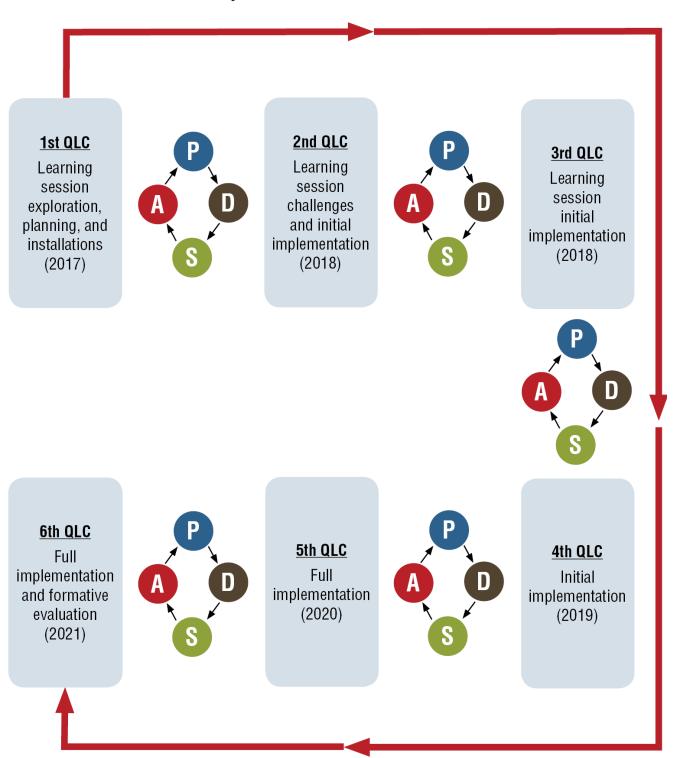
The team based its data-driven approach to CQI on the National Implementation Research Network model, and it based its quality learning collaborative on the Institute for Healthcare Improvement Collaborative Model for Achieving Breakthrough Improvement. A core component of the collaborative is the application of the plan-do-study-act (PDSA) process (Deming, 1986), through which the sites will—

- Plan activities to achieve their goals and identify appropriate performance indicators
- **Do** and collect data on the activities

- Study and analyze the results of the activities
- Act by determining needed modifications and refinements to the activities based on the continuous cycle of data collection and analysis

The PDSA process will promote refinement of interventions over time (see exhibit 5-3). The application of findings through cycles of site-level and cross-site data review will help demonstrate and document best practices.

Exhibit 5-3. QIC-LGBTQ2S Project: PDSA Process





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**Analysis of variance:** A collection of statistical models and their associated procedures used to analyze differences in means (averages) between and among multiple groups. These tests are used to determine whether observed differences across groups are statistically significant, i.e., not likely due to chance.

**Fidelity:** The extent to which an intervention or process is implemented as designed or intended. For example, in the context of a training program, fidelity refers to the extent to which the people conducting the training follow the content, guidelines, and tools (e.g., scripts, learning exercises) provided in a training curriculum.

**Homogeneity of variance:** In statistics, the assumption that the level of variance in the distribution of data in two or more groups (e.g., a treatment group and a comparison group) is equal. If the level of variance between groups is large, any differences in outcomes derived through statistical analysis may be inaccurate.

**Independence of observations:** In statistics, the assumption that the value of one observation or piece of data does not affect the value of another observation or piece of data.

**Inferential analysis:** The process of testing hypotheses using statistical analyses to draw conclusions about a population based on data from a smaller sample of that population.

**Linearity:** In regression analysis, the assumption that the distribution of observed values clusters in a linear pattern. The linearity is often visualized using a "scatter plot" that illustrates how closely observed values cluster around a straight line drawn along the x and y axes of a diagram.

**Multilevel linear modeling:** A group of statistical methods that estimate relationships among variables, and their effects on outcomes, at more than one level. For example, child outcomes may be affected by multiple "nested" factors, such as the biology of the child and family, the family's neighborhood, and the society in which that neighborhood is located. Multilevel modeling enables the study of the individual and interactive effects of these factors on one another and on one or more outcomes of interest.

Normality: In statistics, normality refers to how well a dataset conforms to a normal distribution (referred to informally as a "bell" curve).

Regression: A type of statistical analysis that estimates relationships among variables and their effects on one another. Regression analysis may be used to determine the effect of a particular treatment on a child outcome, controlling for other variables that might also influence that outcome.

Reliability: In statistics, a conclusion that the results of an experiment would be the same if the experiment were repeated, given the same set of circumstances. When used in reference to a data collection instrument or tool, reliability refers to the extent to which a tool produces similar results when administered by different researchers at different times, in different test settings, with different test populations, etc.

