



Data Matters

An Evaluation Newsletter

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Interagency MIS: Higher Order Data Connections

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Children with emotional and behavioral disorders and their families may be receiving services from multiple systems including Mental Health, Substance Abuse, Child Welfare, Education, Juvenile Justice, and Public Health. Few, if any, of these agencies may know that the child receives services from others. Since responsibility to serve children and their families is shared by several systems, it is imperative to develop data **collection** and **connection** strategies that portray a more accurate picture of services and outcomes across and within systems.

Without efficient information systems to integrate clinical/functional measures, administrative data, and service and cost statistics across agencies, systems cannot guarantee quality improvement or sustainability. Data are typically housed in separate silos of information, and it is difficult to track activity and outcomes across service sectors. Comprehensive information management may help systems be more responsive to family needs, fill service gaps, reduce duplication, and design system-wide responses to complex needs of children and families. In this era of managed care, development of integrated information systems would also impact on health plans and our measurement of the access to and quality of care.

Technological advances make connecting data more feasible and affordable today. We have the capacity to move from researching "main effects" within agencies to the "interaction effects" across agencies; to move research and evaluation agendas to a higher order of scientific integrity and joint accountability. So why isn't this more widely accomplished? Organizational interests and priorities for data use differ as do technological capacities to standardize procedures at the federal, state, and local levels. Rapidly changing technology and the push to automate systems have resulted in agencies developing at unequal pace,

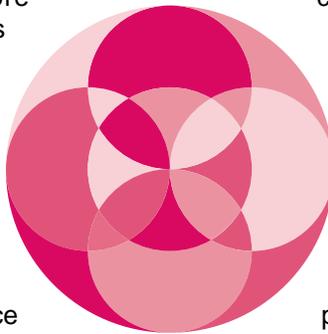
leading to incompatibility between systems. Separate agency regulations and turf issues can stifle efforts to coordinate services and connect data. In addition, confidentiality mandates impose hurdles at multiple levels. Ethical issues and risks of misuse of information are challenges across all systems and professions.

Developing an interagency MIS starts with sharing a high level of communication and commitment from consumers, families, administrators, providers, and policy makers. Potential pitfalls include: lack of clear policies that alleviate fears of mishandling information, structures that hinder development of innovative architectures, unfriendly political environments, and inertia. How do we get beyond these barriers?

It is entirely possible to develop mechanisms for connecting and exchanging data that are effective and practical while protecting the privacy and confidentiality of individuals. We've seen it done in multiple places from the states of Delaware and Oklahoma to the Sault Ste. Marie tribe in Michigan to Santa Clara County, California. Most of these sites and others have accomplished their vision by:

- Developing a shared mission and clear objectives concerning data connection and use,
- Communicating and building partnerships across systems,
- Sharing resources,
- Clarifying intentions in use and storage of data, and
- Building capacity to support interagency MIS through adequate funding, personnel, and training.

The strategies are innovative yet simple, and the rewards are many. We hope these pages offer ideas to support successful and efficient interagency data connection and use in children's systems of care with attention to federal standards, state outcomes regulations, and local quality assurance needs. ♦♦♦



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Introduction to Issue #4

A letter from the Editors...

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Children's Mental Health

"An integrated MIS changes the way folks behave...it requires a reorientation."

"MIS is an essential part of a system of care. It facilitates access to services."

"We need to describe promising approaches to sharing data across systems and better understand community level data linkage."

These statements emerged from a two-day meeting of the Center for Mental Health Services Advisory Workgroup to the national evaluation of federally-funded children's systems of care service sites. Consisting of expert evaluators, researchers, family members and providers, the Workgroup emphasized the need to build cross-system, integrated information systems to facilitate and sustain systems of care. Children with complex needs require comprehensive services spanning different service systems. In order to make the most informed decisions for these children and to evaluate program and clinical outcomes, information must be shared across these systems. This issue of "Data Matters" highlights some of these cross-system challenges and offers concrete ideas and guidance in developing interagency management information systems with attention to federal standards, state regulations, and local contexts for program improvement. We wish you luck in your efforts to connect data and to connect systems. Most importantly, we hope to ensure that the data themselves are well connected to children, families, and communities. ♦♦♦

Copies of **Data Matters** may be distributed freely.

If you would like to contribute to future issues or if you have suggestions/corrections for the mailing list,

please send information to:

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Prior and current issues of **Data Matters** may be found on our Web site:

<http://gucdc.georgetown.edu/eval.html>

"Have You Asked a Parent Yet?"

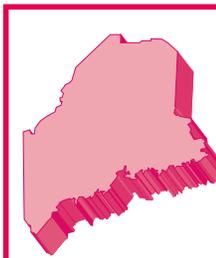
Parent Involvement in MIS Design

Susan Amero

Data Manager, Wings for Children and Families Inc., ME

A quality, cross-system, electronic management information system (MIS) can be a meaningful and useful tool to children's service systems and to the youth and families served. As human services become more integrated and outcomes-oriented, the electronic MIS supporting the services must change and evolve as well. There are many decisions to be made during development of information systems—as well as during implementation when revisions are inevitably required. Several key players should be a part of this process, including Information Technology (IT) staff, clinical staff and other front-line workers, data entry technicians, data analysts, and parents and caregivers of children with complex needs (from here on referred to as "parents").

