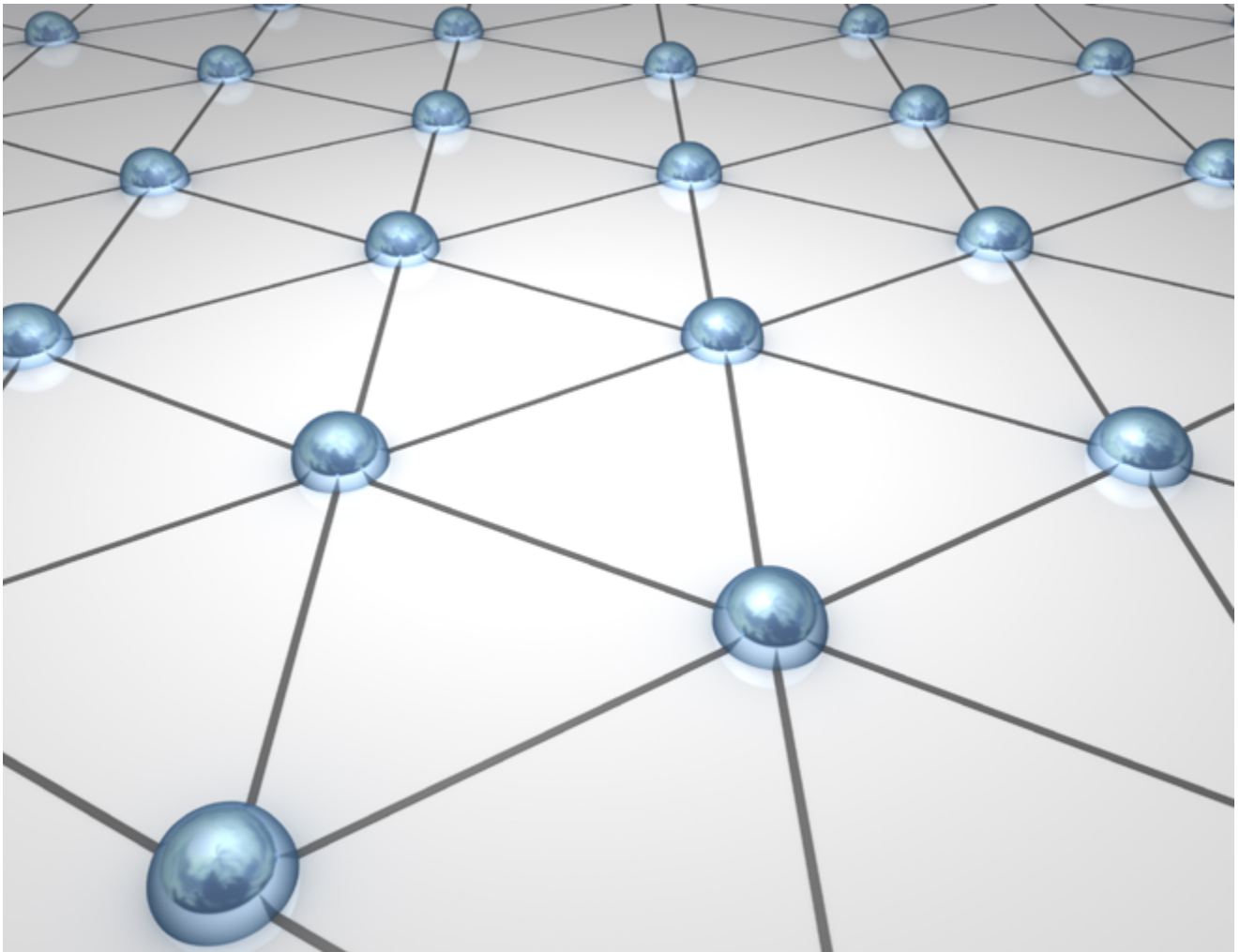


# Sharing Data *for* Better Results



A GUIDE TO BUILDING INTEGRATED  
DATA SYSTEMS COMPATIBLE WITH FEDERAL  
PRIVACY LAWS

[CLICK HERE TO VIEW CONTENTS](#)



# Sharing Data *for* Better Results



PREPARED BY:



**STEWARDS OF CHANGE™**  
THE BUSINESS OF PUBLIC BENEFIT™

100 Centershore Road  
Centerport  
New York, NY 11721  
[www.stewardsofchange.com](http://www.stewardsofchange.com)

*and*



1301 Pennsylvania Avenue  
NW, Suite 550  
Washington, DC 20004  
[www.nlc.org](http://www.nlc.org)

**2014**

*The National League of Cities and Stewards of Change partnered to develop this toolkit to help cities successfully navigate the delicate balance between privacy and the delivery of efficient and effective services. Publication of this toolkit was made possible by the generous support of the Annie E. Casey Foundation.*



## Table of Contents

<b>INTRODUCTION</b> .....	5
<u>What is in this toolkit?</u> .....	5
<u>How can the toolkit be used?</u> .....	5
<u>Who should read and use this toolkit?</u> .....	5
<u>How is this toolkit structured?</u> .....	5
<b>BACKGROUND</b> .....	7
<u>Why Share Data?</u> .....	7
<u>Operating Efficiency</u> .....	7
<u>Program Evaluation and Improvement</u> .....	8
<u>Polymaking</u> .....	8
<u>Program Eligibility and Enrollment</u> .....	8
<u>Case Management</u> .....	9
<u>Getting to Yes</u> .....	9
<u>Narrowing the Scope</u> .....	10
<u>Creating Clear Policies &amp; Engaging Families</u> .....	10
<u>Establishing Governance</u> .....	10
<b>GETTING STARTED</b> .....	12
<u>Necessary Participants</u> .....	12
<u>Key Tasks for Agency Leads</u> .....	12
<u>Shared Vision</u> .....	13
<u>Data Decisions</u> .....	13
<u>Staff Development</u> .....	13
<u>Technology</u> .....	14
<u>Legal Development</u> .....	14
<u>Putting It All Together: The MOU or MOA</u> .....	15
<u>Communications and Public Engagement</u> .....	15



*“This Toolkit is designed to help city leaders build better communities through responsible information sharing.”*

*(Continued)*

# Sharing Data *for* Better Results



*“Enhancing an organization’s ability to responsibly share information is a core competency for improving program effectiveness.”*

<b>EDUCATION</b> .....	16
<a href="#">Major Federal Laws</a> .....	16
<a href="#">The Case for Sharing</a> .....	16
<a href="#">Federal Legislation Related to Educational Information Sharing</a> .....	18
<a href="#">Implementation: What and Who</a> .....	20
<a href="#">Implementation: How</a> .....	23
<b>HEALTH</b> .....	25
<a href="#">Major Federal Laws</a> .....	25
<a href="#">The Case for Sharing</a> .....	25
<a href="#">Federal Legislation Related to Sharing Health Information</a> .....	26
<a href="#">Implementation: What and Who</a> .....	29
<a href="#">Implementation: How</a> .....	34
<b>MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT</b> .....	36
<a href="#">Major Federal Laws</a> .....	36
<a href="#">The Case for Sharing</a> .....	36
<a href="#">Federal Legislation Related to Mental Health and Drug and Alcohol Treatment Information Sharing</a> .....	38
<a href="#">Implementation: What and Who</a> .....	40
<a href="#">Implementation: How</a> .....	40
<b>HUMAN SERVICES &amp; CRIMINAL JUSTICE</b> .....	43
<a href="#">Major Federal Laws, Regulations, and Programs</a> .....	43
<a href="#">Child Welfare, Juvenile Justice, and the Courts</a> .....	43
<a href="#">Child Support and Establishment of Paternity</a> .....	45
<a href="#">Supplemental Nutrition Assistance Program</a> .....	46
<a href="#">Supplemental Security Income</a> .....	46
<a href="#">Temporary Assistance for Needy Families</a> .....	46
<a href="#">Violence against Women</a> .....	47
<b>APPENDIX A:</b>	
<a href="#">Additional Resources</a> .....	48
<b>APPENDIX B:</b>	
<a href="#">Sample MOU’s</a> .....	49
<b>APPENDIX C:</b>	
<a href="#">Laws and Regulations</a> .....	50

# Sharing Data *for* Better Results



## INTRODUCTION

## BACKGROUND

## GETTING STARTED

## EDUCATION

## HEALTH

## MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT

## HUMAN SERVICES AND CRIMINAL JUSTICE

## APPENDIX A: ADDITIONAL RESOURCES

## APPENDIX B: SAMPLE MOU'S

## APPENDIX C: LAWS AND REGULATIONS

## Introduction

### WHAT IS IN THIS TOOLKIT?

THIS TOOLKIT SUMMARIZES IMPORTANT information that elected officials, agency leaders, and city staff need to know about the federal laws and regulations related to individual privacy rights that govern data-sharing. The purpose is to support local leaders in using integrated data to improve services while respecting the privacy of residents.

### HOW CAN THE TOOLKIT BE USED?

THE TOOLKIT CAN BE USED AS:

- » An information resource;
- » An identifier of where and why problems are likely to arise;
- » A foundation of an informed data-sharing dialogue between actors;
- » A structured guide to making good decisions that balance data-sharing and privacy needs;
- » A way to open a conversation with state leaders about revising state policies that may be more restrictive than the federal government when it comes to data sharing; and
- » A “road map” for the city to get to “YES” and be able to share limited but essential and important information regarding clients without violating laws and getting into trouble.

The toolkit should not be used as a replacement for the important process of consulting with your own legal counsel, or a short-cut to a borrowed MOU that does not reflect a locally-shared vision and does not have vested stakeholders.

### WHO SHOULD READ AND USE THIS TOOLKIT?

- » Elected officials
- » City administrators or agency directors
- » Relevant staff for whom integrated data could improve their results and efficiency
- » Ombudspersons
- » City partners engaged in data sharing conversations

### HOW IS THIS TOOLKIT STRUCTURED?

IN THIS TOOLKIT YOU WILL FIND THE QUESTIONS TO ASK:

- » What are the benefits of sharing data? What is the public good to be promoted?
- » Why is it necessary to share the information? What kinds of information can be shared, what may not be, and what is in the “grey” area?

# Sharing Data *for* Better Results



## INTRODUCTION

## BACKGROUND

## GETTING STARTED

## EDUCATION

## HEALTH

## MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT

## HUMAN SERVICES AND CRIMINAL JUSTICE

## APPENDIX A: ADDITIONAL RESOURCES

## APPENDIX B: SAMPLE MOU'S

## APPENDIX C: LAWS AND REGULATIONS

- » What is the best method for information sharing?
- » Who can receive the information?
- » How will those receiving the information maintain its confidentiality and protect it from further disclosure?
- » How long will the records live and be accessible?

Individual chapters addressing confidentiality and privacy through the lens of particular services:

- » Education
- » Health and mental health
- » Drug and alcohol treatment
- » Child welfare, juvenile justice, the courts, and child support
- » Public assistance and food stamps
- » And others.

Reviews of more than twenty federal privacy laws regarding public benefits and public entitlements, medical insurance for the poor and disabled, child care and child welfare services, education and other federally-funded services, through the Departments of Health and Human Services, Education and Agriculture. This toolkit provides:

- » A basic, understandable description of the confidentiality issues raised in each law and the specific language permitting information sharing
- » Case scenarios encapsulating the opportunities for data-sharing
- » Sample MOUs/MOAs and other documents you can adapt for your own situation
- » Tables outlining each law, explaining the information sharing permitted and prohibited, and resolving prevailing myths



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Background

### WHY SHARE DATA?

TODAY, INDIVIDUALS AND FAMILIES RECEIVING government services are often involved with multiple systems. A child who is struggling in school may also be touched by an afterschool mentoring program, a full-day parks and recreation summer program, nutritional supports, and child welfare services. A young adult detained in jail may receive mental health and drug and alcohol treatment services and may have sporadically participated in local job training programs. A mother of a young child may receive income assistance, job readiness coaching, child care, housing assistance, and child support enforcement services. These services are typically designed to act alone, with each requiring data according to different rules and eligibility requirements, creating their own instructional or service plans for the client to follow, and assigning staff unknown to each other to oversee the same case. There are often multiple case managers, teachers, health care providers or other professionals involved in the lives of children and families with no clear lead, and duplicate services provided.