**Structural equation modeling:** An analytic approach in which statistics are used to estimate relationships among manifest variables (things that can be directly observed and measured) and latent variables (underlying constructs). For example, a series of survey items may be used to measure various aspects of a child's mental and physical health. These manifest (i.e., observable) variables may be used together to indirectly assess the underlying construct "wellbeing."

Structured observation: A data collection method in which researchers visually examine activities or processes, without direct involvement with the observation subjects, using predefined criteria and procedures. For example, the observers might use a standardized checklist to record whether certain behaviors or actions occurred among the participants.

**Survival analysis:** An analytic approach in which the outcome variable of interest is time (e.g., days, months, years) until a certain event occurs. This approach produces a "survival curve" showing the cumulative proportion of individuals in a population who have not yet experienced the event across time. For example, an event like exiting foster care might be measured in months from date of entry until date of exit. A related technique, Cox proportional hazard regression modeling, identifies factors (e.g., child gender or age) that might explain variation in the time until the event of interest.

Time-series designs: A type of statistical analysis that involves collecting data at predetermined intervals to measure change in a variable or determine the effect of an intervention over time. Time series designs can be used to measure change within a single group or to make comparisons between groups over time.

**T-test:** A statistical test used to determine whether the observed difference in means (averages) between two groups is statistically significant (i.e., not due to chance). For example, a t-test

could be used to determine whether observed changes in test scores between students exposed to a new teaching curriculum and a control group of students exposed to a traditional curriculum are statistically significant.

**Validity:** In statistics, the conclusion that an observed outcome is likely not random but rather the result of or influenced by factors identified previously in a research hypothesis. When used in reference to a data collection instrument or tool, validity refers to the extent to which the tool actually measures the construct(s) it was designed to measure. For example, a test of reading comprehension would be considered "valid" if it is determined through statistical testing that it in fact measures reading comprehension.



#### C.1. Sample Memorandum of Understanding (New York)

#### State of New York – Master Memorandum of Understanding

The following data sharing agreement is executed within the State of New York's human services department for and between various state public assistance programs and other agencies. The agreement addresses the data sharing roles and responsibilities, and other aspects of data protections relative to the request, use, and confidentiality and protection of program data received and shared with other state law enforcement, judicial, education, health, and human services agencies.

#### **AGREEMENT**

#### Amendment

The data sharing agreement by and between the Department of Health and the Office of Children and Family Services is here by amended to provide as follows.

AGREEMENT by and between the NEW YORK STATE OFFICE OF CHILDREN AND FAMILY SERVICES, 52 Washington Street, Rensselaer, New York (hereinafter OCFS), and the NEW YORK STATE DEPARTMENT OF HEALTH, Corning Tower, Empire State Plaza, Albany, New York (hereinafter called DOH).

#### WITNESSETH:

WHEREAS, OCFS, as the single State agency responsible for the implementation of the State Plan for the Foster Care Maintenance Payments Program and the Adoption Assistance Program established pursuant to Title IV-E of the Social Security Act, is responsible for supervising the activities of social services districts and voluntary authorized agencies in the reception, care and placement of foster care and administration of the adoption subsidy program; and

WHEREAS, OCFS, as the single State agency responsible for the implementation of the State Plan for the Child Care and Development Block Grant (CCDBG) Act of 1990 as amended by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, is responsible for supervising the activities of social services districts in the administration of the child care subsidy program; and

WHEREAS, OCFS, is responsible for the reception, care and placement of children placed with OCFS as juvenile delinquents or juvenile offenders pursuant to Article 3 of the Family Court Act; and

WHEREAS, DOH, as the single State agency responsible for the Medical Assistance Program under Title XIX of the Social Security Act and Title 11 of Article 5 of administration of the Medical Assistance Program in New York; and

WHEREAS, OCFS and DOH have a mutual interest, consistent with their respective statutory obligations in relation to child welfare and medical assistance programs, in the exchange of data, including client specific information; and

WHEREAS, Subdivision 12 of Section 366 of the Social Services Law, as amended by the laws of 1994, authorizes the Commissioner of the Single State Agency for Medical Assistance to apply pursuant to subdivision (c) of Section 1915 of the Federal Social Security Act for waivers to provide Medical Assistance to persons under the age of twenty-one years as further defined in such subdivision; and

WHEREAS, in accordance with the provision of Title XIX of the Social Security Act and Title II of Article 5 of the Social Services law, the Single State Agency for Medical Assistance has submitted to the Secretary of the United States Department of Health and Human Services ("Secretary") for approval three requests for waivers of certain requirements of the State Plan to implement a home and community-based program of services to address unmet health needs for certain children in foster care, and certain children who have been discharged from foster care but continue to be eligible for the waiver program; and