While IT staff have generally been regarded as necessary players in the **development** phase of MIS, there is often less support for the involvement of other partners such as clinical and data entry staff. As recent system reform efforts have placed greater



In the **Wings** program of Bangor, Maine, **parents** have been primary players in the development of an outcomes database.

emphasis on collaboration, additional players have been welcomed to the "design" table—resulting in better outcomes such as increased efficiency and improved data accuracy and comprehensiveness. One notable party often excluded in MIS development, however, has been parents. **Designers of integrated MIS rarely recognize the value, understanding, and insight parents can bring to the process in order to streamline systems, ensure confidentiality, and increase validity of outcome measurements.**

In my role as the MIS Manager for **Wings for Children and Families** for almost six years, parents have been primary players in the development of our database. The Wings' MIS has been designed, maintained, and revised in-house to allow for maximum flexibility to meet the constantly changing climate of our children's services. Parents' input has repeatedly improved our data management efficiency by "cutting to the chase" and quickly focusing on the true needs of families. By supporting their active involvement in the initial stages of system design (rather than bringing them in later to review/revise work already done), parents have had the opportunity to provide indispensable and timely input on relevant measures of outcomes, effectiveness, and quality control. We have found that their insights often contrast or enhance other professionals' views of outcome measurements in evocative and enlightening ways.

For example, if your MIS design team asked educators how to measure success for a child, they might emphasize grade point averages. When you ask parents of children with special needs how they measure

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Service Coordination and Outcome Measurement in Delaware:

A Very Quick Overview Indeed

Julian Taplin, Ph.D.

Delaware Division of Child Mental Health Services

Delaware's Department of Services for Children, Youth and their Families includes three service divisions: child behavioral health, juvenile justice, and child protective/child welfare. The Division of Child Mental Health Services (DCMHS) provides both mental health and substance abuse services. DCMHS is Medicaid's provider for children's extended services in the state's managed care waiver, functioning as a public managed care organization covering both Medicaid and uninsured clients.

The Department's information system, the **Family and Child Tracking System (FACTS)**, was developed using funds from the Statewide Automated Child Welfare Information System (SACWIS, *note 1*). The mental health component of the work was guided by the Mental Health Statistics Improvement Program (MHSIP) principles (*note 2*) and Medicaid and Health



Care Financing Administration (HCFA) requirements. The system itself is both a database and a worklist system, akin to an airline reservation system. Intake staff, clinicians, contract managers, fiscal workers, and providers input information directly into the computer without duplicating their work from a paper-and-pencil system. DCMHS' module includes (a) intake and assessment, (b) clinical services management (service plan, determination of clinical necessity, and discharge), (c) provider contracts, (d) electronic invoicing, and (e) Medicaid claims, among other functions.

FACTS is written in SQL, runs on an Oracle platform and has Citrix-Metaframe remote access. It operates 24 hours a day and has about 700 users statewide. Crystal Reports and Access are used for building routine reports; Centura is available for construction of complex reports. Total development costs exceed \$15 million. Interested readers should note that because FACTS was developed using public funds, it is available **without cost** to other states or to states' delegate agencies.

Such a large data system, with major modules for the three divisions, required agreement on a Department-wide confidentiality policy and on a set of hierarchically designed security firewalls for all users. **Which** staff may review **what** information is carefully arranged by firewall and password hierarchy to permit need-to-know access while protecting confidentiality. All intake workers may

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Sault Ste. Marie Tribe: Meeting Challenges to Data Sharing

Beverly McBride, MA

Anishnabek Community & Family Services
Sault Tribe of Chippewa Indians, Ste. Marie, MI

The Sault Ste. Marie Tribe of Chippewa Indians **Safe Kids Safe Streets** project is launching the development and implementation of a cross agency information sharing system as part of the Tribe's Anishnabek Community and Family Services Division (which provides mental health, substance abuse, children's protective services, foster care, adoption and direct benefit assistance to the Tribe's seven county service area). The project seeks to reduce juvenile delinquency through reducing child abuse and neglect. One of the goals of the project is to develop an **integrated, computer-based MIS system** that will include Tribal and (eventually) non-Tribal service providers, educational agencies, law enforcement, and medical care facilities. As collaborative Tribal workgroups/committees develop this system, they have encountered several



challenges to collaboration including agencies' capacities, technological compatibility, security concerns, and interagency partnerships. They offer their responses to these concerns to assist other sites in developing and implementing data sharing systems in their own local contexts.

Challenge:

Agencies have fears about exchanging sensitive client information without clearly defined legal authority.

Response:

The Safe Kids, Safe Streets project staff, dedicated to hearing all voices of concerned parties, held workshops and meetings for the partners that would be connected by data. They answered questions and addressed concerns with technical assistance providers. During the meetings, they gave details of the proposed system, cited examples, and included training on the value and content of interagency agreements. Due to security concerns, system plans include separate servers for Web and shared data. They will also install password security, ensure that security policies/procedures are in place at all agencies, and restrict update capability on specific data items.

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Analytical Challenges To Data Integration¹

Penelope L. Maza, Ph.D.

Senior Policy Research Analyst, U.S. Children's Bureau

Providers of child and family services are moving toward a model of "seamless delivery" to address clients' needs better and to reduce inefficiencies and costs. Essential to this movement is the integration of social and health services data to implement and monitor the effectiveness of service delivery. Currently, multi-system data integration is increasingly possible due to advances in technology and decreases in cost. This article focuses on the **challenges to using client-specific data** from different service providers in diverse systems for evaluation and research purposes.

