

# CONFIDENTIALITY AND PRIVACY IN HHS: Myth vs. Reality

The University of Pennsylvania’s Field Center for Children’s Policy, Practice & Research, in collaboration with Stewards of Change™, hosts think tank to explore misperceptions about information sharing among human services agencies. The goal: to clarify understanding of privacy and confidentiality rules, resolve related concerns and promote strategies to improve client outcomes.

By Amy Lipton

- » *A woman with a history of drug dependence and mental illness drowns her three children, then attempts to take her own life.*
- » *A man with a record of violence assaults his daughter’s half-sister, who is left in his care, infecting her with HIV.*
- » *Four adopted brothers are discovered neglected and malnourished, their growth severely stunted.*
- » *A caseworker is raped and murdered when she makes a home visit to a client family.*

**L**IKE SO MANY TRAGIC CASES involving vulnerable children and families, each of these scenarios might have been avoided had the various caseworkers, court officers, educators, health practitioners and others involved shared relevant information about their clients.

Every day, thousands of such children and families come into contact with government and

private agency social service providers, teachers, police, medical doctors and mental health professionals, courts and judges who make decisions that shape their lives. Unfortunately, many of these life-altering decisions are made without adequate or accurate information about the panoply of often interrelated issues children and families face.

Before information can be made available and shared, real or perceived barriers regarding which information can be shared and with whom must be overcome. The problem is compounded by the fact that child and family healthcare, educational and social service systems operate within organization- and policy/funding-created silos. The silos themselves are significant obstacles to overcome, even in initiating conversations about information and data sharing, privacy and confidentiality.

The University of Pennsylvania’s Field Center for Children’s Policy, Practice & Research, in collaboration with Stewards of Change, recently brought

“We can’t allow changes in the political landscape to disrupt energies in information sharing and derail interoperability projects.”

— DEAN RICHARD GELLES  
University of Pennsylvania  
School of Social Policy &  
Practice and Field Center for  
Children’s Policy,  
Practice & Research



Dean Gelles: It is essential to get pertinent information in real time “because kids are developing in real time.”

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**“People and families don’t live in silos, they live in connected communities—it’s not one-size-fits-all.”**

— DANIEL STEIN  
Stewards of Change



**Rep. Shapiro:** “You need to be strong voices for kids.”

together the key stakeholders from these governmental and organizational silos to cut through the complexity of the most significant confidentiality and privacy regulations (HIPAA, FERPA, 42 CFR-2, CAPTA and domestic violence, for example), eliminate the related confusion, and work toward developing data-sharing and information-sharing strategies, structures and guidelines to drastically reduce these avoidable catastrophes. That ultimate goal was shared by the 65-plus experts from national, state and local government, nonprofits, the judicial and advocacy community, business, tribes and academia who gathered Nov. 8-9 for the unprecedented conference “Addressing the Myth and Reality of Confidentiality and Privacy in Cross-System Information Sharing,” held at the University of Pennsylvania Wharton School’s state-of-the-art Huntsman Hall in Philadelphia.

The think tank’s conveners shared a common perspective on how to better serve vulnerable children and families.

“People and families don’t live in silos, they live in connected communities—it’s not one-size-fits-all,” said Daniel Stein, managing partner of Stewards of Change, in his opening remarks to summit attendees. Over time, however, “we’ve created complex siloed architectures with multiple siloed agencies and funders.”

“We need mobile, real-time information sharing across systems of care,” concurred Debra Schilling Wolfe, executive director of the Field Center, in her opening remarks. The more rigid our

systems of care, the more difficult it is to meet children’s needs, Wolfe said. “We need to address confidentiality as both a barrier and potential enabler of information sharing, and to establish national standards of practice.”

“There are both realities and myths regarding the privacy and confidentiality of information and data,” noted Richard Gelles, Dean of Penn’s School of Social Policy & Practice and Faculty Director of the Field Center. “We wanted to bring the most knowledgeable experts on privacy law together with the key users of data and information and come to a common understanding of how we can move forward with information sharing and accessibility of critical data.”