WHEREAS, each waiver request is related to a single, specific target group of children having either a severe emotional disturbance, a developmental disability or physical health issues; and

WHEREAS, the waivers shall be hereinafter referred to individually and collectively as the B2H waiver program; and

WHEREAS, it is the intent of OCFS and DOH to enter into this AGREEMENT that will provide for the exchange of data, including client specific information, to further the legitimate needs of each agency; more particularly to facilitate Medical eligibility for the population of children in foster care, children receiving adoption subsidies, children participating in any of the B2H waiver programs and children in the custody of OCFS monitoring of the provision of medical care and services to these populations, consistent with applicable confidentiality standards; the AGREEMENT addresses the needs for current and future exchange of data between OCFS and DOH.

#### NOW, THEREFORE, IT IS MUTUALLY AGREED AS FOLLOWS:

- 1. DOH will provide to OCFS Medicaid enrollment, coverage and child specific payment information related to children in foster care, children receiving adoption subsidies, children participating in any of the B2H waiver programs and children in the custody of OCFS as juvenile delinquents or juvenile offenders, including Medicaid Management Information System (MMIS) known as "EMedNY", medical payments. The information will include:
  - a) Name, Client Identification Number (CIN), Date of Birth (DOB) and all other identifying information;
  - b) Demographic data;
  - c) Medicaid authorization dates, types of coverage;
  - d) Restricted recipient and principal provider data; and
  - e) Family income and resources.
- 2. DOH will provide access to OCFS Medicaid information related to families receiving child care subsidy payments which includes the following:
  - a) Name, Client Identification Number (CIN), Data of Birth (DOB) and all other identifying information:
  - b) Demographic information; and
  - c) Family income and resources.
- 3. OCFS will provide to DOH information related to children in foster care, children receiving adoption subsidies, children participating in any of the B2H waiver programs and children in the custody of OCFS as juvenile delinquents or juvenile offenders who are receiving Medicaid. The information will include:
  - a) Welfare Management System (WMS) data available through the Welfare Reporting and Tracking System (WRTS) including case related, case member, and CIN related data;
  - b) Foster care placement data; and
  - c) WMS Medicaid Subsystem data.
- 4. OCFS and DOH will each designate a principal contact person within its agency to be responsible for the coordination of data exchange. Such person will also be the principle contact person for any future data requests. Each agency will use its best efforts to accommodate such requests consistent with applicable legal standards and administrative capability.
- 5. OCFS and DOH agree to maintain the confidentiality of client specific information received from the other agency consistent with applicable confidentiality standards, including Section 471 of the Social Security Act, Section 372 of the Social Services Law and 18 NYCRR Parts 357 and 465 in regard to foster care records, and Section 1902(a)(7) of the Social Security Act, Section 369(4) of the Social Services Law and the provisions of the Health Insurance Portability and Accountability Act.
- 6. This AGREEMENT may be amended upon the mutual consent of the parties.

	BY:	
DATE	Name	
	Executive Deputy Director	
	NYS Office of Family and Children Services	
	BY:	
DATE	Name Chief of Staff NYS Department of Health	

IN WITNESS WHEREOF, the parties have hereunto signed this AGREEMENT on the day and

year appearing opposite their respective signatures.

# C.2. Sample Confidentiality Agreement (King County, Washington)

CA #16.07 E-052416-S16.07

#### DEPARTMENT OF SOCIAL AND HEALTH SERVICES Children's Administration Olympia, Washington 98504

#### **CONFIDENTIALITY AGREEMENT**

Agreement made between
WHEREAS the UW has submitted a written project proposal entitled "Evaluation of King County Commercially Sexually Exploited Children (CSEC) Task Force" to DSHS dated July 26, 2016, a copy of which is annexed hereto and made a part hereof; and
WHEREAS the Washington State Institutional Review Board (WSIRB) has reviewed said proposal, has determined that it clearly specifies the purposes of the project and the information sought and is of importance in terms of the agency's program concerns, that the project purposes cannot be reasonably accomplished without disclosure of information in individually identifiable form and without waiver of the informed consent of the person to whom the record pertains or the person's legally authorized representative, that disclosure risks have been minimized and that remaining risks are outweighed by anticipated health, safety or scientific benefits, and has approved said proposal with respect to scientific merit and the protection of human subjects; and
WHEREAS the UW agrees to collaborate with staff from the Children's Administration to gain are understanding of the reliability and appropriate use of specific data elements; and
WHEREAS the UW has declared to be in receipt of the DSHS current policy for the protection of human subjects (Washington State Agency Policy on Protection of Human Research Subjects) and the