Administrative databases within any system have inherent strengths and weaknesses. Their greatest **strength** is that they cover entire client populations—not a sample. In addition, properly designed administrative databases track service recipients over time as they enter, leave, and re-enter services systems. Their **drawbacks** are many, however, when used for evaluation and research purposes. First, because their primary functions are to track clients and manage accounts, analysts must manipulate the databases substantially to convert them into analytical files suitable for research. In addition, staff who enter and maintain data are generally not members of the evaluation or research teams. Consequently, inconsistent coding and/or untimely data entry and maintenance may go unnoticed.

Data anomalies are also quite common in administrative databases of child and family services. Sometimes data entry clerks assign clients different identification numbers for each service event. They may also enter client names into information systems differently across databases (e.g. James Arthur Jones, Jim A. Jones, J. A. Jones). Maintaining records by families, as many agencies do, may become complicated because of the fluid nature of household structures and living arrangements. For example, a child may have lived with his biological mother and step-siblings, moved to his maternal grandmother's house, and currently live with his father and half-siblings. Locating the correct "family" in the database in each setting can be very challenging and taxing on the confidentiality protections of any information system.

While these challenges within one service system's database are difficult enough to tackle, **integrating multiple databases will magnify their impact on data analyses and interpretations.** Some critical analytical issues to consider when integrating data include the following:

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¹The interpretations, recommendations, and conclusions in this article are those of the author and do not necessarily reflect or represent the view of the Children's Bureau, Administration on Children, Youth and Families, or the Department of Health and Human Services.

Delaware's MIS

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immediately check a child's involvement in other divisions, for example, but the degree of detail available depends strictly on the inquirer's password status.

Routine reports have been designed to address the Department's strategic goals including: (a) **The Venn Diagram Report**, which describes the enrollment and overlap of active clients within one, two or three divisions; (b) **The Office of Case Management (OCM) Report**, (the Department's overseer of all cases), which lists all clients who may require special attention; and (c) **The Boarder Report**, which identifies children who could appropriately receive community services but have no suitable community placement (due to insufficient foster and group homes).

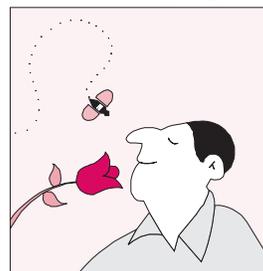
In addition, the Department routinely examines measures reflecting the **Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) Dimensions of Care** (including Efficacy, Appropriate Services, Safety, Timeliness, Respect and Caring, Accessibility, Continuity, Efficiency, and Treatment Fidelity). They have also developed a very short and cursory **screen** to flag cases of children under 12 who are likely to require Department services over a long period of time. The screening is automatically suggested when a young child reaches particular stages in interdivisional service planning. A positive score is automatically reviewed by the Office of Case Management, which may then convene a special planning team.

For more information, relevant policies and reports, see the Department's Web site: www.state.de.us/kids, or contact Nancy Widdoes at nwiddoes@state.de.us or Roberta Ray, Ph.D. at r-ray@state.de.us. ♦♦♦

Notes:

note 1: For more information about SACWIS, please see www.acf.dhhs.gov/programs/oss/sacwis/sacwis.htm.

note 2: For MHSIP guidelines and projects, see www.mhsip.org.



**Special note
from the Editors:**
*Thank you, Julian,
for all your years of service.
We will miss you
during your retirement,
but will carry your lessons
with us forever.*

Wraparound Milwaukee's Web-Based Approach To Service Management and Delivery

Gloria Madison, MS, RHIA
Health Information Administrator

Wraparound Milwaukee is a managed care agency operated by the Child and Adolescent Services Branch of the Milwaukee County Mental Health Division. The Wraparound program focuses on children with emotional, behavioral, or mental health problems and their families. Their goal is to identify child needs and strengths and to develop a collaborative support structure including these other child and family programs:

- (1) **The SafeNow Program:** the child protective services component that provides crisis intervention—a rapid response program designed to meet the child's immediate safety and risk needs.
- (2) **The Ongoing Program:** provides long-term support to families as they work through areas of need, focusing on strengthening the family unit.
- (3) **The Breast Cancer Program:** provides counseling services to children who have a female primary caregiver diagnosed with breast cancer.

Wraparound Milwaukee managed the services of these individual programs, like many organizations, using an off-the-shelf MIS application that initially met their needs. As the organization grew and became more complex, the need for an information system designed around their unique model and procedures (including wraparound needs assessments, planning, and service delivery) was warranted.

A private information technology firm was commissioned to custom develop an information system to support the Wraparound program. The design team solicited input from users and managers to define data, functional, and business-process needs. With these requirements as a base, they designed a **password-protected Web application** that allowed service providers to enter their own data in a **user-friendly, Internet-accessible, aesthetically-pleasing environment**. Because the application was Internet based, other members of the care team could access it via the Web, making it easier for clinicians, case workers, and administrators to share vital information

like assessment, demographic, financial, clinical documentation, and service goals for the individual programs.

An iterative design approach was used to give Wraparound Milwaukee full partnership in the process while keeping the project on track. The client reviewed progress and products at the end of each phase and provided immediate input. This resolved problems quickly and facilitated the eventual acceptance of the system in the field. Throughout the product's development, users were encouraged to interact with a demonstration version of the software. Their feedback led to improvements in usability and uncovered some key training needs. The result was the

creation of a Web-based application that was easy to learn and that automated many inefficient, manual activities. The agency's productivity increased, thanks to a streamlined data entry process, and a layer of clerical personnel was freed for other tasks.