The positive impact of coordinated care and integrated case management on improving the overall health and well-being of individuals is well documented. Better outcomes mean healthier, safer, stabilized individuals and families with a better chance of sustaining self-sufficiency and long-term personal success. Public systems benefit from both efficiencies stemming from data sharing and overall savings resulting from improved outcomes for residents, allowing each agency to do more with limited resources.

There are a number of reasons that city leaders and their community partners choose to pursue data sharing agreements, but they all boil down to: operating in a more efficient and effective way to improve outcomes for residents.

### OPERATING EFFICIENCY

WHEN EDUCATION, HEALTH OR HUMAN SERVICE workers are operating with access only to their own data, their decisions cannot be as targeted and nuanced as they might be with more information. This leads to misplaced or duplicative efforts in many cases, and missed opportunities in others.

**EXAMPLE:** A child welfare system receives an allegation through its hotline that a child is being abused. The caller wishes to remain anonymous but provides the names of the parent and child, the home address, and the child's age. The child welfare worker will investigate the situation with only the ability to see if the child and/or the parent receive or recently received child welfare services from this particular jurisdiction.

If there was appropriate information sharing, the worker would be able to check the names and/or address with other systems to see if the individuals are known to these systems,

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

including but not limited to law enforcement, juvenile justice, behavioral health services, and financial and medical assistance. Without being able to learn the specifics, but having information on whether the person or family is known to another system, the worker could make a better decision as to how to prioritize large caseloads, and what to look into when investigating.

## PROGRAM EVALUATION AND IMPROVEMENT

DATA SHARING CAN BE VERY HELPFUL in the area of program oversight, accountability, and continuous improvement. Local officials can monitor and assess program administration for program performance measures and efficiency on an ongoing basis. Data sharing can offer a more complete picture of service provision and its effectiveness and promote detection and reduction of ineligible or fraudulent applications.

**EXAMPLE:** An afterschool program has a goal of boosting the attendance and educational attainment of students who are enrolled, but has no way of determining whether what they are doing is having the intended effect.

Through data sharing agreements with the school, the program could learn whether their participants' attendance rates and grades do in fact rise. If these results are not seen consistently, the program can try new approaches and monitor results to better meet the needs of students in the program.

## POLICYMAKING

SHARED DATA CAN HELP IDENTIFY TRENDS that can inform policymaking at the city or agency level. By identifying patterns of engagement across different systems, policymakers can better target prevention services to those who are demonstrating system-involvement patterns indicative of a path that will lead to more negative outcomes.

**EXAMPLE:** Without solid data that cuts across system siloes, local officials can only see that a rising percentage of teens and young adults are being convicted for violent crimes.

An analysis of patterns of youth engagement across education (behavior problems, truancy, failing grades), criminal justice, mental health, and child welfare systems in the community identifies that the risk of a conviction for a violent crime is significantly higher for youth flagged in three of these systems. Understanding these patterns allows policymakers to allocate more resources to prevention and wrap around supports, focusing these services on youth who demonstrate early red flags in two systems.

## PROGRAM ELIGIBILITY AND ENROLLMENT

SILOED PROGRAMS WITH INDEPENDENT eligibility rules yield significant inefficiencies for both the agencies involved and the applicants. Eliminating these inefficiencies through a com-



# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

mon application or other system of shared data can make the system less costly to manage overall, and will lead to better outcomes for families.

**EXAMPLE:** A mother with three children who recently lost her job needs housing assistance, financial assistance, child care help and medical insurance. That mother may have to apply for each of these publicly-funded services in four different offices. In each office, she will have to provide similar if not the exact same information even though she already provided the information to another office.

With a common application, the mother could access all of these services through the free internet at a public library and complete one application for a myriad of services. After being determined eligible for the first service, the mother could sign a release permitting information to be shared for case planning among all publicly-funded services except for those specifically barred from receiving or sharing information.

## CASE MANAGEMENT

A MAJOR BENEFIT OF DATA SHARING involves case management, where a frontline staff person assesses client needs, service planning, service referral, and service monitoring. Data sharing can ensure that caseworkers have the necessary and complete information to make appropriate decisions. It makes the caseworker's job more efficient by reducing demands on staff to do everything manually and provides more integrated services for individuals and families with complex and overlapping needs.

**EXAMPLE:** A case worker serving a homeless individual who is seeking shelter services may have very little understanding of prior health and mental health history, others who have been involved in the individual's life, and the outcome of prior interventions.

If the information from these different systems was integrated, with the client's permission the case worker could access helpful demographic and service history information that would aid them in understanding the array of services currently being provided, tried in the past (with a successful outcome or not), and family and friends who wish to be actively involved in helping the homeless person regain his self-sufficiency and self-assurance.

This toolkit will address itself primarily to information sharing that is identifiable to the client for the purposes of individual case planning and decision-making. Aggregated and de-identified information is helpful in the development of policies and programs but does not help the front-line case manager to develop a client's service plan. There are also a number of other helpful subject matter toolkits regarding aggregate data and information sharing which are referenced in Appendix A of this toolkit.

## GETTING TO YES

FEDERAL CONFIDENTIALITY LAWS AND RULES are often an early stumbling block when cities seek to share information. The answer to the question of whether and how information

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

can be shared is too often a resounding “NO” with the reason given being “confidentiality” or more specifically, the Family Education Rights and Privacy Act (FERPA) or Health Insurance Portability and Accountability Act (HIPAA).

This toolkit is a “road map” for city systems to get to “YES” and share limited but essential information on common clients to design intervention or service plans, determine the best way to reach successful closure for a series of cases, assess whether a program is successful, or retool whole agencies to be more efficient and effective.

## NARROWING THE SCOPE

IN ORDER TO GET TO “YES” – and have the data sharing lead to the desired results -- it is important for the agencies sharing the information to determine what specific information is needed and why, from whom they can obtain such information, and how to obtain the information. When a request is written or responded to too broadly, the outcome misses the desired mark. While the easy road may seem to be just to ask for “any and all information that you have regarding John Doe,” such a broad request will typically be denied. Even if approved, the caseworker, teacher or health professional who receives “any and all information” on an individual has the almost impossible job of wading through pages of information seeking something that may help them in providing services. As a result, the information is never carefully reviewed, is not helpful, and is merely filed in the record.

## CREATING CLEAR POLICIES & ENGAGING FAMILIES

AS DISCUSSED BELOW, CITIES NEED to clarify in their own policies and processes about who will have access to information, and how clients will be notified regarding the storage, use, re-use, sharing, and client correction or update of information. If everyone has a shared understanding of why and how data will be shared, with basic privacy safeguarded, the families and individuals being served and those who advocate on their behalf will become allies of these efforts, rather than skeptical observers or outright opponents. Transparency and engagement about goals and processes – with partners and the public – is critical to getting to “yes” and sustaining a meaningful program.

## ESTABLISHING GOVERNANCE

FINALLY, A THOUGHTFULLY ESTABLISHED governance system can allay fears and lead to a better data sharing relationship among partners over time. Through the establishment of the federal State Systems Interoperability and Integration Project, selected states had the opportunity to work on issues presenting barriers to health and human services interoperability and share the learnings with all states and localities. A [handbook](#) based on this project details six common attributes for a successful governance process:

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

1. Identify and assemble strong executive leadership;
2. Create a shared vision;
3. Formalize and document the governance structure;
4. Establish clear decision-making process;
5. Evaluate governance system and adapt as necessary; and
6. Maintain transparent communications.

The handbook, based on experiences in Illinois, goes into depth on the reasons for each of the attributes and discusses how each has been helpful in other successful interoperability projects, and is an indispensable resource in developing a data sharing governance structure.



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Getting Started

This section provides local leaders with a brief overview of the steps required to develop information sharing plans to improve outcomes for clients, increase efficiency of operations, and protect the confidentiality rights of individuals. This undertaking requires a significant investment of time and effort from many people, and an unwavering leadership commitment to drive the process forward.

### NECESSARY PARTICIPANTS:

- » Top leaders of the different systems to convene groups, set the tone and direction, develop a privacy policy, and then use the dictates of that policy to reach a Memorandum of Understanding regarding the information sharing process.
- » Lawyers to determine how to appropriately address confidentiality and privacy issues.
- » Technology personnel to determine the manner of sharing the information that best meets the objectives for the data integration in the most cost-effective manner.
- » Security officers to verify the recipients of the information and ensure ongoing data safety.
- » Last, and of paramount importance, program policy and practice experts, from different roles and positions, to determine the specific information to be shared to achieve better outcomes for the clients.

### KEY TASKS FOR AGENCY LEADS:

- » Taking the lead to get all parties to agree on **“why”** the systems involved should share data.
- » Designating a team of staff representing the systems from which data will be shared to create the **“what,”** or list of minimally necessary information that needs to be shared for the legitimate governmental purpose to succeed and **“who”** needs to receive such information.
- » Forming a team, including the privacy officials and the information technology staff, to determine **“how”** to share the information and how to use it once it has been shared. This group also will develop policies and procedures regarding the privacy security and safeguards of the shared information. The result will be enforced by the privacy officials from the affected agencies.
- » Formalizing these agreements in a Memorandum of Understanding (MOU) or Memorandum of Agreement (MOA).
- » Arranging for extensive training of all members of the workforce on the policies and procedures of the information sharing project once it is initiated and fully implemented.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » Putting in place a system to monitor the implementation and impact of data sharing agreements to determine if they are having the intended positive impact and if not, to make necessary adjustments.

## SHARED VISION

Before diving into the details of confidentiality, technology, or protocols, agencies must come together and answer the **“why”** question. Why should systems share information when we never have shared in the past? How will it help workers do their jobs better? How will it help those being served? Why now?

It is important that partners enter into this work with a shared vision that clearly articulates the reason for the information sharing initiative. What outcomes for individuals or families can be improved through data integration? Is the intention to inform policy, evaluate the impact of programs, or intervene more effectively on behalf of individual children or adults? In what specific ways will shared data help these systems provide better services to residents, make workflow more efficient, or generate cost savings over time? Each party involved in the data sharing effort should be able to see a direct benefit of their involvement to ensure full and sustained participation. Once committed, municipal or agency leadership can play a key role in communicating this benefit – and the importance of data integration – to staff at all levels.

## DATA DECISIONS

As part of any information sharing initiative, it is essential for the staff, at all levels of the involved systems, to meet to decide **“what”** information is minimally necessary to be shared in order to accomplish the mission. The **“what”** includes not only which variables, but also how frequently the data observation is taken and reported, over what period of time, and the level of the data (individual, family, program group, etc.) This is an essential and challenging part of the process because, as noted above, the group must be very selective and specific. Too little information is not useful, but too much information is equally useless. If the information is not necessary, then it should not be shared. While often a frustratingly tedious process, it is worth the effort. This group should also learn from other jurisdictions that have shared similar information to understand how they accomplished the task, their successes, and pitfalls to avoid.

## STAFF DEVELOPMENT

In addition to what information is necessary, this group needs to determine **“who”** needs the information. This part of the process will identify the staff persons or classes of persons—and the supervisory chain—requiring access to the shared protected information, and any conditions appropriate to such access.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

For persons or classes of persons other than case managers and their supervisory chain, this group needs to conduct a careful review to determine whether the shared information is necessary to perform essential functions.