Washington State law on the disclosure of personal records for project purposes (Chapter 42.48 of the

Revised Code of Washington (RCW 42.48)),

#### NOW THEREFORE, IT IS AGREED AS FOLLOWS1:

- 1. DSHS authorizes a Children's Administration staffer to identify and compile a list of youth who are eligible for this project in August 2016, August 2017, and August 2018. Eligible youth have been identified as being commercially sexually exploited or at risk of becoming commercially sexually exploited. The staffer will send the name, date of birth, and a proxy study identification number for each identified youth to three agencies: YouthCare, AOC-WSCCR, and the King County Superior Court.
- 2. AOC-WSCCR, YouthCare, and King County Superior Court will match their records to the list of youth identified by DSHS, see Attachment A. After matching, the agencies will remove the youths' names and dates of birth prior to transmitting to UW, retaining the proxy study identification number.
- 3. AOC-WSCCR, YouthCare, and King County Superior Court will destroy identifiers used to link the records to DSHS following transmission.

#### 4. UW will:

- (a) Match the proxy study identification numbers from each dataset.
- (b) Use the final analytical dataset records ONLY to evaluate the King County Commercially Sexually Exploited Children (CSEC) Task Force Program.
- (c) Create a master identifier file which links the arbitrary study codes, protect this master file with hardened passwords known only to the UW, and maintain all copies of the master file in a secure location at all times when not in use;
- (d) Identify records in the database only with arbitrary study codes, and ensure that, without access to the master identifier file or DSHS source records, all database records are non-identified;
- (e) Notify the Washington State Institutional Review Board if other records not specified in this Agreement are needed for the study;
- (f) Report or publish findings only in a manner that does not permit identification of persons whose records are used in the research;
- (g) Destroy the master identifier file, and remove and destroy all identifiers<sup>2</sup> in the study database, or return all copies of the study database to DSHS, when study purposes have been accomplished, and provide written certification to the Washington State Institutional Review Board that this requirement has been fulfilled.

<sup>&</sup>lt;sup>1</sup> See definitions later in this agreement and the Data Security Requirements exhibit.

<sup>&</sup>lt;sup>2</sup> These identifiers are specified later in this agreement.

#### 5. UW will not:

- (a) Use, publish, transfer, sell, or otherwise disclose any personal record information disclosed under the Agreement for any purpose that is not directly connected with project objectives identified in their proposal to DSHS without the express written permission of the Washington State Institutional Review Board;
- (b) Link DSHS personal record information or study database records, with information obtained from sources other than those identified in their proposal to DSHS without the express written permission of the Washington State Institutional Review Board;
- (c) Contact or attempt to contact any person identified in records provided by DSHS without the express written permission of the Washington State Institutional Review Board;
- (d) Disclose, publish, provide access to, or otherwise make known any individually identifiable information in DSHS records released under this Agreement, except as provided in RCW 42.48.040;
- (e) Copy, duplicate, or otherwise retain individually identifiable information provided or created under this Agreement for any use after study purposes have been accomplished.
- 6. UW will protect and maintain all personal record information disclosed to them under this Agreement against unauthorized use, access, disclosure, or loss by employing reasonable security measures as follows:
  - (a) Maintaining all DSHS personal record information in secure locations or in hard password-protected computer files when not in use;
  - (b) Physically securing any computers, documents, or other media containing personal record information;
  - (c) Restricting access to DSHS personal record information, the study database, and the master identifier file, to persons who have signed this Agreement;
  - (d) Using access lists, unique user IDs and Hardened Password authentication to protect personal record information placed on computer systems;
  - (e) Encrypting all personal record information that is store on portable devices including but not limited to laptop computers and flash memory drives;
  - (f) Encrypting electronic personal record information during transport;

