

Fact Sheet: Barriers to Information Sharing and Data Collection

National Commission on Children and Disasters

Long Term Disaster Recovery Workshop

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Issue Statement

What policy changes are needed so that the Federal government can effectively collect and share data on children with state and local government agencies and voluntary organizations to facilitate evacuee tracking, family re-unification, disaster case management, and the delivery of social services?

Specifically:

- 1) *What type of information should be collected and shared and who should information be shared with?*
- 2) *What are the barriers to information sharing under current laws and policies, and what modifications are necessary to improve sharing of personal information for purposes such as evacuee tracking and delivery of services?*

Desired State

The 2009 Interim Report from the National Commission on Children and Disasters generated the following recommendations relevant to the role of the Federal government and its partners in information sharing, evacuee tracking, and family reunification associated with disaster response and recovery efforts to ensure child safety and well-being:

- Develop a standardized, interoperable national evacuee tracking and family reunification system that ensures the safety and well-being of children.
- Review and modify current privacy policies and laws to permit the timely sharing of relevant disaster victim information among federal, state, local, tribal and non-governmental agencies and organizations engaged in supporting children and families affected by disasters, when it is clearly in the best interest of children to do so.

Challenges to the Desired State

Issues that present challenges to the desired state include:

- **Information confidentiality rules:** There are limitations to information collection associated with the Privacy Act of 1974, the Family Educational Rights and Privacy Act (FERPA), and the Health Insurance Portability and Accountability Act (HIPAA). While these rules include special provisions for circumstances under which private information may be disclosed, there is little precedent associated with the disclosure of children's information in the context of a disaster.
- **Restrictive policies of Federal agencies:** According to the Government Accountability Office, state and local agencies responsible for providing Federally funded disaster case management services following the hurricanes of 2005 faced consistent difficulty obtaining timely and accurate information from the Federal agencies overseeing the programs.¹ A major barrier is the Federal Emergency Management Agency's (FEMA) strict interpretation of information sharing and privacy requirements under the Privacy Act.

¹ "Disaster Assistance: Greater Coordination and an Evaluation of Programs' Outcomes Could Improve Disaster Case Management," GAO-09-561, ed. United States Government Accountability Office (Washington, DC: GAO, 2009), 19-20.

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- **Lack of a universal Release of Information (ROI) form:** Many government and voluntary agencies provide funding or services for unmet needs when disaster-affected individuals are not eligible for FEMA or SBA funds. To help avoid duplication of benefits, FEMA and SBA must share the status of individuals' applications with these agencies. However FEMA does not provide an ROI form to agencies providing services; agencies must create their own form according to FEMA guidance. Major delays in information sharing occur when agencies develop inadequate forms or clients do not provide all the information FEMA requires to release information.
- **Lack of established and interoperable information collection systems:** Many government and voluntary agencies cannot share information on individuals they are serving because they lack interoperable systems to share data. In addition, many existing systems/programs used to collect information in disasters do not collect specific information on children, such as age or their status as an unaccompanied minor.

Current State

Legislative and Regulatory Requirements

Major regulations that govern information sharing directly or indirectly related to children and disasters include:

- **Privacy Act of 1974:** Provides overarching guidance for Federal agencies collection, use, and disclosure of personal information. Prohibits the disclosure of individual's personal information from a system of records absent the written consent of the individual, unless the disclosure is allowed by one of twelve statutory exceptions, including law enforcement purposes and broadly defined "routine use" exceptions. [5 USC §552a]²
- **Family Educational Rights and Privacy Act (FERPA) (1974):** Requires educational agencies and institutions receiving funding under a program administered by the U.S. Department of Education to obtain a student's consent prior to disclosure of education records outside the school system. However, this information may be released without consent if the knowledge is necessary to protect the health or safety of the student or other persons. [20 USC §1232(g)]³
- **Missing Children Act (1982):** Authorizes the Attorney General to collect and exchange information that would assist in the location of any missing persons, including children. [28 USC §534]⁴
- **Missing Children's Assistance Act (1984):** Directs the Administrator of the Office of Juvenile Justice and Delinquency Prevention to establish and operate a national toll-free telephone line for missing children and a national resource center and clearinghouse, the National Center for Missing and Exploited Children. [42 USC §5771]⁵

² Privacy Act of 1974, available at <http://www.justice.gov/opcl/privstat.htm>

³ FERPA, available at <http://www.ed.gov/legislation/FedRegister/finrule/2008-4/120908a.pdf>

⁴ Missing Children Act, available at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2000_uscode&docid=28usc53

⁵ Missing Children's Assistance Act, available at http://www2.law.cornell.edu/uscode/html/uscode42/usc_sec_42_00005771----000-.html