It is also important to be clear how those receiving the data will get it and use it, and to identify training needs so that all such workers are clear about how to interpret and act on the data they receive.

## TECHNOLOGY

The partners should take the next step to clearly spell out **“how”** the data will be shared and reviewed from a technological standpoint.

What system yields the best information for the desired type of data sharing? Is it important that data is available in real time (typically through a federated system), or is it better to have it gathered regularly and cleaned up in a data warehouse?

## LEGAL DEVELOPMENT

Lawyers for cities have the critical job of protecting the government. In many ways, they are truly the epitome of the “public interest lawyer” because their client is the government, which serves the public. It is a tremendously important role in the arena of public services. At the same time, the city attorney’s role is to protect the government from legal attacks and to act in a risk-averse manner. Generally, the government attorney is asked “Is this legal?” or “Will we be sued?” or “Will we win?” These are difficult questions to answer with absolute accuracy. As a result, the government lawyer is mentored in her or his position to be wary of new ways of doing things, arguing: “If we know we’re on solid legal footing doing things the way we’ve always done them, let’s continue on the safe path.”

It is important that leadership can spell out the compelling public and agency case for sharing data, and engage agency lawyers in these initiatives to ensure that the key goals are accomplished in ways that appropriately protect confidentiality. Leadership in all involved agencies must make clear to their legal staffs that they want to share the information, that it is an important initiative, and that the agencies need the lawyers to help make it happen. Therefore, for any barrier identified, the legal group must also present suggestions to overcome the barrier. The process should include reviewing federal, state, and local laws as relevant to determine any barriers or requirements for information sharing. The explanation and discussion must be understandable to the layperson and not only to other lawyers.

The legal group’s accomplishments must also include drafting appropriate notices of information sharing, authorizations, and transparent policies and procedures for clients to understand that information will be shared and the method for its sharing. Such notices and authorizations must be written in plain language and translated into other languages as needed in the community.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## PUTTING IT ALL TOGETHER: THE MOU OR MOA

Before launching a data sharing initiative, cities will need to develop a document — a Memorandum of Understanding (MOU) or Memorandum of Agreement (MOA) — to spell out the agreed upon purpose of the initiative, the human and technological implementation plans, and the agreed upon privacy and security protections associated with an integrated data system. The process used to create these documents may be more important than the actual document, so [samples](#) should not be viewed as shortcuts to the real collaboration required.

Because each system has been accustomed to functioning in isolation from other systems, there is often a lack of knowledge among potential data sharing partners about each other's ways of operating and even a different professional language to discuss clients and services. Given that one system does not know the policies, procedures, laws, and regulations of another system, there is often a lack of trust between practitioners of different areas that can only be overcome through sustained collaboration. Building trust takes time. It must be an inclusive process involving the different levels and roles within the agency to provide input on the importance of information sharing, the ways data sharing could improve job performance, and the specific information required.

## COMMUNICATIONS AND PUBLIC ENGAGEMENT

As emphasized above, the public and the advocates should also be kept informed during the process to address any concerns that the ease of data sharing through electronic information technology will erode confidentiality and privacy rights. Leadership should be clear with the population being served, the advocates, the legislative body, the providers and practitioners, the other system partners, and the public that this project will include an investigation and thorough review of the privacy and confidentiality issues and that these rights will be acknowledged and appropriately protected. Technology will be employed to aid in this process by securely maintaining and protecting any data involved.

Throughout, it will be important to share information—on the data to be shared, how it will be shared, and the protections of that information once shared—with all concerned constituents to ensure the project's transparency and avoid or significantly decrease fears and build support for a more effective system.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Education

### MAJOR FEDERAL LAWS:

**Family Educational Rights and Privacy Act (FERPA)**

**Individuals with Disabilities Education Act (IDEA)**

**McKinney-Vento Act**

### THE CASE FOR SHARING

VARIOUS AGENCIES SERVING CHILDREN AND FAMILIES require information from the education system to fully carry out their missions and provide for the safety and well-being of youth.

Sharing along the spectrum of educational and workforce programs can help educators and other leaders better understand an individual's needs, while providing feedback loops that can lead to program improvement.

- » Data sharing between **early care and education programs** and elementary schools allows kindergarten teachers to be better informed about the progress and special needs of their students right from the start.
- » Sharing data between schools and **out-of-school time (OST)** programs can allow teachers and OST leaders to work in partnership to help students develop to their potential.
- » As a young adult leaves high school and goes to college, schools or their city partners can work with the Department of Education to get **FAFSA completion data** to better target outreach.

## CITY EXAMPLE



**THE CITY OF LOUISVILLE HAS PARTNERED** with the Jefferson County Public Schools (JCPS), Metro United Way and other community-based organizations on a data-sharing system that allows community-based organizations and schools to share and access aggregate and individual data on the youth they serve, including kindergarten readiness, assessment scores and grades, attendance at both school and out-of-school time (OST) programs, suspensions, schools survey data, data from supplemental online learning programs, and readiness for graduation and college or career.

*This system not only allows partners to assess the effects of programs on student achievement; it also helps educators and youth service providers work together to intervene with youth who are struggling in school. JCPS, Metro Government, Metro United Way (including the 211 program) and other community*



# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

*(Continued)*

*members have worked together to create “Louisville Linked” student management system to connect students and families to community partners and programs who are committed to providing academic interventions, securing basic needs, fostering resiliency through social skills and providing physical, mental and emotional healthcare services. Referrals are tracked for follow-up and results. Just seven months into the first year of implementation, over 24,000 students/families had been served, linking them to more than 41,000 services through this system.*

From the perspective of policymaking and program improvement, feedback reports along the educational continuum also provide useful information on opportunities for improvement.

In addition, consistent and accurate information sharing between the child welfare, juvenile justice, court and mental health systems and the education system can greatly improve the outcomes for these involved children.

- » If a child is in the **foster care system**, the local and state foster care systems must be aware of the educational needs, problems, and successes for the particular child. Federal child welfare law requires that when the child welfare system decides on a child’s placement, the system must take into account the proximity of the placement to the child’s home school and whether the child remains in his home school or, if contrary to the child’s best interests, is enrolled and receiving the appropriate educational services in a new school.
- » To implement the McKinney-Vento legislation, dealing with ensuring that **homeless children** can attend their home school and are not uprooted educationally due to their housing instability, the local homeless shelter agency needs to be able to access the school information immediately so that the homeless child does not miss school unnecessarily.

.....  
*“50% of the nation’s 500,000 children in foster care will not graduate from high school. Nearly 94% of those children who do graduate from high school do not finish college.”*  
.....

- » The local **juvenile justice** office needs to have access to a youth’s educational information especially if a condition of probation is having no unexcused school absences.
- » A court can require, as a condition of an adult’s **probation or parole**, whether the adult is the custodial parent or the non-custodial parent, that the parent ensures that his or her school-age child attend school.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » The **mental health system** providing in-school services to a child needs to know if the treatment is improving the child's ability to concentrate, learn, follow directions, and grasp the age-appropriate information.

From an efficiency viewpoint, parents are required to provide the same or similar information multiple times to schools, medical providers, public benefit offices, and human services provider agencies. If these systems had access to basic personal identifying information about the family, it would save time for busy parents and the staff assisting them.

## CITY EXAMPLE



***EVEN BEFORE THE FEDERAL GOVERNMENT PASSED legislation in January 2013, revising the Family Educational Rights and Privacy Act (FERPA) to permit the sharing of educational information for children in foster care with the public and private agencies with custody of such children (Uninterrupted Scholars Act), the Philadelphia Department of Human Services and the Philadelphia School District entered into a Memorandum of Understanding to ensure that children in foster care are able to remain in their school of origin and to ensure that all of their educational rights are protected and enforced. The Philadelphia Department of Human Services created a specially-trained education unit comprised of in-house experts in the educational rights of children in foster care who exchanged information with the Philadelphia School District.***

## FEDERAL LEGISLATION RELATED TO EDUCATIONAL INFORMATION SHARING

FERPA IS THE MAJOR FEDERAL LAW THAT PROTECTS the privacy of student education records. It provides parents and students the right to inspect and review the educational records kept by the school, to demand educational records be disclosed or released to others through a written release, to amend and correct education records which they believe to be incorrect or misleading, and to file complaints against the school for disclosing educational records in violation of this federal law. Educational records are defined as “records that directly relate to a student and that are maintained by an educational agency or institution or be a party acting for the agency or institution.” They contain personally identifiable information and may be written documents, computer files, microfilm or microfiche, video, film or photograph.

FERPA mandates the privacy of education records and requires schools to comply or risk losing federal funding. The law makes clear that education records—all materials maintained by the educational agency or institution containing information directly related to a student—are confidential. At the same time, the following outlines how FERPA supports information sharing with other systems:

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » Availability of education records to student's parent includes natural parent, guardian, or an individual acting as a parent in the absence of a parent or guardian.
- » Well-written consent signed by parent or eligible child enables the disclosure of education information to other specified parties.
- » Information that does not directly relate to a student or obtained from a source other than the child's education records can be shared.
- » Directory information can be disclosed after school gives general notice to parents of intent to release it.
- » If a child is involved in court proceedings, a court order is an avenue to release student-specific information from a child's records.
- » Does not include information for some school professionals such as counselors or psychologists (which may be covered by HIPAA) or law enforcement staff.

There are numerous exceptions to the no-disclosure rule. The exceptions—when written consent or authorization is NOT necessary and FERPA permits an educational institution to release and share educational information and personally identifiable information—include:

- » To appropriate officials where the health and safety of student is at issue.
- » To comply with a court order or lawfully issued subpoena
- » In the event of an emergency.
- » In referring children with disabilities for special education.
- » When there is a suspicion that a child has been abused or neglected or threatened with abuse or neglect, as determined by state statute.
- » When, as a result of a crime of violence, a disciplinary hearing was conducted by the school, a final decision recorded, and the alleged victim seeks the disclosure of the final decision.
- » To state and local authorities within a juvenile justice system, pursuant to specific state law and prior to an adjudication of delinquency, to provide pre-adjudication services and to protect the health and safety of the student or other individuals. In this instance, officials must certify in writing that the institution or individual receiving the educational information will not disclose to any third party other than the juvenile justice system agency.

**EXAMPLE:** The local juvenile probation office contacts the high school about a student who is in the court system under investigation for assault and battery. The probation office provides a written request for particular student records which include the student's history of fighting in school since the age of 13 (age of delinquency by state law) and several reports concerning any impulsive activity and anger issues. In the written request, law enforcement provides assurance that the requested records concern the juvenile justice system and its ability to effectively serve the student, that there is an ongoing investigation, and that information will not be disclosed to any other person except as authorized by law.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

The following outlines the issues, presented by FERPA, that need to be resolved for successful information sharing between education and other systems:

- » Prohibits the disclosure of personally identifiable information from a student's education records without **parental consent or eligible child consent**. This includes any item of information directly related to child which is maintained by the educational institution.
- » If there is court involvement and the issue involves special education, the court can appoint an **educational representative** or surrogate parent and such representative or surrogate has access to the education records
- » For juvenile justice schools may disclose information without consent or court order in certain circumstances, including to state and local juvenile justice systems (prior to adjudication) or their authorities if allowed or required under state law to provide **pre-adjudication services**.

.....  
*In 2013, Congress enacted the Uninterrupted Scholars Act, amending FERPA to permit schools to release to the State or local child welfare agency caseworker or other representative responsible for the care and protection of the student with the provision that education information cannot be subsequently re-disclosed unless to an entity or person engaged in addressing the student's educational needs.*  
.....

## IMPLEMENTATION: WHAT AND WHO

SHARING INFORMATION FOR performance purposes, and not for compliance or research purposes, may cause tension between the systems. Through a joint process, the systems can build trust that the information will be protected and only used for the specified and allowable purpose.<sup>2</sup>

For successful implementation of educational data sharing, a city should consider forming two working groups: a program group and a legal group.