A 3-tiered development approach was implemented including the use of the browser and JAVA Script, an SQL Server, and business logic using ASP. Also included is Crystal Reports for flexible report generation. An independent Internet service provider hosts the application using Secure Socket Layer encryption. Lastly, given the advent of the Health Insurance Portability and Accountability Act's (HIPAA) security focus, legislative security requirements were incorporated into the final design and deployment (*please see HIPAA article on page 6 for more information*). ♦♦♦

For more information including additional details of the tools and technologies utilized, please contact: Gloria Madison at (262) 532-2871 or Aggie Hale at ahale@wrapmilw.org.



**Wraparound
Milwaukee** was
a full partner
in the design
process of their
Web-based MIS.

A Poem for Computer Users Over 30

A computer was something on TV
From a science fiction show of note
A window was something you hated to clean
And ram was the cousin of a goat.

Meg was the name of my girlfriend
And gig was a job for the nights
Now they all mean different things
And that really mega bytes.

An application was for employment
A program was a TV show
A cursor used profanity
A keyboard was a piano.

Memory was something that you lost with age
A CD was a bank account
And if you had a 3-inch floppy
You hoped nobody found out.

Compress was something you did to garbage
Not something you did to a file
And if you unzipped anything in public
You'd be in jail for a while.

Log on was adding wood to the fire
Hard drive was a long trip on the road
A mouse pad was where a mouse lived
And a backup happened to your commode.

Cut you did with a pocket knife
Paste you did with glue
A web was a spider's home
And a virus was the flu.

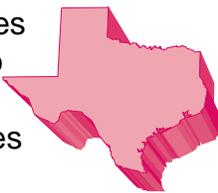
I guess I'll stick to my pad and paper
And the memory in my head
I hear nobody's been killed in a computer crash
But when it happens they wish they were dead.

Author Unknown

Texas' Web-Based MIS: Keeping Kids from Falling Through the Cracks

Through a public-private partnership funded primarily by the Texas Department of Protective and Regulatory Services and supported by the efforts of the ChildTrauma Academy (a joint Texas Children's Hospital and Baylor College of Medicine Program), Texas has developed a multi-domain assessment of families and children for the Child Protective Services (CPS) system in the state. The goal of this project was to develop early identification mechanisms for high-risk infants and children entering the CPS systems, but it has broad application to children in any other public or private system including mental health, juvenile justice, education, and health care.

Texas' WBAT
provides
data to
match
services
better.



The assessment's information management component, the **Web-based Assessment Tool** (WBAT), allows for more efficient and cost-effective planning, delivery, and outcome evaluation of services. As a central repository for data about a child and his or her family, it provides records-keeping, communication, and report-generation tools for authorized users (social workers, clinicians, court personnel, etc.). The WBAT provides the data necessary to match placement and services better for children in the care of CPS thereby reducing time in out-of-home placements. Appropriate users can log on to a secure site and make additions or revisions to their case files, share information with other service providers, and review comprehensive assessment information all in a secure, readily-accessible environment. The assessment and management information systems have helped to identify children who are in need of early intervention, to speed implementation of services, to retain records across various placements, and to avoid repeated assessments of children and families.

The project was first piloted in Houston in 1996; after modifications it was incorporated into existing CPS systems in Austin, and Harlingen. To date, the system has served more than 1,200 children and their families. Quantitative and qualitative information about the emotional, behavioral, cognitive, and physical status of more than 10,000 children will be available at the end of the 5-year pilot phase. Over the next few years, further improvements will be made as the process is taken to scale throughout Texas. ♦♦♦

For more information, please contact
Jana Rubenstein at (832) 824-3738, jlrcata@aol.com,
or visit the Web page at
www.bcm.tmc.edu/cta/Core_Assess_fact_sheet.htm.

HIPAAAlert

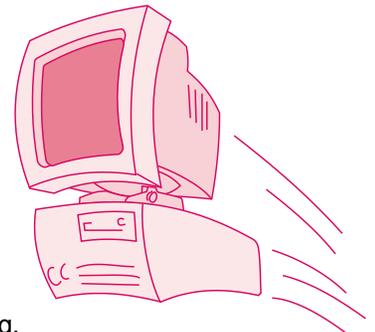
Michelle Woodbridge, Ph.D.
Georgetown Nat'l TA Center

The **Health Insurance Portability and Accountability Act of 1996 (HIPAA)** (PL 104-191) has far-reaching implications for children's services systems—and just about any organization that uses technology to manage health information related to billing or service delivery. While the act contains some reform provisions for health insurance coverage (hence the name), it also includes "Administrative Simplification" provisions that impact healthcare agencies' information systems. These provisions were intended to make electronic administrative records (including claims and encounter data) more efficient, secure, and private through standardization and regulation. But in its requirements, does the law ignore the distinctive needs of *mental health* service systems, disrupting the work of Medicaid and non-Medicaid programs through burdensome provisions and costs?

HIPAA Basics

HIPAA standards will regulate the content, format, security, and privacy of all information within health plans including Medicaid. The law moves us toward the reality of an Electronic Data Interchange (EDI) including more than 1.5 million providers, 7000 hospitals, and thousands of health plans. President Clinton (who signed the final rules and standards on August 11, 2000) cited substantial *cost savings* to the healthcare industry as a result of these streamlining efforts. Using estimates from the federal Department of Health and Human Services (HHS), he touted savings totaling "nearly \$30 billion over the next ten years." Implementing HIPAA, however, will require substantial system costs for conversions, upgrades, training, and troubleshooting—some groups estimating the price to be double that required for Y2K modifications. Furthermore, it may also create undue complications and disruptions to states' public service business needs, especially in the delivery of their mental health services.