When the idea emerged to convene experts in the field, it was a “eureka moment,” Stein observed. “That was the genesis of this conference—to bring you together to see what we can share, what we need to change, what’s real, what’s myth.”

Stein, an expert in information sharing across human services systems, noted, “We need to work together to construct an interoperable framework that allows for connectivity among silos, systems and jurisdictions. As we do so, there’s a lot of opportunity to learn from each other around the country, to take away from today and build on that knowledge base.”

**High-Level Support**

ONE REASON FOR THE enthusiasm evident throughout the conference—despite the challenges associated with altering embedded thinking about privacy and confidentiality and forging new approaches—is what one attendee referred to as “a sense of openness” on the part of the federal government to address related issues. This high-level interest in identifying and eliminating barriers can propel new discussion and help highlight existing challenges.

Ari Schwartz, senior Internet policy advisor for the National Institute for Standards and Technology (NIST) Information Technology Laboratory, shared a November 3, 2010, memorandum from the Executive Office of the President/Office of Management and Budget to the heads of the nation’s executive departments and agencies that states in pertinent part:

*“As advances in technology enhance tools for data sharing, Federal agencies can and should seek new*

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“We need to address confidentiality as both a barrier and potential enabler of information sharing.”

— DEBRA SHILLING WOLFE  
University of Pennsylvania  
Field Center for Children's  
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*approaches for identifying and sharing high-value data responsibly and appropriately. This Memorandum strongly encourages Federal agencies to engage in coordinated efforts to share high-value data for purposes of supporting important Administration initiatives, informing public policy decisions, and improving program implementation while simultaneously embracing responsible stewardship...*

*“The success of many initiatives hinges on the sharing of high-value data.”*

(See the opening page of the OMB memo, next page.)

This is a good time to “ask the feds for clarity,” said Bill Rivera, assistant general counsel to the U.S. Department of Health and Human Services. High-level officials including David Hansell, Acting Assistant Secretary of the Administration for Children and Families/HHS, are “very committed and receptive to helping remove, address or clarify barriers,” Rivera added.

While similar interest exists among state government leaders, today’s particularly challenging fiscal times mean it will require a concerted effort to fuel the conversation. “People like you need to be strong voices for kids,” said Rep. Josh Shapiro (D), Montgomery County, PA, State Legislator and member of the White House Team of State Legislators for Health Reform, addressing the attendees in his keynote remarks. The “slash and burn mentality” demonstrated in New Jersey and other states toward HHS and child welfare programs “will backfire.”

We can’t allow changes in the political landscape or finances to “disrupt energies in information sharing” and “derail interoperability projects,” concurred Dean Gelles in his opening remarks. Citing the Garden State as “a perfect case in point,” Gelles said states are realizing that the stimulus money is running out and they “won’t be amenable,” absent persuasion, to funding costly interoperability projects.

**Why the Urgency?**

WE NEED A ROADMAP to get around the hurdles presented by the confidentiality and privacy laws because human services agencies are “simply unable at present...to bring together the information they need to muster to make better decisions for children and families,” Gelles said.

Of the 6 million children reported in suspected



**Judge Martin:** “Different agencies have different access” to critical information about children.

instances of child abuse and neglect in 2009, 50 percent were involved in an investigation, 11.5 percent were identified as victims of child maltreatment and 2 percent were removed from the home, Gelles said, showing statistics from the National Child Abuse and Neglect Data System. (NCANDS is a national data collection and analysis project carried out by the U.S. Department of Health and Human Services, Office of Child Abuse and Neglect.)

Decisions about children’s safety and well-being are often made without full knowledge and understanding of their actual circumstances, Gelles said, emphasizing the need for relevant client information to be shared in different ways at different key decision points to ensure the best possible outcomes. “It is sometimes the case that you have a caseworker who is a 20-year-old art history major with six months of experience, working with a supervisor and a consulting judge to make a decision about removing a child from his or her home. The decision is difficult enough without having reliable, accurate, up-to-date information readily available.”

It is “absolutely necessary” to get accurate, pertinent information in real time “because kids are developing in real time,” Gelles said. “Kids don’t stop evolving to wait for us to return phone calls and answer e-mails or leaf through 12-inch case files.”