- (g) Physically securing and tracking media containing personal record information during transport;
- (h) Notifying the Washington State Institutional Review Board within one business day of any theft, loss, unauthorized disclosure, or other potential or known compromise of personal record information disclosed under this Agreement.
- 7. UW agrees to comply with all other Data Security Requirements<sup>3</sup> for protection of records, segregation of records, and destruction of records that are incorporated into this Agreement.
- 8. UW agrees to use the information provided by DSHS for no purposes other than those described in their proposal to DSHS. Changes in study design and methods, changes that may affect approved study purposes, and/or use of this record information for thesis, dissertation, or other educational purposes that are not described in the UW proposal to DSHS, will be subject to prior review and approval by the Washington State Institutional Review Board.
- 9. DSHS assumes no responsibility for the accuracy or integrity of data derived or created from the source records provided under this Agreement, or for the accuracy or integrity of the source records once the UW has altered or modified them, or linked the records with other data files.
- 10. DSHS assumes no responsibility for the accuracy or validity of published or unpublished conclusions based in whole or in part on analyses of records provided to the UW.
- 11. UW agrees that DSHS shall have the right, at any time, to monitor, audit, and review activities and methods in implementing this Agreement, in order to assure compliance therewith.
- 12. UW agrees to conduct this project in compliance with all WSIRB approved procedures, and to submit progress reports as requested and study amendments as required, to maintain WSIRB study approval for this research. If WSIRB terminates study approval for any reason, this Agreement also is terminated.
- 13. In the event the UW fails to comply with any term of this Agreement, DSHS shall have the right to take such action as it deems appropriate, including termination of this Agreement. If the Agreement is terminated, UW will forthwith return all information provided by DSHS, including all materials derived from this information, or make such alternative disposition of provided and derived information as directed by DSHS. The exercise of remedies pursuant to this paragraph shall be in addition to all sanctions provided by law, and to legal remedies available to parties injured by unauthorized disclosure.
- 14. UW will hold DSHS harmless from any damage or other liability which might be assessed against DSHS as a result of any information received pursuant to this Agreement.

<sup>&</sup>lt;sup>3</sup> See Data Security Requirements exhibit attached to this agreement.

- 15. Unauthorized disclosure of any identifiable information provided under this Agreement is a gross misdemeanor and may result in a civil penalty of up to ten thousand dollars for each violation, under the provisions of RCW 42.48.050.
- 16. This Agreement becomes effective on the date it is signed by the DSHS official authorized to approve disclosure of identifiable records or record information for project purposes. This Agreement remains in effect until July 25, 2021, or until the UW provides written certification to the Washington State Institutional Review Board that all DSHS records and record information, and all study databases created in whole or in part from DSHS records or record information provided under this Agreement have been de-identified, destroyed, or returned to DSHS.

In Witness Whereof, the parties have signed their names hereto on the dates appearing with their signatures.

DSHS Children's Administration	Date	
Administrative Office of the Co Court Research		
King County Superior Court & C	Department of Adult and Juvenile Detention	Date
YouthCare		 Date
University of Washington		Date
Project Staff Member (Please Print Name)	Signature	Date
Project Staff Member (Please Print Name)	Signature	Date
 Project Staff Member	 	 Date

#### **Definitions**

The words and phrases listed below, as used in this Confidentiality Agreement, shall each have the following definitions:

Confidential information: means information that is exempt or prohibited from disclosure to the public or other unauthorized persons under RCW 42.56 or other federal or state laws.

De-identified records: means that all direct and indirect identifiers have been removed from individual level records. De-identified records are not considered PHI. Public use data sets are comprised of deidentified records.

Direct identifiers: means names; postal address information (other than town or city, state and zip code); telephone numbers; fax numbers; electronic mail addresses; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; web universal resource locators (URLs); internet protocol (IP) address numbers; biometric identifiers, including finger and voice prints; and full face photographic images and any comparable images.

Encrypt: means to encipher or encode electronic data using software that generates a minimum key length of 128 bits.

HIPAA Privacy Rule: standards to protect the privacy and confidentiality of individually identifiable health information. These and related standards are promulgated in federal law at Title 45 of the U.S. Code of Federal Regulations (45 CFR), Parts 160, 162 and 164.

Identifiable records: means that the records contain information that reveals or can likely be associated with the identity of the person or persons to whom the records pertain.

Indirect identifiers: include all geographic identifiers smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code; all elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such age and elements may be aggregated into a single category of age 90 or older.

Limited dataset: means a dataset comprised of records from which all direct identifiers have been removed. A limited dataset is comprised of non-identified records, which are, nevertheless, considered protected health information.

Non-identified records: means that all direct identifiers have been removed from the records, but indirect identifiers remain. Non-identified records are considered protected health information. A limited dataset is comprised of non-identified records.

Personal records: means any information obtained or maintained by a state agency which refers to a person and which is declared exempt from public disclosure, confidential, or privileged under state or federal law.

Physically secure: means that access is restricted through physical means to authorized individuals only.

Protected health information: means individually identifiable health information created or received by a health care provider, health plan, or health care clearinghouse (including business associates) that is a covered entity as defined by the HIPAA Privacy Rule, and which information is transmitted or maintained in any form or medium.

Secured area: means an area to which only authorized representatives of the entity possessing the confidential information have access. Secured areas may include buildings, rooms or locked storage containers (such as a filing cabinet) within a room, as long as access to the Confidential Information is not available to unauthorized personnel.