### The Program Group

Determining the **"what"** is a difficult but essential exercise. When dealing with educational information, it is essential to discuss and carefully refine the data request up-front, which will make easier the **"how"** to share such information.

FERPA protects the privacy of student education records<sup>3</sup> and provides parents and students the right to inspect and review the educational records kept by the school, to demand educational records be disclosed or released to others through a written release, to amend and correct education records which they believe to be incorrect or misleading, and to file complaints against the school for disclosing educational records in violation of this federal law.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

But it is just as important to note that certain information kept by educational institutions and classified as “directory information” is not confidential and can be shared. Such information is not considered part of the educational record and under a strict interpretation of FERPA the school may release such information without the written consent of the parent or student. However, schools must notify parents and eligible students (age of 18 and older or attends a school beyond the high school level) when directory information is to be provided to others to give a reasonable opportunity to request that the school not disclose directory information about them. **Directory Information** may include:

- » Name of student
- » Address
- » Telephone number
- » Electronic mail address
- » Date and place of birth
- » Enrollment date in school (but not daily attendance)
- » Degrees, honors and awards received
- » Enrollment status
- » Major field of study
- » Grade level
- » Honors and awards
- » Participation in officially recognized student activities and sports
- » Photograph
- » Name of most recent school that student attended

In addition, non-personally identifiable information and administrative records kept exclusively by the maker of the records (e.g., school police records) are not protected under FERPA.

If only directory information needs to be shared, then creating a successful Memorandum of Understanding between the educational institution and the other system regarding information sharing should be easier.

**EXAMPLE:** The local public homeless agency enters a Memorandum of Understanding with the local school districts to create electronic access to school locations to more easily facilitate maintaining temporarily homeless children in their own schools. If a mother and school age children become homeless as a result of a fire and enter a family shelter, the homeless office education coordinator could confirm the children’s current schools through the electronic system. This would allow the homeless agency to contact the appropriate McKinney-Vento school district representatives to arrange transportation between the shelter and schools and provide additional funds for replacement of the school uniforms lost in the fire.

In this example, the directory information is sufficient to accomplish the goals of the collaboration and to improve respective services to the children and family.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

**Non-Directory Information** includes:

- » Social Security numbers
- » Student identification number
- » Race, ethnicity, and/or nationality
- » Gender
- » Daily attendance information
- » Transcripts/grade reports
- » Disciplinary actions, including detentions, suspensions, expulsions

If the minimum necessary information needed to accomplish the legitimate governmental purpose includes non-directory, personally identifiable education information, there are three major ways of accomplishing information sharing:

**1. An appropriately signed written consent;**

If parents of children in a city-funded afterschool program are given a data-sharing consent form to sign when they register their children for the program, specific data concerning daily attendance or grades for individual children may be shared between the school district and the program to reinforce the importance of attendance, provide tutoring support as needed, and better coordinate in-school and out-of-school supports.

**2. A court order; or**

If a probationer/parolee is a parent of a school-age child, a condition of probation or parole may be that the child cannot be truant as defined by the local school district. This information is included in the individual probation and parole order which specifies the information to be shared on the particular children. Daily attendance dates for particular children, which is not included as “directory information,” is required by the court order. The Adult Probation/Parole Office and the applicable School Districts enter into a Memorandum of Understanding regarding how and with whom the Probation/Parole Office shares the names of affected children and how the school districts share attendance of such children on a monthly basis to a particular person within the Probation/Parole Office.

**3. A state statute identifying another person or entity to authorize the sharing of the education information.**

Since the enactment of the Uninterrupted Scholars Act, once an order of dependency is entered and the child is placed into foster care, school staff and educators can release education records to a child welfare social worker as long as the child welfare worker certifies that the information will not be further disclosed without parental consent unless further authorized by state law. For example, if a child in foster care is failing a subject, the agency case worker may want to see the youth’s grade for each assignment and test or quiz to see if they are making progress or if there are additional community supports to help the struggling student.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

Who has access to educational information depends on the presenting factual reasons for the information sharing process. The access should be role-based, either because of the person's responsibilities or job classification and should be limited to only those persons who need the information to perform their job responsibilities and improve services to the youth.

The program group must discuss whether or not they believe parents will voluntarily and knowingly sign consent forms releasing information and the factors that would make the signing of consents more likely. This then becomes an agency-wide training and cultural issue. If parents feel respected and understand that information sharing will result in better services for their family, the likelihood that they will sign consents in an informed and voluntary manner will increase. Consents should not be considered a barrier but another opportunity to build the relationship between the system representative and the family.

The recent federal amendments to FERPA allowing the release of educational records to the child welfare caseworker are a step in the right direction, aligning the federal laws related to child welfare and education. But just because the law has changed, there is still the work of changing the organizational cultures of both education and child welfare entities. For so many years, the two fought with one another regarding sharing information. Now, they must work collaboratively to set up efficient information sharing systems. The great hope is that this process will result in reciprocal arrangements, with both educational and child welfare information being shared, so that both systems are working for the best welfare of the child.

## IMPLEMENTATION: HOW

### The Legal Group

The options for the legal group to consider are:

- » Written consent or authorization by parent/eligible student;
- » Individual court order or subpoena; or
- » State statute designating a person to act for the parent/guardian.

Whether the group pursues individual consents/authorizations, specific court orders or court-ordered subpoenas, or state statutory permission to access education information, the school and other involved systems must negotiate and enter into a Memorandum of Understanding, specifying the details of the information sharing. It needs to clarify the following:

- » When and what information is provided;
- » How it is provided (e.g., hard copy or electronically, shared or merely accessed);
- » Who shares and who receives such information; and
- » How the information is maintained in a confidential manner and not shared with other persons/systems.

# Sharing Data *for* Better Results



## INTRODUCTION

## BACKGROUND

## GETTING STARTED

## EDUCATION

## HEALTH

## MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT

## HUMAN SERVICES AND CRIMINAL JUSTICE

## APPENDIX A: ADDITIONAL RESOURCES

## APPENDIX B: SAMPLE MOU'S

## APPENDIX C: LAWS AND REGULATIONS

A number of cities and local entities have entered into such MOU's; examples in [Appendix B](#) will provide new jurisdictions with a wonderful starting off point.

**WRITTEN CONSENT:** The primary method for sharing a child's education record information is through a written authorization or consent signed by the parent.<sup>4</sup> **NOTE:** It is important to review your State and local laws to determine if there are specific entities identified as being the child's parent regarding education records.

**COURT ORDER:** If a court is involved, a court order or subpoena can list any party to whom the schools should release education record information. This may include the juvenile justice or probation officer, caregiver, or youth's attorney. The court can also appoint an educational representative or a surrogate parent (under IDEA) and can order the transfer of the right to sign such an authorization from the parent to educational representative or surrogate parent. When shared, the person receiving the educational information is not permitted to release or share with any other party without the written consent of the parent/eligible child.

When a youth is involved in a criminal matter, a juvenile court is involved and has jurisdiction of the case. In these circumstances, the juvenile justice office can request that the court issue a specific court order or subpoena regarding the release of specific protected educational information. The court could also include, in original disposition orders, this release of information, granting access to the judge and other parties to the court proceeding.

Such information must be part of specific court orders and not a general "Order of the Court" that applies to all children. Such a generalized court order is not sufficient for the educational body to share the requested information. Instead, the individual court order must apply to a specific child.

**NOTE:** Even with a court order/court subpoena, schools must make efforts to notify the parents/eligible child before releasing the information and the court order should include language that parties receiving the educational information must avoid revealing to any other persons and should destroy information when the party no longer requires the information.

<sup>1</sup> The Seattle Times, October 31, 2011.

<sup>2</sup> A multi-systems example of building that trust is the joint letter dated August 25, 2011 to all Chief State School Officers and State Child Welfare Directors from Michael Yudin, Acting Assistant Secretary for Elementary and Secondary Education of the United States Department of Education and Bryan Samuels, Commissioner for the Administration for Children, Youth and Families of the United States Department of Health and Human Services. This was followed by a national convening in November 2011 in Washington, DC by the Departments of Health and Human Services and Education of teams from all 50 states, Puerto Rico and the Virgin Islands comprised of education, juvenile court and child welfare leaders to plan how to improve the education stability and outcomes for children in foster care. Each state team developed specific plans, including practical ways, to work on to achieve the goals of school stability and increase school performance for children in foster care.

<sup>3</sup> In FERPA, education records are defined as "records that directly relate to a student and that are maintained by an educational agency or institution or be a party acting for the agency or institution." They contain personally identifiable information and may be written documents, computer files, microfilm or microfiche, video, film and photograph.

<sup>4</sup> Includes the parent, guardian, or individual acting as the parent in the absence of a parent or guardian.



# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Health

### MAJOR FEDERAL LAWS:

**Health Insurance Portability and Accountability Act (HIPAA)**

**Health Information Technology for Economic and Clinical Health**

**Patient Protection and Affordable Care Act**

### THE CASE FOR SHARING:

A national effort is underway to improve health care while reducing costs, and to use technology—specifically Electronic Medical Records (EMR), Electronic Health Records (EHR), and Health Information Exchanges (HIE)—to reach these lofty goals. This national effort is primarily federally funded through the Health Information Technology for Economic and Clinical Health (HITECH) Act and the American Recovery and Reinvestment Act (ARRA) of 2009, and the Patient Protection and Affordable Care Act.

One of the greatest challenges lies in the interconnectedness of a person's health needs and the person's social needs and services. If a person does not have nutritious food to eat or lives in substandard housing, she is more likely to be in poor health. Conversely, a person's health improves – and the associated costs decrease – if she has nutritious food, adequate and affordable housing, transportation assistance, and gainful employment.<sup>5</sup> Social needs often directly correlate with poor health and the social needs are as important to address as the resulting medical conditions. Therefore, health and human services must work together to achieve affordable health care and wellness for residents, eliminate redundancies, and collaboratively link health and social supports.

Cross-system information sharing impacts the ability to be more efficient and effective:

- » Local jurisdictions pay for health and behavioral health care services to individuals who are incarcerated in **jails** awaiting trial. It is therefore essential to know what treatment is being provided to the individual in the community in order to effectuate continuity of care and avoid unnecessary repetitive tests and evaluations. Such sharing of information should be even more important, to both the local government and the federal government, when the Affordable Care Act expands Medicaid coverage to men living below the poverty line and the cost of that care provided in jails fall to the federal insurance process.

.....  
*“An estimated 15 percent of inmates held in Los Angeles County’s jail system require some type of mental health care; if unaddressed during detention, there is a higher risk of recidivism after being released.”*  
.....

- » When a child is placed into **foster care**, the government becomes the responsible party and must have complete health and treatment information about him or her to prevent

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

a health emergency or duplicative treatment, testing, vaccination, or examinations—all of which waste resources and do not serve the child well.

.....  
*“Approximately 50% of children in foster care (as compared to 12.8% of children in the U.S. population) have special health care needs, including chronic health conditions such as asthma, repeated ear infections, other respiratory problems, severe allergies, epilepsy and skin disease.”*  
.....

» Some **public benefits** are dependent on whether a person is considered “able bodied” or has a defined disability. Information sharing can make this determination more efficient.

Readily available and timely health and treatment information can yield better care and save money by avoiding repetitive and unnecessary costs.