Limited data and information sharing and coordination among providers often leads to tragedy, said Stefanie Gluckman, health policy

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EXECUTIVE OFFICE OF THE PRESIDENT  
OFFICE OF MANAGEMENT AND BUDGET  
WASHINGTON, D.C. 20503

November 3, 2010

M-11-02

MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

FROM:

Jeffrey D. Zients  
Deputy Director for Management

Cass R. Sunstein  
Administrator, Office of Information and Regulatory Affairs

SUBJECT:

Sharing Data While Protecting Privacy

The judicious use of accurate and reliable data plays a critical role in initiatives designed to increase the transparency and efficiency of Federal programs and to enhance our capacity to gauge program effectiveness. Sharing data among agencies also allows us to achieve better outcomes for the American public through more accurate evaluation of policy options, improved stewardship of taxpayer dollars, reduced paperwork burdens, and more coordinated delivery of public services.

As advances in technology enhance tools for data sharing, Federal agencies can and should seek new approaches for identifying and sharing high-value data responsibly and appropriately. This Memorandum strongly encourages Federal agencies to engage in coordinated efforts to share high-value data for purposes of supporting important Administration initiatives, informing public policy decisions, and improving program implementation while simultaneously embracing responsible stewardship.

When agencies share data, they must do so in a way that fully protects individual privacy. The public must be able to trust our ability to handle and protect personally identifiable information.<sup>1</sup> In sharing data, agencies must comply with the Privacy Act of 1974<sup>2</sup> and all other applicable privacy laws, regulations, and policies. In addition to the legal framework that governs the use and disclosure of data, agencies are advised to consult established codes of Fair Information Practices.<sup>3</sup> As OMB has previously noted, “[t]he individual’s right to privacy must

<sup>1</sup> For the definition of “personally identifiable information,” see the appendix to OMB Memorandum M-10-23, *Guidance for Agency Use of Third-Party Websites and Applications* (June 25, 2010), available at [http://www.whitehouse.gov/sites/default/files/omb/assets/memoranda\\_2010/m10-23.pdf](http://www.whitehouse.gov/sites/default/files/omb/assets/memoranda_2010/m10-23.pdf).

<sup>2</sup> 5 U.S.C. § 552a.

<sup>3</sup> Since 1973, several government reports – both general and agency-specific – have established Fair Information Practices that set forth many accepted principles of information privacy. See, e.g., U.S. Dep’t of Health, Educ., and Welfare, Secretary’s Advisory Committee on Automated Personal Data Systems, *Records, Computers, and the*

**“States have been struggling with issues of privacy rights and waivers and have come to varying interpretations and conclusions.”**

— MIRIAM KRINSKY  
UCLA School of Public Affairs and California Blue Ribbon Commission on Foster Care

manager at The Children’s Partnership, which advocates a “whole child” approach. Recalling an incident in which a four-month-old girl died because doctors failed to transfer information about a simple medical condition to the guardians at a temporary home during her transition to foster care, Gluckman said, “The information must move with the child.”

“Each of us is a whole person, with educational needs, emotional needs, and social needs,” one foster youth told me recently,” said Miriam Krinsky, lecturer at the UCLA School of Public Affairs and member of the California Blue Ribbon Commission on Foster Care. “It’s so important that we keep that in mind.”

**Fear Factor**

SO WHAT GETS in the way? Fear is a major obstacle in the over- and under-sharing of information, according to conference participants.

The multitude of complex laws, regulations and rules, written in “legalese” and open to (mis) interpretation by the various federal, state and local agencies, has created a sort of “privacy paranoia” on the part of employees and supervisors who work in regulated environments. The lack of training and consistency in applying HIPAA, FERPA, 42 CFR-2 and other broad federal mandates has stirred concern about liability to the extent that, even if people could get past what one attendee described as “the culture of not sharing” that permeates bureaucracies, they often err on the side of withholding information “just to be safe.” In the process, sadly, they jeopardize consumers’ health and well-being, often with fatal consequences.

