

Abstract

- * With the development of statewide longitudinal data systems, FERPA, HIPAA, and state laws have begun to take a larger role in the conversations and decisions about access to data by researchers.
- * Thus, it is critically important that researchers understand the privacy and confidentiality issues they will face when working with state agencies to access EI and ECSE data for research purposes
- * In this poster, multiple case studies from examples across the country will be described to highlight promising practices about researcher access to state data and understanding of privacy and confidentiality considerations and ways that data can be used to inform state-level decisions.

Introduction

- * Although these programs have had researchers as partners for many years, the current needs are expanding with the growth of statewide longitudinal data systems.
- * These statewide longitudinal data systems have various types of data related to early intervention and early childhood special education, including the various programs and services any one child might be participating in, family-level data, teacher-level data including the qualifications of teachers or service providers working with the children, classroom and organizational data including program quality data, child outcomes data, and most importantly, the integration of these data beyond any one program.
- * States may vary on the types of data collected, but across all states, there is a wealth of data that can be used for research purposes and the resulting information can be used to support state and program decision making.
- * In 2013, the IDEA DaSy Center published a national report on data Part C and Part B 619 data systems.
 - One of the findings showed the states current needs better understand privacy and confidentiality,
 - “Data sharing permissions and/or privacy issues (e.g. confidentiality policies, data access decisions, security models, federal privacy laws) are a priority for more than four-fifths of the states for Part C and for two-thirds of the states for Part B 619.”(Derrington, Spiker, Hebbeler, & Diefendorf, 2013).

Methods

- * To better understand the current state of researcher access to EI and ECSE data, a case studies approach (Patton, 2002) was used to look at two states’ methods around privacy and confidentiality when working with researchers.
- * This approach allowed the team to look at the needs states addressed in terms of access and privacy and then to describe how states are providing access to EI and ECSE data to researchers and to review the types of state decisions researchers can inform using de-identified data with examples from the various case studies.
- * Qualitative documentation from a state data process was analyzed across states.
 - Observations and narratives (Patton, 2002) from the states were used by experts at the Privacy Technical Assistance Center (PTAC) while working with the states the last 2 years.
 - Documentation included state data sharing agreements, state policies for sharing access to personally identifiable data with researchers.

Operational Definitions:

- * The **Family Educational Rights and Privacy Act (FERPA)** is a federal law that affords parents the right to have access to their children’s education records, the right to seek to have the records amended, and the right to consent to the disclosure of personally identifiable information from education records, except as provided by law.
- * The **Health Insurance Portability and Accountability Act (HIPAA)** Privacy Rule establishes national standards to protect individuals’ medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. The Rule requires appropriate safeguards to protect the privacy of personal health information, and sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization. The Rule also gives patients rights over their health information, including rights to examine and obtain a copy of their health records, and to request corrections.
- * FERPA defines **Personally Identifiable Information (PII)** as, but not limited to the child’s name, name of the child’s parent or other family members, address of the child’s parent or family, social security number, date of birth, place of birth, and mother’s maiden name. Also, includes other information that, alone or in combination, is linked or linkable to a specific child; or information requested by a person believed to know the identity of the child to whom the education record relates.
- * **De-identification** of data refers to the process of removing or obscuring any personally identifiable information from student records in a way that minimizes the risk of unintended disclosure of the identity of individuals and information about them. Specific steps and methods used to de-identify information (see disclosure limitation method for details) may vary depending on the circumstances, but should be appropriate to protect the confidentiality of the individuals.

Results

To analyze the cases across states, three main topics were grouped: researcher data requests; access to personally identifiable data; and use of de-identified data.

Researcher Data Requests

- * How can researchers make requests for state-level data in ways that promote its use while respecting privacy?
- State example: Colorado: Results Matter Child and Family Outcomes Program & the Colorado Department of Education
- MOU developed between two entities
 - Transparency established with notice to parents regarding use of data and that reports will be confidential and aggregate in nature
 - Data provided through agreement and established best practices regarding security/storage/transmission

Researcher Access to Identifiable Data

- * How do you as a researcher handle identifiable data? How should researchers handle identifiable data? What strategies are most effective?
- State example: Texas Education Research Center (ERC)
- Introduced new legislation
 - Established data sharing agreements between the K-12 (TEA), Higher Education (THECB), and Workforce (TWC) agencies
 - The three agencies will share all appropriate and available data annually dating back longitudinally a minimum of 20 years where collected and available
 - Each of the three agencies may re-release de-identified individual level data as appropriate with state and federal privacy guidelines

Researchers Use of De-identified Data

- * Under what circumstances is identifiable data needed in research?
- Determine when/if PII is needed other than to link records. In most cases, properly de-identified data sets are more than sufficient to answer the majority of research questions
- * What innovative ways can researchers use to maximize the use of properly de-identified data (e.g. masking, perturbation, noise) to minimize the need for personally identifiable information (PII)? And what types of supports have researchers used to ensure the privacy and confidentiality of their data are maintained?
- The National Center for Education Statistics has released great guidance regarding Core Practices of Managing Research Data Requests: <https://nces.ed.gov/pubs2012/2012809.pdf>
 - The Education Research and Data Center is the P-20W office in Washington State and, by statute, established as an authorized representative of state education agencies to provide access to data sets for purposes of legislative and other research data use.

Conclusion

- * Researchers should always consider the use of de-identified data whenever possible. Researchers should fully understand what questions they are trying to answer PRIOR to asking for the data.
- * When working with researchers, states should focus on understanding the research question and IF personally identifiable data is required, begin the steps for entering into a data sharing agreement that specifies what data will be needed, for what purpose, and usage requirements as specified by federal, state, and local laws.
- * Researchers should be aware of applicable federal, state, and local laws regarding protection and use of data.
- * Ultimately, researchers are key partners to help drive data use within a state to help inform decisions.

References

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The DaSy Center

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