## FEDERAL LEGISLATION RELATED TO SHARING HEALTH INFORMATION

If everyone agrees that information sharing is important, why isn't health information shared more frequently? Protecting the privacy of confidential health information is also important. Therefore, this toolkit is intended to help systems with mutual clients share information in a way that leads to better outcomes and respects individual privacy rights.<sup>8</sup>

### The Health Insurance Portability and Accountability Act of 1996

What is the Health Insurance Portability and Accountability Act of 1996 (HIPAA)? What does HIPAA protect, and if the information is indeed protected health information, how can the systems share it at all? According to the HHS Office of Civil Rights, the HIPAA Privacy Rule establishes a federal foundation for the protection of personal health information, but it is carefully balanced to avoid creating unnecessary barriers to the delivery of quality health care. Therefore, the Rule generally prohibits the disclosure of protected health information unless authorized by the individual, except where this prohibition would result in unnecessary interference with access to quality health care or with certain other important public benefits or national priorities.

Volumes have been written about HIPAA, and this brief toolkit does not attempt to answer every question or provide every nuance, but in brief, there are three purposes for this federal law:

1. HIPAA initiated the creation of a **uniform standard for processing electronic health care claims** in the United States. The HITECH amendment to ARRA built on this processing standard by providing financial incentives for the creation of electronic health records. This was the “portability” purpose so that if a patient moved, the new medical provider would understand and use the same uniform standard.
2. HIPAA established a minimum set of **privacy rules that all health care providers** (as well as health plans and clearinghouses) **must follow when handling patient information**,

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

giving patients greater control over the use of their individual health information. This was the first part of “accountability.” Its intent is to encourage people to truthfully share information with their medical providers without fear that it will be broadly distributed.

3. HIPAA established new standards for protecting the **security of patient information**. This was the second part of the “accountability” purpose.

## COUNTY EXAMPLE



*IN JOSEPHINE AND JACKSON COUNTIES, OREGON, Mid Rogue Health Plan (Mid Rogue) administers health benefits to Medicaid recipients. Mid Rogue, in partnership with the Medicaid agency, the Department of Human Services, and Jefferson Behavioral Health, launched an initiative to create a “medical home” for foster care children in those counties by accomplishing the following: 1) assignment of a PCP within 14 days of health plan enrollment; 2) a primary care health assessment within 30 days of placement; and 3) a mental health assessment within 60 days of placement. After discovering that the enrollment data from the state Medicaid agency did not provide the type of child welfare involvement, Mid Rogue and the local child welfare agency together accurately identified each child’s placement status and date of entry. The next challenges were incomplete foster parent contact information and identifying a sufficient number of primary care physicians to see new and established patients.*

*Through a series of creative actions and educational outreach, the initiative was launched. The results exceeded the overall aims, with 100% of foster care children being assigned PCPs within 14 days of placement and receiving a primary care assessment within 30 days of placement, and 88% receiving a behavioral assessment within 60 days of placement.*

It is interesting to note that even though the law does not prohibit information from being shared, it has in many ways stopped the sharing of information between health service practitioners and those working in other fields and systems. Instead of seeing the protections as a part of the treatment process and the multi-disciplinary practice, HIPAA has become the “red light” of information sharing.

From a policy perspective, HIPAA should not be used as an excuse for communications breakdown. Instead, policy makers must set appropriate information sharing as a goal and apply information technology and legal resources to determine the best approach to accomplish the goal.

The following outlines the perceived barriers that HIPAA presents to the efforts of sharing health information with other systems:

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » Federally-mandated foundation for the protection of personal health information and the confidentiality and privacy of such information.
- » Strong privacy protections regarding the sharing of protected health information unless authorized by the individual.
- » No uniform authorization for an individual but, instead, each covered entity has its own separate authorizations.
- » Fear of violation of the federal law and disclosing protected health information inappropriately even with positive intentions.
- » Does not make clear that “treatment” for many federally-funded recipients is multi-systemic.
- » Does not clearly define the “minimum necessary” protected health information to fulfill a request since it is based on the circumstances of the particular request and the individual’s situation.

To counter the barriers, below are the ways in which HIPAA is supportive of information sharing with other systems:

- » The federal protections are not to interfere with patient access to, or the quality of, health care delivery.
- » It is carefully balanced to avoid creating unnecessary barriers to the delivery of quality health care.
- » Sharing is encouraged if the lack of sharing would result in unnecessary interference with access to quality health care or certain other important public health benefits or national priorities.
- » Permits sharing with the individual or designee of individual.
- » Permits sharing for treatment, payment, or health care operations. Treatment includes the provision, coordination, or management of health care and related services among health care providers regarding the individual.
- » There is a lengthy list of exceptions to the privacy protections and the requirement for a written authorization.
- » Highlights permission to share if required by state law, including to human services entities and the courts.
- » An exception exists for a court order or subpoena with prior notice to the individual.
- » Clear description of the elements of and required statements in an appropriate authorization.
- » Encourages policies and procedures on use, disclosure, and purpose of request for protected health information as well as reasonable criteria for determining the “minimum

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

necessary” protected health information to accomplish purpose of request. Policies and procedures should identify persons or classes of persons granted access to information to carry out job duties, categories or types of protected health information needed, and conditions appropriate to such access.

**Note:** States may have more stringent privacy and security laws and regulations. If so, the state law prevails. For this reason, it is critical for cities and their legal staff, in partnership with the state and its legal staff, to develop tables for state laws regarding this subject, to ascertain whether state or federal law prevails and under what conditions.

**EXAMPLE:** A private organization receiving Federal funding through Medicaid provides a number of health services (physical, mental, drug and alcohol) and human services (housing, employment, children’s services). This integrated, multi-service organization is the legal entity, has one director, one set of policies and procedures, several service locations, and a centralized administrative unit. The umbrella agency in its entirety is designated a covered entity under HIPAA. The agency’s Privacy Notice provided to all clients at initial contact lists the specific various disciplines comprising the covered entity and states that information will be shared within the integrated, multi-service public agency.

Clients/consumers are provided an “opt out” alternative from the total integrated, multi-service agency by requesting a restriction of information sharing and designating a particular type of service information not to be shared with other disciplines. In addition, the agency provides a specific authorization for certain information including protection of the location of an abused person, domestic violence, HIV and AIDS, and alcohol and substance abuse treatment services. HIPAA permits the sharing of protected health information within the agency without requiring specific and separate authorizations under all of the applicable federal laws for the purposes of “treatment” and other “related” health services. In this scenario, the HIPAA definition of “treatment” permits a health care provider to offer or coordinate social, rehabilitative or other services as long as they are associated with and related to the provision of health care.<sup>9</sup>

## Health Information Technology for Economic and Clinical Health (HITECH) and American Recovery and Reinvestment Act of 2009

The Health Information Technology for Economic and Clinical Health (HITECH) Act and the American Recovery and Reinvestment Act of 2009 provide financial incentives to implement the health information exchange (HIE) and the meaningful use of health information technology to improve health outcomes, particularly through better coordination and continuity of care.<sup>10</sup>

### IMPLEMENTATION: WHAT AND WHO

For successful implementation of data sharing, again, the city should consider forming two working groups: a program group and a legal group. Since providers in the health sector come from public, private, and non-profit organization, cities should consider including representa-

# Sharing Data *for* Better Results



## INTRODUCTION

## BACKGROUND

## GETTING STARTED

## EDUCATION

## HEALTH

## MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT

## HUMAN SERVICES AND CRIMINAL JUSTICE

## APPENDIX A: ADDITIONAL RESOURCES

## APPENDIX B: SAMPLE MOU'S

## APPENDIX C: LAWS AND REGULATIONS

tives from all sectors of the provider community on these working groups and throughout the planning process.

Nothing in HIPAA laws, regulations, or official clarifications by the HHS Office of Civil Rights states that personal health information can NEVER be shared. Instead, data sharing must include a process that determines:

- » If the information needed is protected by HIPAA;
- » If protected information can be shared under the Privacy Rule or if an authorization signed by the patient is required; and
- » The best methods for sharing -- and protecting the future confidentiality of -- the minimally necessary information.

What health information is protected by HIPAA? It must be either information that could be used to identify the individual patient or protected health information. Such individually identifiable health data includes both demographic information about a patient (name, address, employer, etc.) and medically-related information (diagnosis, treatment, condition, medications prescribed, etc.). Timeframe of data also includes past, present or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present or future payment for the provision of health care to an individual.

As a general rule, all individually identifiable health information is confidential and protected. The next question, then, is when protected health information under HIPAA can be disclosed and shared. There are three general circumstances when such information can be shared:

- » **For treatment, payment and health care operations:** This circumstance is important when dealing with individual case information, especially when looking at **treatment**<sup>11</sup>, which:
  - Is the provision, coordination, or management of health care and related services among health care providers regarding an individual;
  - Is NOT limited to medical services but rather is a holistic approach including human services related to the health treatment; and
  - Includes related services from HHS-funded areas related to the health care
- » Examples of **“payment”** activities are billing and collections, utilization review, reviewing health care services for medical necessity determinations, coverage, justification of charges, and determining eligibility and coverage.
- » Examples of **“health care operations”** are quality assessment and improvement, credentialing and peer review, compliance, auditing services, business planning and development, legal services, training health care and non-health care professionals, accreditation, certification and licensing.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » **For other purposes if the patient has authorized the disclosure:** This circumstance is also important when an individual is involved in multiple systems. If there is a trust relationship between the individual and the caseworkers in the different systems to partner together for the client's benefit, obtaining authorization will be considerably easier.
- » **For certain public and research purposes:** In some instances sharing for public and research purposes is allowed even if the patient has not authorized the disclosure. This circumstance is primarily for research, planning, and program effectiveness and not case-specific situations.

In addition, there are 12 exceptions to the rule that describe circumstances under which protected health information can be shared without authorization:

1. Victims of abuse, neglect, or domestic violence
2. Judicial and administrative proceedings
  - Court or administrative tribunal order
  - Subpoena if certain assurances regarding notice to individual and ability to request a protective order is provided
3. Law enforcement purposes
  - Required by law (court orders, court-ordered warrants, subpoenas)
  - To identify or locate a suspect, fugitive, material witness or missing person
  - In response to request for information about victim or suspected victim of a crime
  - To alert law enforcement of a person's death if there is a suspicion that criminal activity caused the death
  - When health care provider believes that protected health information is evidence of a crime that occurred on its premises
  - Medical emergency not occurring on its premises, when necessary to inform law enforcement about the commission and nature of a crime, the location of the crime or crime victim, and the perpetrator of the crime.
4. Incidental use and disclosure (for example, a sign-in sheet at a doctor's office)
5. Public interest and benefit activities
  - Required by law (statute, regulation or court orders)
6. Public health activities
  - Public health authorities for prevention and controlling disease, injury, or disability
  - Government authorities authorized to receive reports of child abuse and neglect
  - Entities, products and activities subject to the Food and Drug Association

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- Individuals who may have contracted or been exposed to communicable disease when notice is authorized by law
  - Employers in compliance with Occupational Safety and Health Administration or similar state law
7. Uses and disclosures with opportunity to agree or object
    - Example: asking a patient for emergency contact information
  8. Decedents (funeral directors, coroners, medical examiners)
  9. Cadaveric organ, eye or tissue donation
  10. Serious threat to health or safety
  11. Essential government functions
  12. Research, under a number of stringent circumstances

## PERMITTED DISCLOSURE TO CORRECTIONAL INSTITUTIONS



***SPECIFICALLY, WHEN DEALING WITH DETAINEES in local jails, how does HIPAA apply? Disclosure of medical information may be necessary for the health and safety of both the patient and the large patient community in a locked facility. Officers may need to know about medical conditions or disabilities that require special equipment or scheduled appointments. Some medication side effects require additional attention or changes in work duty. Fortunately, HIPAA regulations take into account the need for some information sharing within the correctional setting “if the correctional institution represents that such protected health information is necessary for:***

- » *The provision of health care to such individuals;*
- » *The health and safety of such individuals or other inmates;*
- » *The health and safety of the officers or employees of or others at the correctional institution;*
- » *The health and safety of such individuals and officers or other persons responsible for the transporting of inmates or their transfer from one institution, facility, or setting to another;*
- » *Law enforcement on the premises of the correctional institution;*
- » *The administration and maintenance of the safety, security, and good order of the correctional institution.”<sup>12</sup>*



# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

Whether the information can be shared under one of the three general circumstances or one of the 12 exceptions, the information should be provided only to a person who has a **“need to know”** for legitimate purposes. In addition to the “need to know” rule, and when providing the information outside of the traditional “treatment” circumstances (for example physicians, nurses, and other health practitioners), the information shared should be limited to the **“minimum necessary.”** This requires careful thought as to the needed information and its purpose.