“The complexities of the legal restrictions and bureaucratic parameters around confidentiality stifle innovation because people are afraid to make mistakes and are worried about the consequences,” said Stein. “Technology only amplifies that fear because it can exponentially increase the magnitude of the mistakes, whether through human error or security breaches.”

Lack of clarity on the following issues complicates matters further, participants observed:

» **Who owns and controls client data?** “Different agencies have different access,” said the Hon. Patricia Martin, presiding judge in the Child Protection Division of the Circuit Court of Cook County, IL, and president-elect of the National

Council of Juvenile and Family Court Judges. When a child’s future rests in her hands and she has to make a potentially life-or-death decision, Martin explained, she wants just the information she needs—no more and no less. “But I’m concerned about my constituents, especially the children, because it’s not clear: Who owns the information, who is entitled to it? Is it the guardian or is it the agency? Who is the customer?”

» **Should children’s privacy be guarded more vigilantly than that of adults?** “Everybody wants their own privacy protected, but they want information about everybody else,” said Cindy Christian, faculty director of the Field Center, chair of Prevention of Child Abuse & Neglect and associate professor of pediatrics at Children’s Hospital of Philadelphia, eliciting a collective chuckle.

» **Who is entitled to assert and to waive privacy rights on behalf of a system-involved child?** States have been struggling with these issues of privacy rights and waivers and have come to varying interpretations and conclusions, said UCLA’s Krinsky, noting that the issues are particularly complex in the case of children in out-of-home placement. Is the holder of the privacy privilege the appropriate party to consider any waiver on behalf of the child, the court, the child’s advocate, the child’s caregiver or the noncustodial biological parent? And what standard are those parties to use in making those decisions, especially when bearing in mind that children can’t protect themselves, so “the line has to be skewed” in their best interests?

That, of course, raises the question: What are a child’s best interests? It’s a vicious circle of sorts, participants agreed, and philosophical viewpoints abound. “Privacy is incredibly important for human dignity and autonomy, yet we have a system of government based on imposing [it on us] and depriving [us of it],” observed Anita Allen, deputy dean for Academic Affairs, Henry R. Silverman professor of law and professor of philosophy at the University of Pennsylvania Law School. “Children don’t know now what data will make them vulnerable later,” she explained. “Do we take their privacy away or do we force it on them because they’re vulnerable?”

In child welfare and juvenile courts, parties’ motives are often “murky,” added Christopher

**“In child welfare and juvenile courts, parties’ motives are often ‘murky.’ Part of it is trying to figure out if we’re protecting the children or the adults.”**

— CHRISTOPHER WU  
California Administrative Office of the Courts, Center for Family and Children in the Courts

Wu, supervising attorney for the California Administrative Office of the Courts, Center for Family and Children in the Courts. “Part of it is trying to figure out if we’re protecting the children or the adults.”

- » **What happens when shared data overlaps with protected data?** Children’s school records may contain medical information, for instance, so it is seemingly impossible to share the former without the latter. Similarly, medical records may contain information about mental health or substance abuse that, if disclosed broadly, could stigmatize a patient in later years and in other contexts.
- » **How do we best interpret and reconcile so many rules?** Many state and local jurisdictions have their own, more stringent requirements than the overarching regulations set at the federal level. While states and localities rely on the federal regulations to serve as minimum guidelines, government officials and employees need to understand how to apply the general rules as well as those specific to their organizations. Moreover, reconciling conflicting rules and regs can be particularly challenging.
- » **If the technology exists, why don’t we have it?** Microsoft Health Vault and other electronic medical records systems are designed to accommodate confidentiality requirements; they’re making inroads into public, private and nonprofit organizations, but there’s a long way to go. Lack of understanding of cost/benefits keeps many agencies from pursuing the requisite funding, labor, infrastructure and training.
 

“There’s a lot of criticism, angst and anger about data sharing,” said Lyndsay Pinkus, policy manager for the Data Quality Campaign. It’s “a big ugly cycle. We want to move forward but we don’t necessarily have the tools.... The federal, state and local [governments] are all doing different things with data, and they’re not necessarily connected and not helpful to each other.”