Tracking: means a record keeping system that identifies when the sender begins delivery of Confidential Information to the authorized and intended recipient, and when the sender receives confirmation of delivery from the authorized and intended recipient of Confidential Information.

Transport: means the movement of Confidential Information from one entity to another, or within an entity, that (1) places the confidential information outside of a Secured Area or system (such as a local area network) and (2) is accomplished other than via a trusted system.

Trusted systems: include only the following methods of physical delivery: (1) hand-delivery by a person authorized to have access to the Confidential Information with written acknowledgement of receipt, and (2) United States Postal Service ("USPS") delivery services that include Tracking, such as Certified Mail, Express Mail or Registered Mail. Any other method of physical delivery will not be deemed a Trusted System.

## De-identification Standard (45 CFR 164.514(b)(2)(i-ii), (c))

Individual level records are considered de-identified under the HIPAA Privacy Rule if the following standards are met:

(b)(2)

- (i) the following identifiers of the individual or of relatives, employers, or household members of the individual, are removed:
  - (A) Names;
  - (B) All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code if, according to the current publicly available data from the Bureau of the Census:
    - (1) The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and
    - (2) The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people are changed to 000.
  - (C) All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
  - (D) Telephone numbers;
  - (E) Fax numbers;
  - (F) Electronic mail addresses;
  - (G) Social security numbers;
  - (H) Medical record numbers;
  - (I) Health plan beneficiary numbers;
  - (J) Account numbers;
  - (K) Certificate/license numbers;
  - (L) Vehicle identifiers and serial numbers, including license plate numbers;
  - (M) Device identifiers and serial numbers;
  - (N) Web Universal Resource Locators (URLs);
  - (O) Internet Protocol (IP) address numbers;
  - (P) Biometric identifiers, including finger and voice prints;
  - (Q) Full face photographic images and any comparable images; and
  - (R) Any other unique identifying number, characteristic, or code, except as permitted by paragraph (c) of this section; and
- (ii) The covered entity does not have actual knowledge that the information could be used alone or in combination with other information to identify an individual who is a subject of the information.

- (c) Implementation specifications: re-identification. A covered entity may assign a code or other means of record identification to allow information de-identified under this section to be re-identified by the covered entity, provided that:
  - (1) Derivation. The code or other means of record identification is not derived from or related to information about the individual and is not otherwise capable of being translated so as to identify the individual; and
  - (2) Security. The covered entity does not use or disclose the code or other means of record identification for any other purpose, and does not disclose the mechanism for re-identification.

### **Data Security Requirements**

- 1. Definitions. The words and phrases listed below, as used in this Exhibit, shall each have the following definitions:
  - a. "Authorized UW(s)" means a UW staff with an authorized business requirement to access DSHS Confidential Information for this project.
  - b. "Hardened Password" means a string of at least eight characters containing at least one alphabetic character, at least one number and at least one special character such as an asterisk, ampersand or exclamation point.
  - c. "Unique User ID" means a string of characters that identifies a specific user and which, in conjunction with a password, passphrase or other mechanism, authenticates a user to an information system.
- 2. Data Transport. When transporting DSHS Confidential Information electronically, including via email, the Data will be protected by:
  - a. Transporting the Data within the (State Governmental Network) SGN or UW' internal network, or;
  - b. Encrypting any Data that will be in transit outside the SGN or UW' internal network. This includes transit over the public Internet.
- 3. Protection of Data. The UW agrees to store Confidential Information on one or more of the following media and protect Confidential Information as described:
  - a. Hard disk drives. Confidential Information stored on local workstation hard disks. Access to Confidential Information will be restricted to Authorized RESEARCHER(s) by requiring logon to the local workstation using a Unique User ID and Hardened Password or other authentication mechanisms which provide equal or greater security, such as biometrics or smart cards.
  - b. Network server disks. Confidential Information stored on hard disks mounted on network servers and made available through shared folders. Access to Confidential Information will be restricted to Authorized UW through the use of access control lists which will grant access only after the Authorized UW has authenticated to the network using a Unique User ID and Hardened Password or other authentication mechanisms which provide equal or greater security, such as biometrics or smart cards. Confidential Information on disks mounted to such servers must be located in an area which is accessible only to authorized personnel, with access controlled through use of a key, card key, combination lock, or comparable mechanism.

