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SHIFTING THE DEBATE: USING CHILD WELFARE WAIVERS TO PROMOTE EVIDENCE-BASED PRACTICE

by Joelle Ruben, MSW Candidate

In September 2010, the U.S. House of Representatives passed H.R. 6156 to encourage innovative strategies in state child welfare programs. H.R. 6156 sought to renew the Department of Health and Human Services’ (HHS) authority to extend waivers allowing states to redirect federal funds—specifically, Title IV-E funds for foster care—toward pre-approved demonstration projects. Despite taking only one week to pass the House, the waiver extension bill remained untouched by the Senate Committee on Finance and died when the Congressional session ended. The bill’s initial progress, however, sparked renewed debate about the utility of child welfare funding waivers versus the need for comprehensive funding reform.

This article provides a brief history of Title IV-E waivers, current federal funding streams, and the growing use of evidence-based practice to highlight a benefit overlooked in most waiver conversations—namely, the mandatory completion of project evaluations that can inform future child welfare practice. In requiring states to employ scientific measures to gauge project outcomes, Title IV-E waivers can build upon child welfare’s burgeoning foundation of evidence-based practice while gathering the data needed to secure broader financial reform.

History of Title IV-E waivers

In 1994, Congress leveraged the Social Security Act Amendments (P.L. 103-432) to fund creative demonstration projects designed to improve child and family outcomes at the state level. The law authorized...
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The University of Pennsylvania Provost’s Office has again awarded the Field Center for Children’s Policy, Practice & Research a University Research Foundation grant to help support the Field Center’s Community Symposium Series. Our next symposium, entitled Child Welfare and Juvenile Justice: Challenges of Cross-system Policy and Practice, is scheduled for March 22, 2011 at Penn Law’s Levy Conference Center.
convening hosted Nov. 8-9, 2010 by the FieldCenter. The conference, "Addressing the Myth and Reality of Confidentiality and Privacy in Cross-System Information Sharing," was held at the University of Pennsylvania Wharton School.

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

“We need mobile, real-time information sharing across systems of care,” said Debra Schilling Wolfe, Field Center Executive Director, in her opening remarks. The more rigid our systems of care, the more difficult it is to meet children’s needs, Wolfe noted. “We need to address confidentiality as both a barrier and a potential enabler of information sharing, and to establish national standards of practice.”

“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. “Over time, however, we’ve created complex siloed architectures with multiple siloed agencies and funders.”

“There are both realities and myths regarding the privacy and confidentiality of information and data,” noted Field Center Faculty Director Richard Gelles. “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.”

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 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.”

This is a good time to “ask the feds for clarity,” said Bill Riviera, 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,” Riviera 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, a 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 Richard Gelles in his opening remarks. States are realizing that the stimulus money is running out, Gelles said, and they “won’t be amenable,” absent persuasion, to funding costly interoperability projects.

Why the Urgency?

We need a roadmap to get over or 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,” said Gelles.

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.

Limited data and information sharing and coordination among providers often leads to tragedy, noted Stefanie Gluckman of 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.”

Fear Factor

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 have stirred concern about liability to the extent that, even if people could get past what one participant 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, at times 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 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, Field Center Faculty Director, Chair of Prevention of Child Abuse & Neglect at Children’s Hospital of Philadelphia, and Associate Professor of Pediatrics at the University of Pennsylvania School of Medicine.

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 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 and 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 one bears 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 and 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 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.”

“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 DiDomizio, CFO/CIO of Montgomery County, PA, Office of Children & Youth, which worked with the Field Center and Slewars 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 the county’s interoperability project is under way, DiDomizio said, “the biggest obstacle we’re hitting is confidentiality.”

HIPAA “is the biggest excuse we have for not working as a team,” said Uma Ahiwuadila, director, Montgomery County, MD, Department of Health & Human Services. “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 is the solution? There’s no single easy answer, but through two days of presentations and brainstorming sessions, participants mapped out a wish list of sorts, including recommendations to debunk confidentiality myths so that data sharing efforts and interoperability of system data could be achieved.

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

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

Concluded 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.”

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.” 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 Christopher 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.”

Break down language barriers.

Put HIPAA and other rules in terminology specific to the various agencies, staff and clients they affect, to help make them understandable.