“It’s ironic,” echoed Frank DiDomizo, CFO/CIO of the Montgomery County, PA, Office of Children & Youth, which worked with the Field Center and Stewards of Change to develop its Information Portability Project, integrating the county’s human services programs. “We all have the same goal—we’re trying to help families, yet we don’t have a holistic approach.”

Now that Montgomery County’s interoperability project is under way, DiDomizo said, “the biggest obstacle we’re hitting is—yup—confidentiality.”

HIPAA “is the biggest excuse we have for not working as a team,” said Uma Ahluwalia, director, Montgomery County, MD, Department of Health & Human Services, who worked with Stewards of Change to implement its extensive Service Integration Policy; her staff now includes a HIPAA expert, with a risk manager position in the works. “It’s terrifying. If you don’t know how to evaluate risk, you don’t know what monsters [will emerge] when you open the doors. You have to put appropriate safeguards in place or you can be paralyzed with fear and do nothing.”

**Taming the Privacy Beast**

SO WHAT’S THE SOLUTION? There’s no single easy answer, but through two days of presentations and brainstorming sessions, participants mapped out a collective wish list of sorts. Suggestions were aimed at debunking confidentiality myths more broadly and putting confidentiality and privacy in context to advance data-sharing and interoperability efforts and outcomes.

“Data is wealth—it’s a treasure, it’s like gold—but it’s sensitive,” said Lillie Coney, associate director of the Electronic Privacy Center (EPIC), a Washington, DC-based public policy think tank. “We have to make sure the right data is in the right hands at the right time, but no longer than necessary.”

The group’s recommendations for addressing the myriad privacy and confidentiality issues included:

- » **Allow and encourage local flexibility and experimentation, including federal waivers when appropriate.** Yes, we need federal uniformity when it comes to confidentiality, participants said, but we also need room for states to innovate. Where national guidelines run counter to state and local purposes, those jurisdictions should be entitled to bow out through waivers or other mechanisms, suggested Judge Martin. They should also be eligible for federal funding to develop reasonable alternates.
- » **Stick to a need-to-know basis.** “Confidentiality laws should be tailored to context,” said Prof. Allen. “Keep the ‘cluster of confidentiality’

**“If you don’t know how to evaluate risk, you don’t know what monsters [will emerge] when you open the doors.”**

— **UMA AHLUWALIA**  
Montgomery County, MD,  
Department of Health &  
Human Services

small—don’t let it expand exponentially... Confidentiality is not like a chain around our neck with no keys to get out of it.”

Concurred Dean Gelles, “Child welfare is not about services but about street-level decision-making... We only need the information that is relevant for a specific decision and action at a specific juncture of a case.”

There are “different privacy concerns for the data at each decision point,” he added, citing four decision-support questions caseworkers and child welfare advocates must answer: “Who’s the client, what’s my job, what information do I need to do [my job] and what mistakes am I willing to make to do it?”

- » **Clarify who has the right to opt in and opt out.** Because HIPAA and other regulations are only minimum standards, “what works in one state may not work in another state,” explained Rebecca Gudeman, director of the Adolescent Health Law Program and a senior attorney at the National Center for Youth Law. “It’s not all or nothing... Each state needs a roadmap.” California has a statewide form, which others are welcome to adapt to their needs, Gudeman noted.
- Development of a universal opt-in/opt-out form would be ideal, some participants said.
- » **Consider workarounds.** Many organizations share data on a sort of “don’t ask, don’t tell” basis. “Some agencies just share,” said Wu. “You have to assess the landscape, assess your resources... Essentially, don’t use privacy as a barrier if it’s not in the best interest of the child.”
- Sometimes, differentiating between aggregate data and individual data and refining the needed information can help. In some cases, for example, a single piece of information about a specific client may be more readily available than a mass report. In other instances, sharing nonclient-specific aggregate data is useful in discerning system gaps and trends.
- » **Break down language barriers.** Put HIPAA and other rules in terminology specific to the various agencies, staff and clients they affect, to expand understanding.
- » **Take advantage of technology to simplify and facilitate information exchanges.** Granted, the computerization of data is “both a wonderful thing and a terrible thing,” said Lauren Steinfeld, chief privacy officer at the University of Pennsyl-

vania, who cited electronic medical records as “one of the most hopeful developments for data sharing.”