What does this mean to electronic transactions of data in children's systems of care? The major areas to which the administrative simplification rules and standards apply include: **(1) Code sets for electronic transmission of health information.** Standard electronic formats must be adopted such that all health care providers use the same codes (including transactions related to claims, encounters,



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Parent Involvement

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success in the educational environment, they might tell you “when the school doesn’t call me as much.” Similarly, in our early years of collecting educational outcomes without the benefit of ample parental input, we made assumptions about the desirability of specific indicators. For instance, we assumed that an increase in the number of children receiving special education services was a negative outcome. Parents explained to us that this could be viewed instead as a positive indicator—representing delivery of a needed service. As a result, we now interpret this measurement as a service and cost indicator, not an outcome indicator.

When you ask a juvenile correctional worker to measure effectiveness, the answer typically involves “compliance with probation officers” or “no further arrests or law enforcement contacts.” These are very important and desirable outcomes. Yet when we talked with parents, they told us that sometimes their child does not comply with all probation and parole visits because of issues such as transportation or family need, not because the child is being defiant. This greatly impacts data analysis conclusions.

Parents **KNOW** which data elements measure effectiveness. They **KNOW** which items are not helpful and don’t get to the real issues. They **KNOW** what is really meaningful to them and their family across different service systems. They **KNOW** what policy makers need to hear. And they **KNOW** which elements, if worded or used inappropriately, can be harmful to the cause of children and families.

From a design standpoint, we have asked parents to review the database user-interface. Parents have provided excellent feedback such as pointing out data labels that

promote stigma and suggesting changes that better protect privacy and security (such as moving a field with sensitive information so it is not easily viewed when the program is first opened). Parents have been able to look at our design and ask questions such as “Why aren’t you tracking *this* item?” which often results in a very helpful revision.

From a cross-systems perspective, parents have first hand knowledge of where duplication of information occurs as well as legitimate concerns with privacy and security of information. At the very least it is respectful to involve parents and ask about their concerns and ideas for responsible use of information policies. Our experience has been that parents have a very reliable sense of how quality data systems can inform and improve children’s systems of care.

It is important to remember that simply having a parent in the room or even as an employee is not going to provide effective results. The parent should be currently or recently involved in multiple systems of care on behalf of their child. That parent will also require training to look for, identify, and advocate for quality. The parent should have the opportunities not only to provide input but also to receive cross-training from the team so as to understand fully the needs of the agency on behalf of the families they serve. Ideally you should also include more than one parent to avoid isolation and to encourage creative thinking. Support and respect from agency leaders must be strong and constant. *Wings* has truly embraced this concept with amazing results, and the phrase “**Have you asked a parent yet?**” rolls off the tongues of *Wings* staff as easily as asking about the weather.

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Susan Amero's experience as a family member enhances her work as Data Manager for *Wings*, a system of care serving five counties. Susan provides ongoing technical assistance and support to the State of Maine on their statewide evaluation and management information systems development. For more information, please contact her at: SAmero@wingsinc.org.

Interagency MIS Development

American Public Human Services Association - Information Systems Management:

<http://www.aphsa-ism.org/index.htm>

The Centers for Disease Control and Prevention’s (CDC)

“Integration Project: National Electronic Disease Surveillance System:”

http://www.cdc.gov/od/hissb/act_int.htm

The Department of Commerce's Technology Opportunities Program (TOP):

<http://www.ntia.doc.gov/otiahome/top/>

The Digital Divide Network:

<http://www.digitaldividenetwork.org>

National Association of Health Data Organizations,

Health Information Dissemination Systems Clearinghouse:

A Forum and Resource Center for Web Enabled Data Dissemination Systems:

<http://www.nahdo.org/hidsc/index.htm>

The IT Advisory Board:

<http://www.theitadvisoryboard.com/>

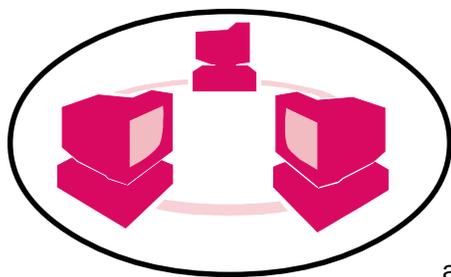
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SITES

Building the Capacity to Integrate Administrative Data: A Florida Perspective

Kristen Snyder, Ph.D. & Paul Stiles, J.D., Ph.D.
University of South Florida

The need to integrate data between public serving institutions is becoming increasingly more pressing, as we understand that health, welfare, and education of the public are complex, interrelated phenomena. No longer are educational institutions the only ones who serve children during the pre-adult years. Nor are those who end up in the prison system completely without the need for other kinds of social services.



With the growing rates of at-risk youth, crime, and violence, and the increasing awareness of mental health and substance abuse disorders, we

quickly beginning to see the need to coordinate care between public institutions. To assist this model of care, often referred to as a *system of care model* (Stroul & Friedman, 1986), it is important to share data between agencies about the needs and conditions of the people they serve. This is not an easy task.

For the past five years, I have had the pleasure of participating in a services research data center at the **Louis de la Parte Florida Mental Health Institute**, whose main focus is to utilize large administrative data sets to understand the impact of legislative and program policies on the well-being of society's most vulnerable populations, typically those with mental illness or substance abuse problems or children at risk of dropping out of school or who have entered the juvenile justice system. Through our work, we gained important insights into the challenges of integrating data sets as well as the need for it. We would like to share with you some of the vagaries that we experienced working with large administrative data sets, particularly as we integrated them in a systems of care model.