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 Pennsylvania, 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 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, he said, is “a very sharp two-edged sword.” The key is to use it responsibly to improve clients’ lives.

Moving Ahead: Next Steps

Conference participants said they came away “energized” despite the lingering challenges. More work is needed across the board and across the silos, they concluded, but there is tremendous potential to unmuddify 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, Department of Health and Human Services. His key takeaways: To enable interoperable data sharing, “the technology is secondary. We [in IT] really need to learn
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An envelope is attached for your convenience, or you may give a gift online by visiting www.fieldcenteratpenn.org. For more information, please contact Field Center Executive Director Debra Schilling Wolfe at (215) 573-5442 or dwolfe@sp2.upenn.edu.
Field Center Advisory Board Profile: Allison Turkel

Allison Turkel joined the Field Center Advisory Board in 2010. She started her career as a uniformed police officer investigating high crime areas; she rose to the rank of lieutenant. Her career has included appointments as an Assistant District Attorney in the New York County District Attorney’s Office, Assistant State’s Attorney in McLean County, and Director of the National District Attorneys Association’s National Center for Prosecution of Child Abuse.

Ms. Turkel is currently a Senior Policy Advisor in the SMART (Sex Offender Sentencing, Monitoring, Apprehending, Registering and Tracking) Office for the U.S. Department of Justice, Office of Justice Programs. Her primary assignment is working with the Indian Tribes to implement the Sex Offender Registration and Notification Act (SORNA).

Although Ms. Turkel is relatively new to the Field Center’s Advisory Board, she is not new to the area. She lived in Philadelphia for twelve years and studied in Philadelphia as well, receiving her BA from the University of Pennsylvania and her J.D. from Temple University.

The relationship between the Field Center and Ms. Turkel is a “win-win.” The center provides an opportunity for Allison to stay connected with her Alma mater in a way that aligns perfectly with her expertise. In her words, “The Field Center’s mission is very specific and you’ve targeted exactly what is near and dear to my heart.” In return, the center has added a passionate member to the Advisory Board who can provide invaluable expertise on matters relating to child abuse, neglect, maltreatment, and exploitation. In her short tenure as part of the team, Ms. Turkel has already jumped in with both feet. Her contributions in action can be seen at this year’s One Child, Many Hands conference, where she is presenting a workshop on Compliant Adolescent Victims.

Field Center Student Profile: Joelle Ruben

Joelle Ruben joined the Field Center as an MSW intern in September 2010. She is currently a graduate student at the University of Pennsylvania’s School of Social Policy & Practice, where she is pursuing the macro concentration.

Joelle grew up in Fort Lauderdale, FL, before attending the University of North Carolina at Chapel Hill. As a journalism and international studies major, she studied abroad twice in Beijing and achieved conversational proficiency in Mandarin.

Joelle later worked as the Director of Education & Research for the Joint Council on International Children’s Services, an advocacy organization that promotes informed, ethical practice in the field of international adoption. She also traveled to China to volunteer at Starfish Foster Home, which cares for medically fragile orphans, before serving on their Board of Directors.

Last year, Joelle worked intensively with families and children through her first-year field placement at the Philadelphia Ronald McDonald House. This past Summer, Joelle interned at the Department of State’s Office of Children’s Issues in the International Parental Child Abduction unit.

Joelle’s research interests lie in child welfare, with special emphasis on international and domestic adoption, as well as kinship and foster care. She hopes to pursue a policy or programmatic position in the field following graduation.

"Field Center Breaks New Ground" (continued from page four)

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-average 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- and information-sharing practices are already being implemented across the country. For example, several jurisdictions 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 multi-program system now operates as a single, holistic unit, sharing data and information as appropriate for the client. Other entities 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 county who have interest and expertise on the subject is crucial, 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 Charge are committed to sustaining the momentum gathered at the conference. Stewards of Change has created a home for this material, including sample forms, case studies, links to related sites and reference documents, and serves as a forum for ongoing conversation about relevant issues and the Field Center has video-recorded conference sessions on the Field Center’s website, www.fieldcenteratpenn.org.

A white paper focused on conference findings and implications for child welfare and human services is being prepared by the Field Center under the oversight of Faculty Director Richard Gelles and will be available later this year.
HHS to redirect funds associated with Title IV of the Social Security Act—money mostly reserved for foster care reimbursements—toward a handful of state efforts to launch alternative services.

