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## Families Need the Whole Truth

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While policies increasingly favor heightened information sharing between child welfare agencies and foster and adoptive parents, practice often lags behind. Confidentiality directives hold such sway for some that child information does not flow freely between workers or to children's caregivers. Now, concerns about privacy mandates in HIPAA (the Health Insurance Portability and Accountability Act) are inspiring even less sharing—a trend we find deeply troubling since full disclosure about a child's medical, educational, and social background is key to adoption success.

### Why Information Matters

When it comes to successful parenting, more information is better. In *Promoting Successful Adoptions*, Susan Smith and Jeanne Howard list "knowing the child's history" as a factor tied to adoption stability. Richard Barth and Marianne Berry, in *Adoption and Disruption*, observe that "families with less accurate preplacement information about the child will have less realistic expectations about behavior, resulting in long-term frustration for both parent and child." In fact, Barth and Berry found that "better information" was clearly associated with fewer disruptions.

Children adopted from foster care have endured pain and loss. To even begin to prepare for and address the child's needs and behaviors, parents must thoroughly understand the child's history. Parents cannot effectively care for and bond with new sons and daughters knowing only fragments of their children's past.

Disclosure is in agencies' best interest too. Workers would certainly rather not watch families suffer, see placements disrupt, or be charged with withholding crucial information from parents. Wrongful adoption lawsuits hurt agencies and workers, and cannot make up for families' pain.

### Disclosure Laws and Standards

The federal Social Security Act mandates that state agencies collect complete health, education, and other information about foster children. Each time a child changes placements, the agency must supply updated records to the new parent(s).

Most states also have disclosure laws and policies. Likely places include the state's children's code, family law code, social services code, or other adoption-related statute.\* "As a general rule," Madelyn Freundlich (co-author

of *Wrongful Adoption: Law, Policy and Practice*) states, "adoption professionals must disclose [to pre-adoptive parents] all known, material information about a child's health, social, and other background."

Ideally, the Child Welfare League of America (CWLA) proposes in *Standards of Excellence for Adoption Services*, agencies should supply pre-adoptive parents with complete medical, mental health, developmental, psychological, educational, and social information about the child, as well as his or her immediate birth family, and other birth relatives back several generations. CWLA also calls for detail, asking for instance that agencies disclose the child's prenatal care (including drugs or medications used during pregnancy) plus genetic links to diseases or disorders or positive family traits like longevity.

Under CWLA's standards, agencies would offer adopting parents enough information to fairly assess their ability to parent specific children and gain a realistic sense of needed supports and services. Adoptees would be able to know and own their family history, and be able to provide valuable background information to medical and mental health providers.

## HIPAA

HIPAA has gained increasing attention since April 2003 as compliance dates have brought the law's privacy provisions into reality for "covered entities." As one legal expert asserts, HIPAA regulations are "chock full of ambiguities" concerning child welfare agencies' responsibilities under the law. Does HIPAA prohibit agencies from releasing identifiable health information about foster children to pre-adoptive and adoptive parents? Are child welfare agencies covered entities?

In a February 17th Information Memorandum, HHS states that "[s]ome title IV-E child welfare agencies may be defined as health care providers." The memo concludes, however, that "HHS and the Children's Bureau cannot determine whether all child welfare agencies are subject to HIPAA's regulations."

In short, most state agencies have had to decide for themselves whether HIPAA regulations apply. Unfortunately, many agencies that try to follow HIPAA have begun to limit key medical information disclosure to pre-adoptive parents.

## Advice for Agencies

HIPAA regulations assert that the federal law supercedes state laws, unless the state law is (among other things) "serving a compelling need related to health, safety, and welfare." To ensure that your agency's practices are legal, and children's best interests are being honored:

**Continue to seek clarification about how or if HIPAA applies to your agency.** The New York State Citizens' Coalition for Children, Inc. wrote to the State Office of Children and Family Services last summer about HIPAA mandates. In return, the deputy commissioner explained how, in New York, HIPAA does *not* prohibit "protected health information" from being disclosed to foster and adoptive parents. If asked, your state commissioner may come to the same conclusion.

**Follow state and federal laws.** HIPAA may apply, but other laws do too. As stated above, the Social Security Act outlines foster care and adoption disclosure requirements. The Child Abuse Prevention and Treatment Act governs child protection disclosure rules. And, as outlined in *Making Good Decisions about Confidentiality in Child Welfare*, confidentiality exceptions are allowed to provide child and family services, supply information to caregivers, and protect children from future abuse.

**Work to prevent wrongful adoption actions.** Kathleen Hogan Morrison, an Illinois adoption attorney, offers this advice. First, workers must actively seek out birth and birth family records. Second, instead of simply summarizing information about the child, workers should copy the original documents for adopting parents. Finally, agencies should establish a system for learning about and complying with relevant laws.

## Thoughts for Parents

When a child is about to join an adoptive family, parents must learn all they can. "Information gathering," observe Regina Kupecky and Gregory Keck in *Adopting the Hurt Child*, "is the most important step prospective parents must make." To maximize chances for a successful adoption:

**Appreciate the value of the child's background information.** Complete disclosure is crucial for early diagnosis, to address the child's needs, to qualify for support services, and to avert possible problems down the road.

**Acquaint yourself with state and federal laws and agency rules.** Protect your family by learning about services you are entitled to receive, and then advocate for what you need.

**Ask questions and listen carefully.** Quell the inner voice that says, "This will never happen to us." Ask lots of questions and record details that workers, therapists, teachers, and former foster parents volunteer about your child.

## Conclusion

The federal government is duty-bound to safeguard children's and families' well-being. As written, unfortunately, HIPAA regulations have caused some agencies to fear penalties for inappropriate health information disclosure more than the potentially dire consequences of inadequately preparing families for adoption.

To promote families' well-being, the government must clarify ways in which HIPAA applies to child welfare practice, and amend provisions that adversely affect children's best interests. Waiting children need families well-equipped to help them overcome troubling pasts and reach for promising futures.

\* The [Child Welfare Information Gateway](#) has a searchable state-by-state listing of statute citations that deal with information access.

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