When using administrative data, we really must consider multiple levels of interaction:

- (1) the **relationship** level,
- (2) the **data quality** level, and
- (3) the **organizational** level.

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HIPAAAlert

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enrollment, eligibility, and payment). Currently, approximately 400 different formats exist for these codes, but HHS has selected codes that providers are now obligated to use to exchange information. Most importantly, the law stipulated that *all local codes (used for Medicaid claims) be eliminated*. Local codes are those that providers may use to bill for non-traditional services—sometimes these services may be unique to a particular state or county. For example, the formats did not include codes for psychosocial services, juvenile justice involvement, and wraparound models.

(2) **Privacy and security standards.** As HIPAA regulates electronic codes to streamline the healthcare system, it also sets rules to protect the privacy of medical records. Under HIPAA, all covered agencies must maintain “reasonable and appropriate administrative, technical, and physical safeguards to ensure the integrity and confidentiality of the information, protect against reasonably anticipated threats or hazards to the security or integrity of the information, and to protect against unauthorized disclosure of health information.” To this degree, every agency must establish detailed privacy and security policies and procedures, appoint privacy and security officers, implement staff training, conduct regular audits, post regulations, and inform patients of the policies and their rights.

Effective Dates and Compliance Issues

The first set of final rules for code sets went into effect on October 16, 2000, and agencies must comply within two years. Privacy regulations went into effect April 14, 2001, and the Administration announced that the security rules will be released by mid June. Therefore, both of these rule sets will have compliance deadlines of 2003.

HHS (through their Office of Civil Rights) has the authority to impose civil penalties for violations of HIPAA with maximum penalties of \$100 per violation (\$25,000 limit annually). Federal criminal prosecution is a possibility for any person who knowingly uses a unique health identifier, obtains individually identifiable health information, or discloses this information to another person for non-health purposes. Criminal penalties range from \$50,000 and/or one year in prison to \$250,000 and/or ten years in prison.

Reactions and Support

In November 1999, the National Association of State Medicaid Directors (NASMD) formed the National Medicaid EDI HIPAA workgroup (NMEH) to give states a forum to assess the impact of HIPAA Administrative Simplification on Medicaid systems. One of NMEH's subgroups has been working to identify and categorize local mental health procedure codes and modifiers to create a standardized

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Sault Ste. Marie

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Challenge:

It is awkward to convert from paper to electronic systems.

Response:

The project surveyed the sites to determine their current paper-sharing routines and their needs for electronic sharing. Many agencies were already involved in developing and utilizing electronic systems, but others strictly maintained paper operations. Despite some fears of confidentiality and legal authority, most sites were amenable to exploring possibilities of a shared data system.

Challenge:

Agencies handle data from individual cases differently.

Response:

Interagency agreements will spell out clearly the common uses of data across agencies. In addition, the system selected will be very user friendly and implemented on a component basis. Familiar uses such as email and Web page capability will introduce users to the system; then other capacities will be added incrementally.

Challenge:

The community has a wide variety and complexity of demographic data needs.

Response:

The project conducted a survey on information that sites would be interested in seeing collected and accessible in the system. They are working on accommodating all information needs to maximize the ease and utility of the new system.

Challenge:

The rural geographic area poses additional challenges.

Response:

The project recognizes that rural areas require additional travel time, lower meeting attendance, and pose challenges in inclement weather. Many agencies may be single staffed or under staffed without additional resources for data entry and maintenance. Transportation needs and limited resources magnify the complexity of assessments, service provision, and data sharing. A great deal of concern has been dedicated to building a low maintenance system with a high degree of sensitivity to small town environments.

Challenge:

Interfacing among agencies is very labor intensive.

Response:

The project promotes accessibility to useful, local statistics. Various agencies will have the capacity to import/export data, and ease-of-use icons will be built into the system. In order to assure that participants' support does not dwindle, interagency agreements and a workable, secure system will be implemented as soon as possible. ♦♦♦

For more information, please contact Bev McBride at bmcbride@saulttribe.net

Planning Sooner Not Later:

Developing Databases and Relationships to Improve Children's Services in Oklahoma

Steve Davis, Ph.D.

Oklahoma Department of Mental Health

This is a story about **persistence**, about taking advantage of opportunities, building relationships, and establishing formal agreements to improve information and services for children. In Oklahoma there are eight state agencies that provide or monitor children's services. Almost all have developed their own data systems, and few systems talk to each other (probably a familiar story in many states).

Six or seven years ago (the exact date has faded in the memories of those who have aged with this project,) a now-defunct interagency work group studied ways to improve coordination of children's services and maximize available funding for service delivery. Members agreed that they first needed to determine how many unique children their agencies served, and they called upon their Information

Services units for answers. The result was a crude records matching from four agencies using client initials, genders, and birth dates. The results did not show as large an overlap of clients served as some had anticipated—about 56% were served in one of 18 programs

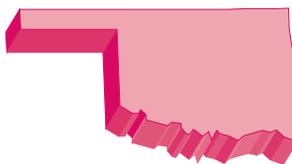
offered by the four agencies, and only 5% were served by more than four programs. But the most startling finding was that **over half of the children were served by one or more of the 18 programs in the four agencies** (including Food Stamps, Child Support, Mental Health, Substance Abuse, Maternal and Child Health, and Special Education).