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- **National Child Search Assistance Act (NCSA) (1990):** Requires each Federal, state, and local law-enforcement agency to enter specific information about missing children less than 18 years of age into the FBI National Crime Information Center database, and establishes state reporting requirements.⁶ [42 USC §§5779-80]⁷
- **Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) as amended (1988):** Constitutes the statutory authority for most Federal disaster response activities); establishes the National Response Framework (NRF) that drives mass care and public health and human services support associated, in part, with children; and requires establishment of an MOU between Department of Justice, the National Center for Missing and Exploited Children, HHS, American Red Cross, and other relevant private organizations to enhance information sharing and facilitate reuniting displaced individuals with families. [42 USC §§5121-5207]⁸
- **Health Insurance Portability and Accountability Act (HIPAA) (1996):** Regulates the use and disclosure of certain protected health information from covered entities under its Privacy Rule. This rule allows for information to be disclosed without authorization from an individual who is displaced and in need of health care as a result of a severe disaster as necessary to provide treatment, to identify, locate and notify family members, guardians, or anyone else responsible for the individual's care, and to prevent or lessen a serious and imminent threat to the health and safety of a person or the public. [42 USC §201]⁹
- **E-Government Act of 2002:** Ensures sufficient protections for the privacy of personal information as agencies implement citizen-centered electronic government. [44 USC §101]¹⁰
- **Child and Family Services Improvement Act (2006):** Includes a requirement that state child welfare agencies establish procedures during a disaster including continued communication with caseworkers and other essential child welfare personnel, preservation of essential program records, coordination of services and sharing of information with other states. [P.L. 109-288]¹¹

⁶ A portion of this Act was amended by the Adam Walsh Child Protection and Safety Act (2006) to mandate law enforcement entry of information about missing and abducted children into the National Crime Information Center database within two hours of receipt of the report. In addition, "Suzanne's Law" amends Section 3701 (a) of the Crime Control Act of 1990 to include similar reporting requirements for missing persons 18 to 21 years of age.

⁷ NCSA, available at http://www.law.cornell.edu/uscode/42/usc_sec_42_00005779----000-.html

⁸ Stafford Act, available at http://www.fema.gov/pdf/about/stafford_act.pdf

⁹ HIPAA, available at <http://www.gpo.gov/fdsys/pkg/PLAW-104publ191/pdf/PLAW-104publ191.pdf>; Additional guidance on permissible disclosures that covered entities may make to respond to the needs of evacuees in disaster situations available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/enforcementstatement.pdf>

¹⁰ E-Government Act of 2002, available at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=107_cong_public_laws&docid=f:publ347.107.pdf

¹¹ Child and Family Services Improvement Act, available at <http://frwebgate6.access.gpo.gov/cgi-bin/TEXTgate.cgi?WAISdocID=121820466851+0+1+0&WAISSaction=retrieve>

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Relevant Agency Responsibilities and Information Sharing Initiatives

Several agencies bear responsibility related to collecting, sharing, and tracking data on children (explicitly or implicitly), and facilitating family re-unification and delivery of services. Future work with the following agencies may lead to the desired state.

- **American Red Cross (ARC):** Provides individual long-term family services and referral support under Emergency Support Function (ESF) #14; facilitates reunification programs in ARC-operated general population shelters. ARC of Greater Chicago operates Patient Connection, a “turn-key” information management system that allows hospitals to share information with ARC following any local incident in which 10 or more people are hospitalized, facilitating reunification following an event.
- **Department of Education (DoEd):** The Family Policy Compliance Office implements FERPA and provides guidance on the disclosure of personally identifiable information from students’ education records to outside entities.
- **Department of Health and Human Services (HHS):** Provides subject-matter expertise, consultation, and technical assistance to ESF #6 partners on disaster human services issues (e.g., working with special needs populations which include children); informs people receiving services under HHS direction about the National Emergency Family Registry and Locator System and the National Emergency Child Locator Center. The HHS Office for Civil Rights enforces the HIPAA Privacy Rule.
- **Federal Emergency Management Agency (FEMA):** Explicitly and implicitly addresses the needs of children in the context of disaster events under ESF #6 and #8 in the National Response Framework (NRF). Under the “Routine Use” policy for information collected for disaster recovery assistance purposes, FEMA can share information with Federal and state agencies and voluntary organizations to mitigate duplication of benefits and allow these entities to address unmet needs; however, FEMA attorneys at the Regional level interpret the “Routine Use” policy differently for each disaster and often have strict interpretations that cause delays in the delivery of service. Runs the National Mass Evacuation Tracking System (NMETS), which tracks individuals as they arrive/depart certain locations, such as shelters. While NMETS is presently being made available to states, no state currently uses the system.
- **National Center for Missing and Exploited Children (NCMEC):** Operates the National Emergency Child Locator Center (NECLC) as mandated by the Post-Katrina Emergency Management Reform Act when a national disaster is declared by the President. NECLC assists in the location of children and the reunification of families resulting from the disaster or subsequent evacuations.
- **Office of Management and Budget (OMB):** The Privacy Act of 1974 provides that OMB shall develop and prescribe guidelines and regulations and provide continuing assistance to and oversight of the implementation of the operative provisions of the Act by the agencies.
- **State Responsibilities:** The National Child Search Assistance Act (NCSA) of 1990 establishes state reporting requirements for missing children younger than 18 years of age. Each state and their local jurisdictions may have its own laws, regulations, policies and ordinances that focus on supporting children in disasters.