As part of the funding agreement, state waiver recipients were required to submit evaluations of their completed demonstration projects including detailed outcome measurements and cost analyses. Evaluation reports, which were to be conducted by an independent body, were typically completed within six months of a project’s completion or termination. Title IV-E demonstration projects thus began to address the field’s historical failure to evaluate child welfare interventions, particularly those linked to federal funding.

Service implications of federal funding

For nearly 40 years, the U.S. Government has linked its legislative mandates to funding offered through Titles IV-B and IV-E of the Social Security Act. This linkage establishes basic standards of care, while incentivizing the use of certain services over others. For example, the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) authorized Title IV-E as a source of uncapped (i.e., unlimited) entitlement funds for costs associated with foster care and adoption assistance. States receive billions of dollars each year to reimburse foster care maintenance payments, as well as training and administrative costs tied to eligible children. In contrast, Title IV-B typically funds the family support and preservation services designed to keep children in their biological homes. This includes the Stephanie Tubbs Jones Child Welfare Services Program, which promotes state flexibility toward building a coordinated child and family services effort. However, the discretionary nature of the program’s funding limits the amount of available money and allows for funding cuts based on changing federal priorities.

The disparities between open-ended Title IV-E funding and limited Title IV-B funding arguably create a perverse incentive for agencies to keep foster beds full. Disproportionate funding also reduces the potential delivery of family preservation or reunification services due to insufficient resources. According to the National Child Abuse Coalition, for every dollar spent on foster care and adoption subsidies, only 15 cents are spent on prevention and treatment.

Current need for evidence-based interventions

As waiver recipients completed evaluations of their respective demonstration projects, they indirectly contributed to the data needed to embrace evidence-based practice—the identification and delivery of service interventions supported by scientific research. Social service organizations increasingly utilize evidence-based practice due to its simultaneous emphasis on research, clinical experience, and individual client values. Unfortunately, the shift toward evidence-based practice is particularly slow within child welfare, a field historically driven by anecdotes rather than empirically proven research findings. According to Field Center Faculty Director Richard Gelles, there is a significant need to increase the amount and quality of evaluative research as applied to specific child welfare interventions.

In many respects, HHS has already begun to pursue the goal of evidence-based practice by mandating rigorous evaluations of approved waiver demonstration projects. According to a 2008 summary report prepared by James Bell Associates, more than 50% of states incorporated random assignment designs, often considered the “gold standard” of evaluation, into their required analyses. States focused on more systematic reform chose comparison site designs to measure their results against other geographic regions, while others utilized time-series designs to gauge historical change.

Increasingly, national child welfare organizations like the Center for Law and Social Policy and the National Association of Public Child Welfare Administrators promote the need for comprehensive child welfare reform rather than an extension of Title IV-E waiver authority. Proponents of comprehensive reform urge Congress to change Title IV-E itself to allow for a broader array of federally funded reimbursements rather than a handful of exceptions.

That said, Title IV-E waivers provide a solid, empirical foundation from which to support specific legislative changes rather than sweeping finance reform based on generalities. This incremental path to reform is exemplified by the Title IV-E Guardianship Assistance Program (GAP), which was approved as part of the Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351). The federal passage of GAP, which supports state assistance payments for children living with relative guardians, largely resulted from the success of state demonstration projects. In completing their requisite evaluations, many states found a statistically significant correlation between the presence of subsidized guardianships and children’s net permanency rates while uncovering significant cost savings when comparing ongoing guardian subsidies to long-term foster care maintenance.

The transition from subsidized guardianship projects into federal legislative change highlights the potential use of Title IV-E waivers to develop empirically tested intervention methods. Empirical results are not only more effective than purely theoretical arguments to facilitate policy change, they can also provide the data needed to convince lawmakers to implement broader financial reform.

Footnotes

2 Ibid.
7 Not 2008.
16 Ibid. 
17 Ibid.
NEWS FROM THE FIELD
March 2011

Newsletter Highlights...

- The Field Center’s Think Tank on Confidentiality and Information-Sharing Breaks New Ground
- Shifting the Debate: Using Title IV-E Waivers to Promote Evidence-Based Practice
- Bill Cosby to Deliver Opening Keynote at One Child, Many Hands: A Multidisciplinary Conference on Child Welfare in June