The work group's results were presented to an early intervention coordinating committee, agency directors, a state children's conference, and to legislators. While it generated interest, it did not immediately generate legislative support and funding. This is where the persistence comes in. Led by staff of the Oklahoma Commission on Children and Youth (OCCY), data and policy people involved in the analysis and other interested agency representatives met as a **task force**: (1) to develop a common confidentiality and release of information form, and (2) to compile justifications for sharing data in a **"Children's Coordinated Data System" (CCDS)**.

Several task force members presented materials to legislators to garner support for funding the planning of the

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"Good will and trust established through shared resources increases cooperation on data sharing projects."



**-S. Davis,
OK Dept. of Mental Health**

Analytical Challenges

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Location of service populations: Some populations may be served by a variety of provider systems. For example, due to fiscal incentives, some children who have historically been served by the juvenile justice system are being placed into the child welfare foster care system. Some analysts may erroneously attribute criminal activity by these children after discharge to their foster care experience without taking into account their prior behavior.

Definitional inconsistency: Systems may use the same term with very different meanings. For example, providers of child welfare services and education use the term “children with special needs.” In education, the term refers to children who have a disability. In child welfare, the term is used primarily as an eligibility criteria for adoption (financial) assistance for children waiting to be adopted. Older age is the most common “special need” for most of these children.

Vague service content: The name or description of a service does not necessarily convey what a provider delivers. For example, “family preservation services” using the Homebuilders model implies that services are delivered in-home and on a 24-hour basis. Some people may misinterpret this to mean that the workers live with the family; others may provide family preservation services under a different model altogether.

Misinterpretations about service quantity: The quantity of services provided can also lead to misinterpretations. A classic example is the relationship between quantity of services and child outcomes. An

evaluator might find that children who receive more mental health services are more likely to enter foster care than children who receive fewer services. Analysts must take into account a comprehensive view of children and families who receive multi-agency services—such as who might be more likely to get services—before drawing conclusions.

Varying service delivery conditions: Providers deliver services under a variety of environmental conditions and degrees of coercion. For example, children may receive services in their homes, in private offices, in clinics, or in locked facilities. Comparing the outcomes of mental health services delivered to adolescents in locked juvenile justice facilities to outcomes from community-based mental health service providers should be done cautiously. In addition, parents in the child welfare system and children in the juvenile justice system may perceive their services as punitive and involuntary in contrast to other system services (such as education). Therefore, the circumstances under which the client receives services may impact the compliance with treatment and its effectiveness.

In conclusion, the movement toward data integration is an exciting and necessary development that should assist in improving services to children and their families. However, inherent in using integrated databases for evaluation and research purposes are the strengths and weaknesses of administrative data. Analytical issues, many mentioned above, may be especially magnified when using data from different service systems. Analysts, evaluators, researchers, and stakeholders need to take these factors into account before basing any decision on one interpretation. ♦♦♦

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HIPAAAlert

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set that could be used by states. This initiative proposes to include the standardized local codes in the HCPCS (HCFA Common Procedure Coding System) currently being used by Medicaid programs (and allowed by HIPAA).

The National Association of State Mental Health Program Directors (NASMHPD) and the NASMHPD Research Institute are actively trying to educate Mental Health Commissioners on the subject of HIPAA. They have also joined with other national groups such as NASMD to encourage HHS to adopt additional codes that may be utilized locally for mental health services (both Medicaid and non-Medicaid programs). Individual states are also working on ways to ensure that their individual needs and practices are reflected in the standardization processes of HIPAA, and that their systems understand the realities and costs of HIPAA implementation. ♦♦♦

For more information on HIPAA:

- Final rules and regulations in full: <http://aspe.hhs.gov/admnsimp/final/txfin00.htm>.
- Summary of the final privacy regulations can be found on the HHS Web site at: <http://www.hhs.gov/news/press/2000pres/00fsprivacy.html>.
- Statement by HHS Secretary Tommy Thompson on the Patient Privacy Rules: <http://www.hhs.gov/news/press/2001pres/20010412.html>.
- HCFA Medicaid-related HIPAA information: <http://www.hcfa.gov/hipaa/hipaahm.htm>.
- HIPAA Advisory Web page: <http://www.hipaadvisory.com/>
- The Mental Health Statistics Improvement Program (MHSIP) Web site contains relevant articles/presentations related to HIPAA: <http://www.mhsip.org>.
- The Work Group for the Computerization of Behavioral Health and Human Services Records: www.workgroup.org.
- Litwak, Paul (2000, December). It's time to get ready for HIPAA: Behavioral health organizations need to ensure privacy in electronic health transactions. *Behavioral Healthcare Tomorrow*, 9 (6), 17, 41-45.
- Yennie, Henry (2001, Jan/Feb). HIPAA: What does it mean for Behavioral Health? *Behavioral Health Management*, 21 (1).

A Florida Perspective

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The **relationship level** focuses on building connections to state agencies to learn what kind of data are available, to explore potential sources of collaboration, and to build a trust between you and the agency data department. This is a critical component, without which, we believe, you cannot go very far. You must develop relationships with people who can give permission to use the data, as well as with those who understand the data. Typically they are not the same person.

The **data quality level** is another world altogether. There are two main issues:

- (1) the quality of an individual data set, and
- (2) the ability to link data sets.

First you must understand your data. What are the variables, what do they represent, and how reliable is the information? This can take quite some time, and for most of us, it is about 90% of the work. **It is very common to find users who think about the information differently from the agencies collecting the data.** In part, it has to do with different values in the data. And in part it has to do with how well trained the end user is in the purpose and meaning of the items being collected. One of the things that we continuously experience is that you cannot rely on any standard from year to year or data set to data set. Sometimes the cards are with you, but often times not. Information systems in agencies change as do program policies and end user incentives (i.e., using data for reimbursement). Each of these issues, as well as others not mentioned, can dramatically affect the data from year to year. The lesson in all this is that you must check any new data constantly, even if you received the same variables in the same format from the same agency the year before.