## The Program Group

This group has a challenging task: to create very specific lists of information needed, the purpose, and which persons shall have access. The Program Group must be willing to question each other to insure that the final list of data elements to be shared is necessary to accomplish the mission, or the **“Why?”** set forth by the agency heads.

From a day-to-day practice perspective, in order to improve the outcomes for the client and to be more efficient in the workplace, **what** specific information is necessary to be shared? What is the information that the staff person needs to improve the outcomes for the client? Consult with the medical experts to determine the information they believe is most needed to improve outcomes. Be specific. The goal is a complete list of the minimum information necessary—and nothing unnecessary. This kind of specificity is truly the time-consuming part of this task.

**EXAMPLE:** A county TANF agency is working with unemployed adults with diabetes. Based on a longitudinal review, this group is growing exponentially, negatively affecting the TANF agency’s desire to achieve its self-sufficiency goals as well as the goals of the agency providing medical assistance. Medication, emergency room, and inpatient costs for this population are on the increase. The agency heads agree to partner to improve health and self-sufficiency outcomes and to decrease costs. The proposed solution and the “why” for the project is to insure that these persons have regular preventive care visits with their PCP. The TANF and Medical Assistance Agencies assign one supervisory unit from each agency apply an integrated case management model. What is the minimum necessary information to be shared?

- » Identity
- » Diagnosis of diabetes
- » Receiving TANF for diabetes-related reasons
- » Name of PCP
- » Date(s) of upcoming appointments with PCP
- » Did the person attend the appointment? If not, the operations manual for the project designates follow-up contact by the TANF case manager as to reasons and working on solution to the problem?

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » Is the patient following the medication regimen? If not, follow-up contact by the Medical Assistance case manager as to reasons and working on solutions to the problem?
- » Are there any other preventive measures required for the patient? For example, weight loss due to obesity? If so, is the patient following the medication regimen?

The next task is **“who”** needs access to the shared information. This designation must include job classifications and the specific units involved. The designated group must limit access to only those persons involved with the clients, the supervisory chain for those staff persons, and any other persons involved with the direct contact to the clients. This group then reviews persons within the agency ancillary to the project. This may include quality management/assurance staff and others. For any person not involved either directly with the client or with the staff person working with the client, reasons for access to shared information must be explicit.

## IMPLEMENTATION: HOW

### The Legal Group

The Legal Group must first determine whether or not the entity or entities are covered by HIPAA. If not, then there may be no HIPAA-related issues involved. The law is specific as to what type of entity is covered and what type of entity is not covered.

If the entity is covered, then the next question is whether or not the requested information is protected health information under the applicable federal laws. Not all information is protected and a careful review must occur. If the information is protected, the group must determine if it falls within one of the exceptions to HIPAA. This review should also look at other jurisdictions with the same or similar information sharing arrangements to determine how that jurisdiction reached its decisions.

Once this review occurs, the Legal Group next examines relevant state laws to determine if there are any additional state requirements regarding confidentiality for health information. If the decision is that the information is protected, the lawyers must look at the details of other jurisdictions that are successfully sharing health information and review the options:

- » Is a state law or state law amendment appropriate for enabling this information to be shared?
- » Is an authorization used by both systems the appropriate vehicle to enable the information to be shared? If so, the group should draft such and provide to the agency heads for review and distribution to internal government and external partners and interested and involved groups for comment and input. Should the authorization be drafted so that the clients “opt in” or “opt out” of the information sharing opportunity? The concept of “opt out” must be fully explained in the Notice of Privacy. Instead of the person specifically stating that the provider can share information with another entity, the person is

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

told that information will be shared among different entities in order to better serve the person. Only if the person selects the “opt out” of sharing with a particular entity is the information not allowed to be shared; otherwise the information is shared. Such “opt out” procedures are now being used in HIPAA notices and by health care alliance entities. For some personally identifiable information, the federal law explicitly states how information may be shared and therefore, the “opt out” process may not apply under those circumstances.

- » Does the legal entity enable it to be classified as the covered entity for HIPAA purposes? If so, can information be shared for treatment purposes between health and human services case managers who are part of the covered entity? Are these other services within the definition of treatment to help provide, coordinate with, or manage health care? HHS has determined that this definition allows health care providers to coordinate or offer social, rehabilitative and other services that are associated with the provision of the health care for that individual. The service must be related to the health care but does not have to be medical in nature pursuant to the definition.<sup>13</sup>
- » Is the patient or client group involved in on-going court proceedings? If so, and in working with the appropriate court officers, can a court order be crafted and used to enable the information sharing to occur?

This group also needs to review and determine under state law which person(s) have the right to provide the consent. Each state law may differ from other states so in reviewing the initiatives in other jurisdictions, it is important to know the ways in which consent laws differ.

The legal group’s recommendations must be based on its interpretation consensus of the applicable federal and state laws governing the confidentiality of health information and a review of legal interpretations reached in other jurisdictions where such information is being shared.

<sup>5</sup> “Health Care’s Blind Side: The Overlooked Connection between Social Needs and Good Health”, Robert Wood Johnson Foundation, December 2011.

<sup>6</sup> Los Angeles Times. October 14, 2013, Opinion. (fonts not consistent)

<sup>7</sup> HHS, ACF, Office of Planning, Research and Evaluation, National Survey of Child and Adolescent Well-Being, No. 7: Special Health Care Needs Among Children in Child Welfare, Research Brief, Findings from the NSCAW Study (Washington DC: HHS, 2007); R.L. Hansen, et al., “Comparing the Health Status of Low-Income Children in and out of Foster Care,” *Child Welfare*, Vol. LXXXIII, No. 4 (July/August 2004). Halfon, et al. “Health Status of Children in Foster Care. The Experience of the Center for the Vulnerable Child,” *Archives of Pediatrics and Adolescent Medicine*, Vol. 149, No. 4 (April 1995); R. Chernoff, et al. “Assessing the Health Status of Children Entering Foster Care,” *Pediatrics*, Vol. 93, No. 4 (April 1994); M.D. Simms, “The Foster Care Clinic: A Community Program to Identify Treatment Needs of Children in Foster Care,” *Journal of Developmental and Behavioral Pediatrics*, Vol. 10, No. 3 (June 1989)

<sup>8</sup> It should be noted that there is not a personal right to litigate pursuant to HIPAA. A person cannot sue an entity and allege that the person’s HIPAA rights were violated.

<sup>9</sup> Federal Register, Volume 65, No. 250, December 28, 2000/Rules and Regulations at 82628.

<sup>10</sup> Electronic Health Records and Meaningful Use, HHS Office of the National Coordinator for Health Information Technology, May 19, 2011

<sup>11</sup> Treatment is defined as the provision, coordination, or management of health care and related services for an individual by one or more health care providers (between doctors, nurses, medical technicians, hospital social workers, hospice workers), including consultation between providers regarding a patient and referral of a patient by one provider to another.

<sup>12</sup> 45 C.F.R. §164.512(k)(5)(i)

<sup>13</sup> Federal Register, Vol. 65, No. 250, December 28, 2000.



INTRODUCTION

BACKGROUND

GETTING STARTED

EDUCATION

HEALTH

MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT

HUMAN SERVICES AND CRIMINAL JUSTICE

APPENDIX A: ADDITIONAL RESOURCES

APPENDIX B: SAMPLE MOU'S

APPENDIX C: LAWS AND REGULATIONS

## Mental Health and Drug and Alcohol Treatment

### MAJOR FEDERAL LAWS:

**Health Insurance Portability and Accountability Act (HIPAA)**

**Confidentiality of Alcohol and Drug Abuse Patient Records regulation (42 CFR PART 2)**

### THE CASE FOR SHARING:

**EXAMPLE:** James is 23 years old and has been diagnosed and is being treated for schizophrenia at a community mental health organization located in his neighborhood. James was arrested for soliciting to purchase narcotics from an undercover police officer. James is addicted to Oxytocin. In negotiating a plea arrangement, James agreed to enter a drug treatment program and complete the program satisfactorily. Due to his mental health and addiction conditions, it is impossible for James to negotiate both the mental health system and the drug and alcohol systems, but without shared data, neither of the programs is aware that the other is providing treatment services to James, including but not limited the prescription of psychotropic medications and the possibility of anti-addiction medication.

Many recipients of government-funded services are also involved with the mental health system and/or the drug and alcohol treatment system. The high incidence of dual or multiple system needs among vulnerable youth and families means that the cost of the current “silo approach” – to individuals and to public systems -- is significant. These systems with significant overlapping populations with mental health or drug and alcohol treatment include:

» **The correctional system:** Jails are referred to as the new mental health hospital system.

.....  
*Of the mentally ill inmates who are admitted into the McLean County, Illinois jail, there is almost a 40 percent recidivism rate. Multiple bookings into the jail have been the case for 39 percent of mentally ill inmates from January 2007 to September 2013. The study conducted by Illinois State University’s Stevenson Center for Community and Economic Development also showed a steady increase over the past five years of mentally ill inmates.<sup>14</sup>*  
.....

» **Child welfare and foster care:** Children in foster care comprise three percent of the total Medicaid population under age 18, but this population comprises 32% of the recipients of behavioral health services in this age group.<sup>15</sup> Mental health issues and drug and alcohol abuse also represent a significant and growing cause of families coming to the attention of the child welfare system.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

*In 2010, in Marion, Polk and Yamhill Counties in Oregon, there were 1,481 victims of child physical, sexually or emotionally abuse and neglect and 2,165 children spent time in foster care because they could not remain safely at home. Parental drug and alcohol issues were the largest single factor in 44% of child abuse cases. After drug and alcohol, the next largest single factor was domestic violence.*

## COUNTY EXAMPLE



**A SPECIALTY PLAN CALLED the Child Welfare Prepaid Mental Health Plan (CW PMHP) is a limited partnership created between the Magellan Behavioral Health of Florida and the community-based care agencies in 58 Florida counties. To be eligible for the CW PMHP, a child must have a mental health disorder or require two or more coordinated mental health services to successfully live in the community. In Brevard County, Magellan and the child welfare agency shared information to identify eligible children in kinship care and then offer them support to maintain the children in their homes. The results were astounding—100% of the children were maintained in kinship placement or reunification was achieved. In addition, there were cost savings from avoiding more restrictive placement settings and other more intensive services.**

Children and youth removed from abusive and neglectful homes are among our nation's most vulnerable and, because of their exposure to trauma, often exhibit more numerous and serious medical and mental health conditions than other children. A recent GAO report found that foster children of every age are receiving psychotropic medications at a rate of 4.5 times of non-foster children on Medicaid.<sup>16</sup> The treatment for these conditions may include the prescription of psychotropic medications which, when prescribed for children, raises additional questions of safety and effectiveness.<sup>17</sup> The situation is complicated by fragmented coordination of mental health care due to movements in placement and changes in service providers. On November 23, 2011, the U.S. Department of Health and Human Services (HHS) sent a letter to all State child welfare directors, State Medicaid directors, and State mental health authority directors alerting them to the tremendous and growing concern about the safe, appropriate, and effective use of psychotropic medications among children in foster care, and encouraging cross-system collaboration to improve services and outcomes for children.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## CITY EXAMPLE



**WRAPAROUND MILWAUKEE (WAM)** is a national model of a local child welfare system and a behavioral health Medicaid carve-out sharing information and working together to improve services to families and youth in the foster care system at risk of residential treatment, especially those taking two or more psychotropic medications. WAM collaborated with the Bureau of Milwaukee Child Welfare (BMCW) to integrate primary care and behavioral health care. As a result of the partnership, 94% of the identified children had a Primary Care Physician (PCP) and 84% of children on three or more psychotropic medications visited their PCPs. As a result of effective medications monitoring, the number of children using three or more psychotropic medications dropped from 87% to 39%.