- For DSHS Confidential Information stored on these disks, deleting unneeded Confidential Information is sufficient as long as the disks remain in a Secured Area and otherwise meet the requirements listed in the above paragraph.
- c. Optical discs (CDs or DVDs) in local workstation optical disc drives. Confidential Information provided by DSHS on optical discs which will be used in local workstation optical disc drives and which will not be transported out of a Secured Area. When not in use for a study purpose in accordance with this Agreement, such discs must be locked in a drawer, cabinet or other container to which only Authorized UW has the key, combination or mechanism required to access the contents of the container. Workstations which access DSHS Confidential Information on optical discs must be located in an area which is accessible only to authorized personnel, with access controlled through use of a key, card key, combination lock, or comparable mechanism.
- d. Optical discs (CDs or DVDs) in drives or jukeboxes attached to servers. Confidential Information provided by DSHS on optical discs which will be attached to network servers and which will not be transported out of a Secured Area. Access to Confidential Information on these discs will be restricted to Authorized UW through the use of access control lists which will grant access only after the Authorized UW has authenticated to the network using a Unique User ID and Hardened Password or other authentication mechanisms which provide equal or greater security, such as biometrics or smart cards. Confidential Information on discs attached to such servers must be located in an area which is accessible only to authorized personnel, with access controlled through use of a key, card key, combination lock, or comparable mechanism.
- e. Paper documents. Any paper records must be protected by storing the records in a Secured Area which is only accessible to authorized personnel. When not in use, such records must be stored in a locked container, such as a file cabinet, locking drawer, or safe, to which only authorized persons have access.
- **Remote Access.** Access to and use of Confidential Information over the State Governmental Network (SGN) or Secure Access Washington (SAW) will be controlled by DSHS staff who will issue authentication credentials (e.g., a Unique User ID and Hardened Password) to Authorized UW. UW will notify DSHS staff immediately whenever an Authorized RESEARCHER in possession of such credentials is terminated or otherwise leaves the employ of the UW, and whenever an Authorized RESEARCHER's duties change such that the RESEARCHER no longer requires access to perform work under this Agreement.
- g. Data storage on portable devices or media.
  - (1) Except where otherwise specified herein, DSHS Confidential Information shall not be stored by UW on portable devices or media unless specifically authorized within the terms and conditions of this Agreement. If so authorized, Confidential Information shall be given the following protections:

- (a) Encrypt Confidential Information with a key length of at least 128 bits.
- (b) Control access to devices with a Unique User ID and Hardened Password or stronger authentication method such as a physical token or biometrics.
- (c) Manually lock devices whenever they are left unattended and set devices to lock automatically after a period of inactivity, if this feature is available. Maximum period of inactivity is 20 minutes.

Physically secure the portable device(s) and/or media by

- (d) Keeping them in locked storage when not in use
- (e) Using check-in/check-out procedures when they are shared, and
- (f) Taking frequent inventories
- (2) When being transported out of a Secured Area, portable devices and media with DSHS Confidential Information must be under the physical control of UW with authorization to access the Confidential Information.
- (3) Portable devices include, but are not limited to; smart phones, tablets, flash memory devices (e.g. USB flash drives, personal media players), portable hard disks, and laptop/notebook/netbook computers if those computers may be transported outside of a Secured Area.
- (4) Portable media includes, but is not limited to; optical media (e.g. CDs, DVDs), magnetic media (e.g. floppy disks, tape), or flash media (e.g. CompactFlash, SD, MMC).

### h. Data stored for backup purposes.

- (1) DSHS Confidential Information may be stored on portable media as part of UW' existing, documented backup process for business continuity or disaster recovery purposes. Such storage is authorized until such time as that media would be reused during the course of normal backup operations. If backup media is retired while DSHS Confidential Information still exists upon it, such media will be destroyed at that time in accordance with the disposition requirements in Section 5. Data Disposition.
- (2) DSHS Confidential Information may be stored on non-portable media (e.g. Storage Area Network drives, virtual media, etc.) as part of UW' existing, documented backup process for business continuity or disaster recovery purposes. If so, such media will be protected as otherwise described in this exhibit. If this media is retired while DSHS Confidential Information still exists upon it, the data will be destroyed at that time in accordance with the disposition requirements in Section 5. Data Disposition.

- 4. Data Segregation. DSHS Confidential Information must be segregated or otherwise distinguishable from non-DSHS data. This is to ensure that when no longer needed by the UW, all DSHS Confidential Information can be identified for return or destruction. It also aids in determining whether DSHS Confidential Information has or may have been compromised in the event of a security breach. As such, one or more of the following methods will be used for data segregation:
- a. DSHS Confidential Information will be kept on media (e.g. hard disk, optical disc, tape, etc.) which will contain no non-DSHS data. And/or,
- b. DSHS Confidential Information will be stored in a logical container on electronic media, such as a partition or folder dedicated to DSHS Confidential Information. And/or,
- c. DSHS Confidential Information will be stored in a database which will contain no non-DSHS data. And/or,
- d. DSHS Confidential Information will be stored within a database and will be distinguishable from non-DSHS data by the value of a specific field or fields within database records.
- e. When stored as physical paper documents, DSHS Confidential Information will be physically segregated from non-DSHS data in a drawer, folder, or other container.
- f. When it is not feasible or practical to segregate DSHS Confidential Information from non-DSHS data, then both the DSHS Confidential Information and the non-DSHS data with which it is commingled must be protected as described in this exhibit.
- 5. Data Disposition. When the project has been completed or when DSHS Confidential Information is no longer needed, DSHS Confidential Information shall be returned to DSHS or destroyed. Media on which Confidential Information may be stored and associated acceptable methods of destruction are as follows:

Data stored on:	Will be destroyed by:
Server or workstation hard disks, or	Using a "wipe" utility which will overwrite the Data at least three (3) times using either random or single character data, or
Removable media (e.g. floppies, USB flash drives, portable hard disks) excluding optical discs.	Degaussing sufficiently to ensure that the Data cannot be reconstructed, or
	Physically destroying the disk.
Paper documents with sensitive or Confidential Information.	Recycling through a contracted firm provided the contract with the recycler assures that the confidentiality of Data will be protected.
Paper documents containing Confidential Information requiring special handling (e.g. Protected Health Information).	On-site shredding, pulping, or incineration.
Optical discs (e.g. CDs or DVDs).	Incineration, shredding, or completely defacing the readable surface with a coarse abrasive.
Magnetic tape.	Degaussing, incinerating or crosscut shredding.

- 6. Notification of Compromise or Potential Compromise. The compromise or potential compromise of DSHS shared Confidential Information must be reported to the WSIRB within one (1) business day of discovery. UW must also take actions to mitigate the risk of loss and comply with any notification or other requirements imposed by law or DSHS.
- 7. Data Shared with Subcontractors. If DSHS Confidential Information provided under this Agreement is to be shared by UW with a subcontractor, UW's contract with the subcontractor must include all of the data security provisions within this Agreement and within any amendments, attachments, or exhibits within this Agreement. If the UW cannot protect the Confidential Information as articulated within this Agreement, then the contract with the sub- UW must be submitted to the WSIRB for review and approval.

# **C.3. Sample Release of Information Form**

Authorization to Release & Exch	ange Information Within The System of Care	
Child's Name	Date of Birth	
Child's ID #	Parent/Guardian	
I hereby authorize the disclosure and a	receipt of the following protected health information	
	v, indicating that you agree to share the noted information).	
Admission Assessment & Screening	Alcohol or Drug History & Treatment* Specifically note what is to be released in "OTHER" below. If over the age of 12 - child must also sign:	
Discharge Evaluation	Medication History	
Psychiatric Evaluation	Psychological Evaluation	
Progress Notes from: to	School Performance & Attendance Information	
Juvenile Justice Assessment & Service Plan Mental Health Treatment Plan & Diagnosis		
Other*		
This information will	be used for the specific purpose(s):	
<ul> <li>To make the application for services easier for</li> <li>To coordinate the services that are delivered</li> <li>To collect data for use in evaluating this system</li> </ul>		
Other	Parent/Guardian Initial Here	
	pating in Alamance System of Care may include:	
	rith whom you wish to share the above initialed information):	
Alamance-Bur lington School System (ABSS)	Alamance County Law Enforcement Agencies	
Alamance County Social Services	Alamance County Health Department	
Alamance County DJJDP	Alamance County District Attorney's Office	
Alamance Regional Medical Center	Guardian Ad Litem	
Crossroads Sexual Assault	Alamance- Caswell LME	
Response & Resource Center Exchange Club Family	Alamance System of Care	
Center in Alamance Alamance County Dispute Settlement & Yout	(SOC) Review The Family Abuse Services	
Services  Mental Health Provider(s) Specify:	Other	
protecting health information may not apply to the recip disclosing it. When mental health and developmental disc substance abuse treatment information protected by Federa disclosure is prohibited except as permitted or required by the I understand that I may revoke this authorization at any threvoked earlier, this authorization expires automatically on authorization form. I understand that the Alamance System this authorization. I certify that this authorization is m	time except to the extent that action has been taken in reliance on it. If not he year from the date it is signed. I understand that I may refuse to sign this n of Care will not condition my child's treatment on receiving my signature on hade freely, voluntarily and without coercion. I understand that ONLY the brmation is needed I will be asked to sign an authorization for the disclosure of	
Signature of Parent/Legal Guardian	Date	
<u>-</u>		
Signature of Service Provider/Staff Agency	Date	
Confidential	11/22/2010	
Revocation Date:	Signature:	