To link data requires at least one common linking variable, such as personal identifier or name and address. As many of us have learned, this is easier said than done. Often when using state agency data files, you will find that one agency (Medicaid, for example) uses the social security number as well as Medicaid ID, while another system might use their own identifier. If they share the social security number in common, then you can link. If they don't, then you have to find other ways, for example probabilistic matching techniques. Often data sets will contain the same variable (e.g., date of birth), but the format of the field might be different. If you are going to link data sets, you will need

to standardize the variables ahead of time.

The last level to consider when working with and integrating administrative data is the **organizational level**: having the commitment and participation of different representative agencies to provide common variables so that linking is possible. This, too, is complicated to enact. Data systems were designed years ago to fit the specific needs of the clients they serve. Some, like education, are mostly for graduation purposes; in juvenile justice they can be more for tracking, and in health care the data serve for reimbursement of services. So how do you bring it all together? We believe that it requires representatives from the different agencies to come together and discuss **how** data will be shared and **for what purposes**. Decisions need to be reached about how and where data will be stored once integrated. If it is for a specific research project, data are typically stored with the researcher. If the integration is for

systems administration to monitor the progress and success of people, then who administers the "system"? There are a number of questions to consider about integrating data beyond the traditional research project. They include political, economic, and functional issues and should have the core goal to insure client confidentiality and anonymity.

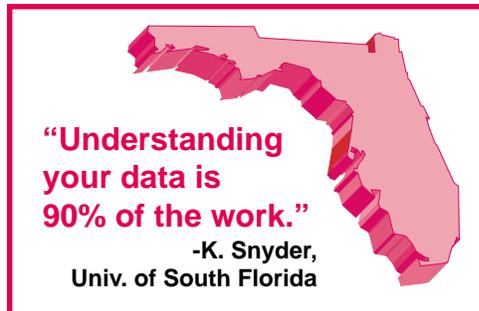
The need to integrate data between public agencies is clear. Federal funds are supporting this with such endeavors as the Community Mental Health Service sites and projects like THINK (Tampa Hillsborough Integrated Network for Kids) in Florida. It will take a keen understanding of the data available, a commitment among agencies and community stakeholders, legislative creativity, and a willingness to make changes in the current model of individual agency data systems to understand the complexities of meeting the needs of people today. ♦♦♦

Reference:

Stroul, B. A. & Friedman, R. M. (1986). A system of care for emotionally disturbed children and youth. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

Note:

Kristen Snyder is formerly the co-director of the Policy and Services Research Data Center at the Louis de la Parte Florida Mental Health Institute, and now serves as Research Director of the International Schools Connection Project in the College of Education at the University of South Florida. Paul Stiles is the current director of the Policy and Services Research Data Center at the Louis de la Parte FMHI. **For more information, please contact Kristen Snyder at KSnyder@tempest.coedu.usf.edu**



Lots O' Work and Persistence

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CCDS. Consultants conducted a "joint application design" with representatives of the eight child-serving agencies, the Department of Commerce, Office of State Finance, and legislative staff members. People with administrative, legal, programmatic, and technical concerns from each of the agencies came together in workgroups to establish goals and guidelines. They voiced concerns, identified solutions, compiled proposed elements of a data system, and estimated implementation costs.

Persistence comes in (again). Armed with a plan and an interagency agreement which most agencies had signed, task force members returned to the legislature the next year and asked for first-year implementation funding. Although there were legislative supporters who introduced language that added start-up funds to OCCY's budget, low state revenues and other funding priorities led to the language being dropped. The next year's efforts yielded similar results.

In the interim, the task force worked on small (but contributory) projects, and players and technology changed. Department of Mental Health and Substance Abuse Services (DMHSAS) used grant funds to hire a programmer to help State Department of Education staff redesign and implement a new SoonerStart early intervention database. The new system provides users with easier access to the data and gives analysts more functional data summaries. **The good will and trust established through the shared resources is fostering increased cooperation on data sharing projects.** DMHSAS and Department of Human Services staff have also met to negotiate sharing data and identifying data

elements to study families served by both agencies. The protocols established by this two-agency project will help lay the groundwork for multi-agency CCDS analyses.

In another development, our state's Employment Security Commission (OESC) received funds to implement a data system to support Workforce Improvement Act initiatives. The proposed system had referral functions similar to those of the CCDS plan, and the OESC project director was willing to include the CCDS data repository that the analysts were exploring. Thus, a new partnership was established. At the same time, technology was moving to Web-based applications, and both the CCDS and the OESC plans were revised to reflect this new approach that promised increased accessibility and less infrastructure investment.

Finally this past year, a threshold of momentum was reached, and funding for three staff and equipment was appropriated for the CCDS project (with agency matching funds). Does this mean smooth sailing ahead? Not likely. OESC still has to decide which one among three different plans it will implement, and each has different implications for how and when the CCDS project will fit into the process. In the meantime, the Legislature is back in session and expecting to hear how the CCDS team has spent that last appropriation before agreeing to more. A project manager has been hired and the OESC liaison has been established, but will that be enough? We'll know for certain in another two months. But you can be sure, whatever the outcome this year, the persistent members of the CCDS workgroup will continue their efforts until they have reached their goal of providing efficient data sharing that supports effective services for children. ♦♦♦

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Data Matters