» **Juvenile justice:** The Office of Juvenile Justice Programs states that a significant number of youth in detention suffer from psychiatric disorders. To address the needs of such youth, justice officials need to know the kinds of disorders that are most common and their prevalence among the juvenile detainees. Research indicates that providing the detained youth with a continuity of mental health services may reduce recidivism, but identifying and responding to such mental health needs is challenging,<sup>18</sup> especially if there is no access to prior diagnoses and/or treatment, including but not limited to psychotropic medications.

Sharing individual mental health and, even more so, drug and alcohol treatment information for case management purposes is arguably more sensitive than sharing physical health information because, for example, it could allow the authorities to gain knowledge about illegal drug-related acts. But for systems to be effective and to achieve optimal outcomes for the people they serve, cities must determine the minimal amount of information needed and how best to share, utilize, protect, and ensure that it is not further shared.

## FEDERAL LEGISLATION RELATED TO MENTAL HEALTH AND DRUG AND ALCOHOL TREATMENT INFORMATION SHARING

HIPAA is the major federal law relating to the sharing of mental health information (discussed in greater detail in the prior section). For alcohol and drug abuse information, the laws are Title 42, CFR Part 2 (specifically dealing the alcohol and drug abuse) and HIPAA.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

<b>MAJOR FEDERAL LAWS</b>	<b>Title 42, CFR Part 2 Health Insurance Portability and Accountability Act (HIPAA)</b>
<b>Overall Purpose</b>	To encourage more individuals to seek treatment by removing fear that privacy and confidentiality will be compromised by reason of the availability of the patient record.
<b>Key Components</b>	<p>Must be conducted, regulated, assisted or funded in any way, directly or indirectly, by federal government</p> <p>Very clear language provided as to the required elements of the written authorization to disclose information</p> <p>Provides other exceptions to prohibition including court order</p>
<b>Perceived Barriers to Sharing</b>	<p>Provides strong confidentiality protections for all substance abuse and alcohol abuse services.</p> <p>Records of the identity, diagnosis, prognosis, or treatment of any patient maintained in the performance or activity relating to substance abuse or alcoholism or alcohol abuse education, prevention, training, rehabilitation or research</p> <p>Confidential forever, irrespective of whether or not person ceases to be a patient</p> <p>State law cannot override federal law but can be more restrictive</p> <p>If permission to disclose is provided, removes prohibition but does not compel provider's disclosure; instead, program may disclose records in accordance with authorization</p> <p>Very specific requirements regarding the procedures that a court must follow before issuing a court order</p> <p>Conditions placed on the validity of a court order regarding disclosures of information</p> <p>Additional conditions placed on disclosures for medical emergencies, research, management or financial audits, program evaluation, central registries or the criminal justice system</p>
<b>Other Issues for Consideration</b>	<p>Since Title 42, CFR Part 2 was enacted prior to the passage of HIPAA, there is a need to determine which provisions prevail when contradictory. This is especially relevant when dealing with the discretion of a provider to refuse to provide information pursuant to a valid authorization or court order. There is a need for a current federal review and guidance regarding how the law interplays with interoperability and multiple systems working with the same client/patient and how to provide effective, efficient and outcomes-based behavioral health, health and human services. For example, if the disclosure is for "treatment, payment or health care operations", does the agency require a specific consent/authorization if dealing with alcohol or drug abuse treatment? Under HIPAA, it requires a written revocation of an authorization, but 42 CFR Part 2 permits oral revocations.</p>

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## IMPLEMENTATION: WHAT AND WHO

How does a system move from a commitment to sharing key information to actually sharing it in real time? It is essential that this group determines the minimal necessary information (“what”) for the group (“who”) to successfully achieve the governmental purpose.

### The Program Group

The first step is to bring together a group of policy and practice staff to work on “**what**” information needs to be shared and “**who**” requires the information to perform their responsibilities. From a practice perspective, the group must determine “**what**” specific information is necessary to be shared in order to improve outcomes for the client. As part of this determination, it is often useful to consult with outside experts who work in the areas to determine the information necessary to accomplish improving the desired outcomes. Be specific. The task is to share the minimum information necessary—and nothing unnecessary. This kind of specificity takes time, but is important and will start the process off on sound footing.

For example, the local jail system—with the goal of improving health services for inmates, continuity of care, and saving local funds by reducing redundant testing and services—might enter into a collaboration MOU with the Medicaid agency, the local mental health agency, and mental health providers. The collaborating agencies agree to exchange information regarding shared clients when they enter the local jail system and when they exit the corrections system. The jail system has access to what psychotropic medications the inmate is prescribed and the treatment regimen for the individual, including psychiatric admission history, and the community system learns what services were provided to the individual while incarcerated awaiting trial. The corrections system, Medicaid, local mental health agency and private mental health providers have assigned either a unit from each agency to work on these cases or a designated person through an integrated case management model.

After a decision on information to be shared, making sure that it is absolutely the “minimum necessary” to achieve the desired outcomes, the next task is to determine who needs access to the shared information. This designation must include job classifications and the specific units that are involved. Access must be limited to only those persons involved with the clients, the supervisory chain for those staff persons, and any other persons involved with the direct contact to the patients/clients. For any person not involved either directly with the patient/client or with the staff person working with the patient/client, a strong and explicit case must be made for why they should have access to the individual client information.

## IMPLEMENTATION: HOW

### The Legal Group

An internal legal group should be assembled to assist with implementation. The first task of the legal group is to determine if the entity or entities are covered by HIPAA as defined by the law.



# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

The law is specific as to what type of entity is covered and what type of entity is not covered.

- » If not a covered entity, then there may be no HIPAA-related issues involved.
- » If the group determines that the entity is covered, then the next question is whether or not the requested and shared information is protected health information under the applicable federal laws. This is a much easier question when dealing with mental health and alcohol and drug treatment information.
  - If the information is protected, the legal group must determine if it falls within one of the exceptions to HIPAA.
- » Does 42 CFR Part 2 apply? This question involves looking at other jurisdictions where the same or similar information sharing arrangements have been developed to determine how those jurisdictions reached their decisions. For example, schools may have drug and alcohol education and referral services provided by the city's health department or behavioral health department. Such services are not treatment services and 42 CFR Part 2 may not apply.
- » Once that review occurs and is explained, the legal group must examine any relevant state laws to determine if there are any additional state requirements regarding confidentiality for mental health and alcohol and drug treatment information. In many jurisdictions, there is more restrictive state law which controls so this is an essential exercise for the lawyers. Again, the legal group should answer the following questions:
  - Is a state law or state law amendment appropriate for enabling this information to be shared for the purpose of improving outcomes for persons and for government to be more effective and efficient, with the necessary safeguards provided to the information once shared?

Each state's law determines consent rights for mental health treatment for minors and minors in state custody. This presents its own particular issues when dealing with psychotropic medications. For example, in Florida, the parent/legal guardian can consent; the foster care agency cannot and must seek court authorization. Maryland permits consent by both the parent/legal guardian and the local social services director. Massachusetts and Michigan require court approval. In Oregon, the Department of Human Services could consent when the legal guardian but also any child 14 year years or older may consent themselves. Pennsylvania permits the parent to consent but also the 14 year old may consent themselves. Texas has a process where the court can order an individual or state department to consent, and a 16 year old child may also consent if the court determines the child has sufficient capacity.
  - Is an authorization used by both systems the appropriate vehicle to enable the information to be shared? If so, the group should draft such a document and pro-

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

vide to the agency heads for review and distribution to the internal government and external partners and other stakeholders for comment and input. Should the authorization be drafted so that the client “opts in” or “opts out” of the information sharing opportunity?

- If the initiative is only dealing with mental health information, does the legal entity enable it to be classified as the “covered entity” for HIPAA purposes? If so, can information be shared for “treatment” purposes between health and human services case managers who are part of the same covered entity? Are these “other services” within the definition of “treatment” to help provide, coordinate, or manage health care? Does the privacy statement for the legal entity and provided to the client make clear that information is shared between different areas of services within the larger legal entity?
- Is the patient/client group involved in on-going court proceedings (for example, adult probation and parole)? If so, and in working with the appropriate court officers, can a court order be crafted and used to enable information sharing?

» The Legal group also needs to review and determine under state law which parties have the right to provide consent. Each state law may differ from other states so in reviewing the initiatives in other jurisdictions, it is important to know the ways the consent laws differ.

The legal group’s recommendations should be based on their interpretation of the applicable federal and state laws governing the confidentiality of mental health and/or alcohol and drug treatment information and a review of legal interpretations reached in other jurisdictions where such information is being shared.

<sup>14</sup> Pantagraph.com, October 11, 2013

<sup>15</sup> Center for Health Care Strategies, Inc., Analysis of Medicaid Claims Data for 2005.

<sup>16</sup> GAO, Foster Children: HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions, GAO-12-201 (Washington, DC: December 15, 2011).

<sup>17</sup> Psychotropic prescription claims information for children in foster care showed higher rates of potential health risk indicators, based primarily on three prescribing practices: 1) concomitant prescriptions of five or more medications; 2) doses exceeding maximum levels in FDA-approved drug levels; and 3) prescriptions for infants. Increasing the number of psychotropic drugs used at the same time increases the likelihood of long-term side effects (including high cholesterol or diabetes) (GAO 2011, p. 12-14).

<sup>18</sup> OJJDP, Psychiatric Disorders of Youth in Detention,” April 2006



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Human Services and Criminal Justice

### MAJOR FEDERAL LAWS, REGULATIONS, AND PROGRAMS:

The laws and regulations about confidentiality and privacy rights for several additional human service programs may be helpful to consider, including child welfare, juvenile justice, the courts, child support, nutritional supports (SNAP), Supplemental Security Income (SSI), Temporary Assistance for Needy Families (TANF), and the Violence Against Women Act (VAWA).

**The Statewide Automated [Child Welfare Information Systems \(SACWIS\)](#), [Child Abuse Prevention and Treatment and Adoption Reform \(CAPTA\)](#), the [Child and Family Services Improvement and Innovation Act](#), the [Fostering Connections to Success and Increasing Adoptions Act](#), [Title IV-E of the Social Security Act](#), [Title IV-B of the Social Security Act](#), and [Title XX of the Social Security Act](#);**

**[Title XVI of the Social Security Act](#), [Supplemental Security Income for the Aged, Blind and Disabled](#), [42 USC §1381](#); [\(SSI\)](#)**

**[Supplemental Nutrition Assistance Program](#), [7 USC §2011](#); [\(SNAP\)](#)**

**[Title IV-A of the Social Security Act](#), [Temporary Assistance for Needy Families \(TANF\)](#), [42 USC §601](#);**

**[Title IV-D of the Social Security Act](#), [Child Support and Establishment of Paternity](#), [42 USC §651](#);**

**[Violence Against Women, Violent Crime Control and Law Enforcement](#), [42 USC §13925](#);**

### CHILD WELFARE, JUVENILE JUSTICE, AND THE COURTS

Most, if not all, federal child welfare and foster care laws recognize the need for information sharing by the child welfare system with other systems and encourage or mandate that systems work together to increase successful outcomes for children and youth in foster care.