For example, a large hospital can have “upward of 100 systems, none of which talk to each other,” which makes it extremely difficult to coordinate care, according to George Scriban, senior global strategist for privacy, security and online trust and safety at Microsoft Health Solutions. The company’s Amalga patient records platform lets practitioners “deliver services without having to worry about privacy or security” because Microsoft manages the information repository, cross-state and cross-provider, to assure coordinated care, Scriban said.

The technology we need to ensure interoperability while respecting confidentiality laws does exist, noted Dean Gelles—in fact, the technology is “way ahead of practice, the law, the Supreme Court,” he said. But technology is “a very sharp two-edged sword.” The key is to use it responsibly to improve clients’ lives.

FedEx, eBay and other online sites “allow financial transactions and data tracking without any privacy violations,” Gelles added, so there’s no reason HHS can’t use similar technology to achieve its goals. “If I can find my wife’s iPhone in a five-story row home using an app on a laptop, I can find a kid [who might otherwise be lost in the foster care system]!” he said.

- » **Develop and share return on investment models.** It’s easier to cost-justify any interoperability expense if you show tangible ROI models. Draw on others’ experiences and share the results of your own projects.
- » **Train your staff.** “We’ve made it incredibly complicated for caseworkers to do their jobs,” said Ahluwalia. “Confidentiality laws are often misunderstood. We need training, training, training.”
- » **Know when restrictions do not apply.** Federal laws such as HIPAA and FERPA do not cover disclosure and information sharing with regard to all medical and education records. In addition, numerous exemptions to these and other regulations exist—it may take some work to find them, but it can pay off, for agencies and consumers. (See next item.)
- » **Hire an expert.** Many attorneys and risk managers now specialize in HIPAA and other

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— LILLIE CONEY  
Electronic Privacy Center

massive regulations. Find room in your budget to bring trained and trusted advisors on staff, or at least on retainer. “You have to put appropriate safeguards in place or you can be paralyzed with fear and do nothing,” said Ahluwalia.

» **Remember that privacy is not secrecy.** Use the Fair Information Practices Code for basic guidelines as you put appropriate policies, structures and practices in place. (Go to [http://epic.org/privacy/consumer/code\\_fair\\_info.html](http://epic.org/privacy/consumer/code_fair_info.html) or <http://aspe.hhs.gov/DATACNCL/1973privacy/toprefacemembers.htm> for more about the Code of Fair Information Practices.)

**Making It Happen**

CONFERENCE PARTICIPANTS said they came away “energized” despite the lingering challenges. More work is needed across the board and across the silos, they concurred, but there is tremendous potential to un muddy the confidentiality waters and advance interoperability, ultimately improving people’s lives.

“This has been a real learning experience,” said David Jenkins, director, Division of Information Resources, Management and Security, Administration for Children and Families/HHS, which is working with Stewards of Change to develop a national human services enterprise architecture and a series of demonstration pilots to facilitate interoperability across all HHS programs within states. Jenkins’ key takeaways from the confidentiality conference: To enable interoperable data

sharing, “the technology is secondary. We [in IT] really need to learn about child welfare. And we need to look at the other federal agencies—see what they’re doing—to see how we can work across agencies.”

We need to “take a more private-sector approach, keep our eye on the prize and ensure good service—give as much choice to the individual as possible,” said Eric Goldstein, director, Montgomery County (PA) Behavioral Health and Developmental Disabilities.

The changes to information-sharing practices discussed at the conference represent a “critical paradigm shift” for social service systems, said Dean Gelles. We need to give judges “a better-than-even chance” of making good decisions for every child and family.

“When it comes to child welfare,” he added, “we can do a vastly better job.”

Despite the myriad challenges, Dean Gelles and others said, some promising data-sharing and information-sharing practices are already being implemented across the country.