There are a number of different situations where the child welfare system could share information to improve outcomes, increase efficiencies, and reduce redundancies. They include linking with:

- » Medicaid/TANF systems, to facilitate a child's eligibility determination for Title IV-E foster care maintenance payments;
- » Medicaid/health systems on the medical treatment for the parent with a chronic disease;
- » Schools to facilitate school stability and education improvement for children in foster care;
- » TANF to transfer information from the child under the parent's coverage to the child welfare system;

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

- » The juvenile justice system to avoid both the child welfare case worker and the probation officer having to include the same information in each of its systems for shared cases;
- » The mental health system on mental health services provided to the child to determine appropriateness of the child's treatment; and
- » Drug and alcohol treatment system on treatment services to the addicted parent for permanency purposes, including the parent's ability to provide custodial responsibilities.

Cities and counties have enacted legislation which enable and/or force child welfare information sharing. Such legislation should be reviewed to see if appropriate to replicate in your jurisdiction.

## CITY EXAMPLE



***IN 2005, NEW YORK CITY ESTABLISHED THE Health & Human Services Connect program (HHS-connect) in order to allow for data sharing between the Administration for Children's Services, Department of Finance, Department of Homeless Services, Housing Authority, and Human Resources Administration, among others. In doing so, the city took steps to ensure that the needs of its residents would cease to be met in a fragmented fashion, but rather would be approached in a comprehensive method that focused on the individual needs of each person. By providing city service employees with critical, up-to-date information, not only did data sharing allow the city to maximize cost efficiency in providing much needed services, but it ensured that those services provided were based on a holistic understanding of the child and their family. As service providers were able to obtain a comprehensive understanding of the many services involved in the lives of the children and families of New York, they were able to make timely and knowledgeable decisions in order to ensure the best possible outcomes for the children that they served.***

In the chart attached for child welfare — including a review of the Child Abuse Prevention and Treatment and Adoption Reform (CAPTA), the Child and Family Services Improvement and Innovation Act, the Fostering Connections to Success and Increasing Adoptions Act, the State-wide Automated Child Welfare Information Systems (SACWIS), Title IV-E of the Social Security Act, Title IV-B of the Social Security Act, and Title XX of the Social Security Act — there is an examination of the encouragement to share information with other systems as well as the areas that need confidentiality protection and attention. Additionally, the Children's Bureau's Child Welfare Policy Manual (CWPM) provides departmental policies on information-sharing and confidentiality.

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

There are a number of information-sharing relationships, models, and toolkits regarding the relationship between juvenile justice and child welfare and the courts. The federal Office of Juvenile Justice and Delinquency Prevention provides several references to juvenile delinquency prevention information sharing.

## CITY EXAMPLE



**THROUGH AN MOU BETWEEN THE BUREAU of Milwaukee Child Welfare and the Social Development Commission, the city of Milwaukee established a system of data sharing aimed at providing an increased level of services to vulnerable children. This program emphasizes early detection of children's unique mental or physical needs, establishes support (educational and developmental) for parents and other family members, and works to provide a positive and beneficial learning environment for at-risk children. By collecting and sharing data between Head Start, the Bureau of Milwaukee Child Welfare, and the Social Development Commission, the agreement provides information on the health status of the child, any interventions on the part of the school, any changes in the living situation of the child, etc. Through this, the agreement establishes a powerful network of groups working to ensure the well-being of the child through the various services that are provided to the family, and simultaneously decreases the likelihood of any abuse or neglect of the child going undetected.**

## CHILD SUPPORT AND ESTABLISHMENT OF PATERNITY (TITLE IV-D OF THE SOCIAL SECURITY ACT, CHILD SUPPORT AND ESTABLISHMENT OF PATERNITY, 42 USC §651)

Child support and the establishment of paternity law states that the system must have security and interface requirements in its management system. Included are references to improved information exchange with the state agency administering Medical Assistance (Title XIX). Child support and education must exchange information about persons who take loans under the Higher Education Act and are in default or owe an obligation to refund an overpayment of a grant. This federal law discusses information sharing with the Department of Housing and Urban Development, the Unemployment Compensation Program, and the Supplemental Nutrition Assistance Program (SNAP). The Child Support's state plan must include information sharing with TANF, Foster Care Maintenance, Medical Assistance and SNAP.

It is important to note that this law clearly states that, subject to safeguards on privacy and information sharing, there can be access to records of other state and local government agencies, including vital statistics, tax and revenue records, real and titled personal property,

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

occupational and professional licenses, ownership and control of corporations, partnerships, and other business entities, employment security records, public assistance programs, motor vehicle department, and corrections. From an operational viewpoint, the child support system may be very helpful to include in any attempts to create an integrated system due to its working relationships with the Social Security Administration, the Internal Revenue Services, and other federal agencies.

## SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (7 USC §2011)

Commonly referred to as the “food stamps” law, the SNAP program does not present any barriers to information sharing but there should be notice given to applicants for food stamps that information may be provided to other human services and health services systems. Obviously, food and nutrition affects and impacts all health and human services.

## SUPPLEMENTAL SECURITY INCOME (TITLE XVI OF THE SOCIAL SECURITY ACT, SUPPLEMENTAL SECURITY INCOME FOR THE AGED, BLIND AND DISABLED, 42 USC §1381)

The law regarding the Supplemental Security Income (SSI) program states that it may enter into agreements for making determinations or providing information or assistance in making determinations with State and local public and private agencies and organizations. It discusses the relationship between SSI and Title IV-A of the Social Security Act (TANF) and Title IV-E of the Social Security Act (Foster Care Maintenance). It also states that Social Security will provide information obtained pursuant to such agreements to any Federal or Federally-assisted cash (TANF), food (SNAP), or Medical Assistance program (Title XIX) for eligibility and other administrative purposes as well as social services programs (Title XX). The law also discusses the relationship between Social Security and law enforcement.

## TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TITLE IV-A OF THE SOCIAL SECURITY ACT, TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF), 42 USC §601)

Under Temporary Assistance for Needy Families (TANF), there is the mandate to reach out to other systems but, at the same time, to take reasonable steps to restrict the use and disclosure of information about individuals and families receiving TANF. The law specifically discusses the TANF system developing relationships and information sharing processes with domestic violence programs, child support, law enforcement, medical assistance, Social Security, child care, and foster care maintenance.

A recent United States Governmental Accountability Office (GAO) report recommends increased data sharing with child welfare programs to improve access to benefits and services. Relative caregivers were of specific concern in the findings, recommending coordination efforts including collocating TANF and child welfare services and collaboration between staff from each agency in helping relative caregivers' access services. The GAO reports that, al-

# Sharing Data *for* Better Results



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

though it would be beneficial, information and data sharing between TANF and child welfare does not occur consistently, hindering the relatives' access to available benefits.

Half of the states reported obstacles to sharing data including but not limited to confidentiality and privacy concerns.<sup>19</sup>

## VIOLENCE AGAINST WOMEN (VIOLENCE AGAINST WOMEN, VIOLENT CRIME CONTROL AND LAW ENFORCEMENT, 42 USC §13925)

Explicit in the Violence against Women law is strict confidentiality regarding information disclosed by victims of domestic violence, including their location. Any information shared by domestic abuse and violence programs must strictly ensure that the client authorizes the release of such information.

---

<sup>19</sup> GAO, GAO-12-2 (Washington, D.C.: Oct. 7, 2011).



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Appendix A: Selected Additional Resources

There have been numerous writings and conferences about the value of information and data sharing to improve outcomes of government programs, and the opportunities to do so while protecting privacy:

Stewards of Change: [www.stewardsofchange.com](http://www.stewardsofchange.com)

National League of Cities:

- » Stephen Goldsmith and Christopher Kingsley. [“Getting Big Data to the Good Guys.”](#) Data-Smart City Solutions, 2013.
- » [Building Management Information Systems to Coordinate Citywide Afterschool Programs: A Toolkit for Cities](#)

Actionable Intelligence for Social Policy:

- » Legal Issues in the Use of Electronic Data Systems for Social Science Research: <http://www.aisp.upenn.edu/best-practices/legal-issues/>
- » Dennis P. Culhane, John Fantuzzo, Heather L. Rouse, Vicky Tam, and Jonathan Lukens. 2010. [“Connecting the Dots: The Promise of Integrated Data Systems for Policy Analysis and Systems Reform”](#) Actionable Intelligence for Social Policy
- » Case studies also available at the AISP website

Department of Education, Privacy Technical Assistance Center (PTAC). [Protecting Student Privacy While Using Online Educational Services: Requirements and Best Practices](#)

[Establishing Governance for Health and Human Services Interoperability Initiatives.](#) A report of the Illinois Interoperability and Integration Project, 2013.

Office of Management and Budget, Memorandum for the Heads of Executive Departments and Agencies, [“Sharing Data While Protecting Privacy,”](#)<sup>1</sup>

United States Government Accountability Office, [“Sustained and Coordinated Efforts Could Facilitate Data Sharing While Protecting Privacy,”](#)<sup>2</sup>

<sup>1</sup> M-11-02, November 3, 2010

<sup>2</sup> GAO-13-106, February 2013





INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Appendix B: Sample Memoranda of Understanding (MOUs)

In order to give a sense of how other communities have worked through the confidentiality issues raised in this toolkit, four sample MOUs are provided for reference. As noted in the text, these MOUs are not intended to be a short cut to developing an agreement that fits the needs of the participating agencies, is rooted in a positive engagement with families, and aligns with any state-specific privacy laws. However, these examples can be helpful in understanding how such agreements can be structured.

### [Jefferson County Memorandum of Understanding](#)

A comprehensive MOU detailing Jefferson County's initiative to develop a full-service network to support children and families in the overlapping areas of education, physical and mental health, safety, and lifestyle choices.

### [Alameda County Master Agreement](#)

A data-sharing agreement between Alameda County and the Oakland Unified School District to meet the varied health needs of the at-risk students in the area.

### [Milwaukee Memorandum of Understanding](#)

A memorandum of understanding between the Bureau of Milwaukee Child Welfare and Head Start to ensure the existence of broad support across many different sectors for children, especially those targeted families or the child welfare system.

### [New York Data Sharing Agreement](#)

An agreement between the New York State Office of Children and Family Services and the New York State Department of Health to exchange information relating to Medicaid for children, including those in foster care, those who have been adopted, and those who are in the juvenile justice system.



INTRODUCTION

BACKGROUND

GETTING  
STARTED

EDUCATION

HEALTH

MENTAL HEALTH  
AND DRUG  
AND ALCOHOL  
TREATMENT

HUMAN  
SERVICES  
AND CRIMINAL  
JUSTICE

APPENDIX A:  
ADDITIONAL  
RESOURCES

APPENDIX B:  
SAMPLE MOU'S

APPENDIX C:  
LAWS AND  
REGULATIONS

## Appendix C: Laws and Regulations

Given the complex nature of these agreements, it is important to understand the more detailed legal language related to data-sharing confidentiality agreements. These tables dissect the sections of the federal laws discussed in this toolkit that are relevant to designing sharing data or creating integrated data systems.

While individual states may have more specific laws related to these areas that must be considered when creating any data-sharing agreement, knowing the federal laws is an important place to start.

[Family Education Rights and Privacy Act \(FERPA\)](#)

[Health Insurance Portability and Accountability Act \(HIPAA\)](#)

[Medical Assistance](#)

[Supplemental Nutrition Assistance Program \(SNAP\)](#)

[Supplemental Security Income for the Aged, Blind and Disabled \(SSI\)](#)

[Temporary Assistance for Needy Families \(TANF\)](#)

[Child Care and Development Block Grant/Fund \(CCDBG/CCDF\)](#)

[Child Support & Establishment of Paternity \(Title IV-D of the Social Security Act\)](#)

[Child Welfare \(various laws, regulations and guidance\)](#)