For example, several jurisdictions—including Allegheny County, PA; Montgomery County, MD; Nebraska; and Vermont—have reorganized their HHS agencies, by statute, as single administrative social services districts, which facilitates information sharing across programs; the barriers have been removed and each multiprogram system now operates as a single, holistic unit, sharing data and information as appropriate for the client. Other

entities, such as New York City, have made progress by issuing executive orders strongly encouraging cross-program data sharing while recognizing and complying with applicable privacy laws, regulations and policies.

The conference ended with broad agreement that this cross-cutting national dialogue was a much needed, if long overdue, step toward understanding confidentiality and privacy from all perspectives to find the proper balance and achieve the best possible client outcomes. Just bringing people together from across the country who have interest and expertise on the subject is crucial,



**NIST’s Schwartz:** With copanelists Scriban (Microsoft) and Coney (EPIC)

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**“We need to look at the other federal agencies...to see how we can work across agencies.”**

— DAVID JENKINS  
 Division of Information Resources,  
 Management and Security, Administration for Children and Families/  
 U.S. Department of Health and Human Services

many said. More work is needed to clarify the issues, separate myth from fact, provide guidance, and share emerging approaches.

Conference attendees said a repository of successful models and promising practices would be invaluable. To that end, the Field Center and Stewards of Change committed to sustaining the momentum gathered at the conference.

The Field Center has since posted video-recorded conference sessions on its Web site ([www.fieldcenteratpenn.org](http://www.fieldcenteratpenn.org)), and Stewards of Change has created an online home for related material, including downloadable sample forms, case studies, links to relevant sites and reference documents, and forums for ongoing conversation. (The SOC confidentiality site is part of the National Interop-

erability Community of Practice site. Go to [www.stewardsofchange.com](http://www.stewardsofchange.com) to request access.)

“There’s an Albert Einstein quote I love,” said UCLA’s Krinsky as the confidentiality conference wrapped up: “The significant problems we face cannot be solved at the same level of thinking we were at when we created them.”

“If we truly hope to turn the corner and craft improved outcomes for vulnerable children and families, we must force ourselves to engage in new collective thinking and innovation on their behalf,” Krinsky said.

“This applies as much if not more to issues of confidentiality and privacy,” she added, “as to any other issues affecting children and families today.”

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## The Privacy Debate Rages On

JUST THREE DAYS AFTER THE FIELD CENTER/STEWARDS OF CHANGE confidentiality conference, the *New York Times* published an article titled “I.R.S. Sits on Data Pointing to Missing Children” (<http://www.nytimes.com/2010/11/13/business/13missing.html>), essentially underscoring the conference discussion about the critical need to balance individuals’ privacy rights with children’s rights to health and well-being.

About 200,000 family abductions are reported each year in the U.S., and about 12,000 last longer than six months and involve parental abductors who assume false identities and travel the country to escape detection, according to Justice Department statistics quoted in the article. A 2007 Treasury Department study found that the Social Security numbers of approximately one-third of missing children and the relatives suspected of abducting them are used in tax returns filed post-abduction, the article says.

Ironically, though, it’s illegal for the Internal Revenue Service to share any relevant data it collects to aid in missing children investigations, except in rare cases that are being investigated as a federal crime and in which a U.S. district judge orders the information released. And changes to the law have been slow in coming, due largely to congressional fears that the release of I.R.S. data could lead to loss of taxpayer privacy, according to the article.

This effectively ties the hands of the National Center for Missing & Exploited Children and other organizations working to reunite abducted children with their parents or legal guardians.

“It’s incredibly frustrating, because there’s so much information at their fingertips, but they can’t use it,” says Stewards of Change managing partner Daniel Stein. The ACF Office of Child Support Enforcement is currently reviewing the situation and efforts are under way, Stein notes, to “clear up the misunderstanding about what information can be shared” so the relevant information the I.R.S. collects can help facilitate reunification.

—A.L.

***A detailed review of the conference findings and implications for child welfare and human services is being prepared by the University of Pennsylvania’s Field Center under the oversight of Faculty Director Dean Richard Gelles. It will be available later this year.***

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