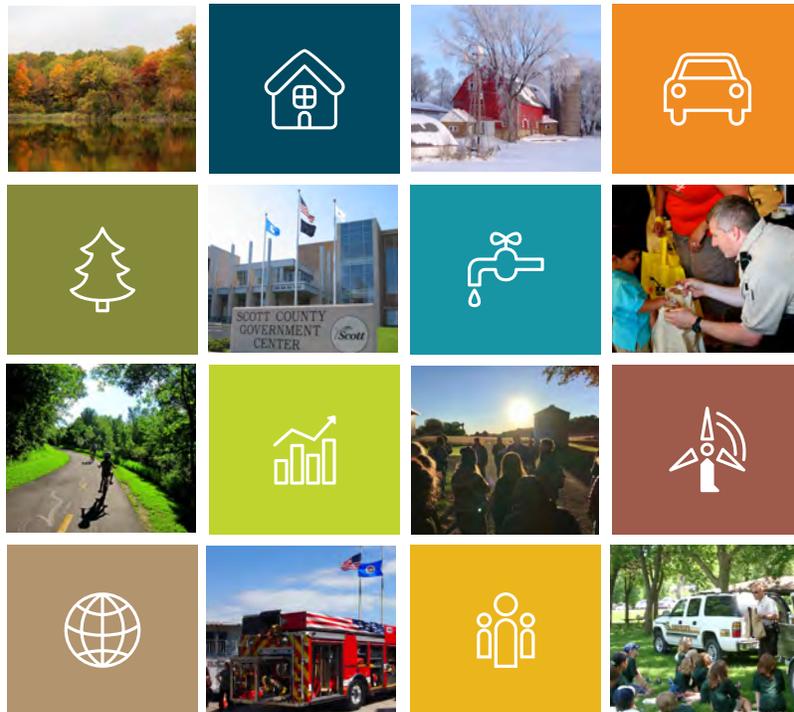


Integrating Early Childhood Data



Prepared by:

Sarah LeNeave, LAW 7606: Law
Independent Research
Advisor: Steve Kelley, Senior Fellow

Humphrey School of Public Affairs

Prepared in Collaboration with:

Jake Grussing
Library Director, Scott County



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Resilient Communities Project

University of Minnesota
330 HHHSPA
301—19th Avenue South
Minneapolis, Minnesota 55455
Phone: (612) 625-7501
E-mail: rcp@umn.edu
Web site: <http://www.rcp.umn.edu>



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Integrating Early Childhood Data: Consent to Use and Share

Sarah LeNeave
University of Minnesota Law School

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Introduction

Early childhood education, specifically reading proficiency at or before grade three, has been identified as a key indicator of future educational and professional success. Access to data on childhood reading proficiency is therefore critical in ensuring that all children have the opportunity to prosper. Through a partnership with the University of Minnesota Resilient Communities Project, Scott County seeks to build on the work of SCALE, the Scott County Association for Leadership and Efficiency, and its *Live, Learn, Earn Educational Preparedness* Work Group in identifying and closing gaps in the education system.

Data integration on early childhood education has been identified by SCALE as a priority for Scott County, as it requested an inventory of existing early childhood programs and initiatives throughout the county. A secondary request of the County, which will be addressed in this memo is information about early childhood data integration programs from across the nation, which could inform decisions about an integrated database in Scott County. Finally, and as this memo will also address, County staff requested information on the legal barriers to sharing early childhood data.

The legal barriers to sharing protected data are significant but not insurmountable. FERPA, the Family Educational Rights and Privacy Act, protects education records by disallowing disclosure with three exceptions illustrated below. The Health Insurance Portability and Accountability Act (HIPAA) protects personally identifiable information held by health care providers by disallowing disclosure with a few exceptions explained later. The Minnesota Government Data Practices Act (MGDPA) protects data held by government entities and

restricts disclosure as well. Each of these laws allows for a few, narrow paths for integrated databases of early childhood data.

The path considered in this memo is informed parental consent. Other exceptions to the rules of non-disclosure are viable, but these options require extensive legal negotiations with stakeholders. The goals of SCALE include providing access to caregivers throughout the County to medical, educational and governmental records of children from birth to age eight, which could improve individual and system outcomes and allow program directors to evaluate the efficacy of existing educational initiatives or programs. This memo will analyze the use of informed parental consent under FERPA, HIPAA and MGDPA.

Given the goals of the project identified by SCALE, this memo addresses how Scott County and its partners may gain access to protected data for purposes of integrating early childhood data through parental consent. First, this memo will briefly discuss the benefits and thus justifications for use of an integrated database. Second, the relevant privacy laws will be discussed from the lens of utilizing parental consent as justification for sharing and re-disclosing protected data. Third, this memo will briefly outline current practices from other local governments across the United States, which will highlight the need for a specific purpose to access data or legislation which validates data release. Fourth, this memo will justify use of the parental consent form presented in Appendix A, with an annotated version in Appendix B. Finally, this memo will provide directions for use of the parental consent form and recommendations for further legal work. Informed consent to disclose children's health and education records is a first step in the process of evaluating interests, establishing infrastructure and consolidating efforts to create the proposed integrated database.

Justification for Integrated Database

SCALE's interest in creating an integrated database of education, medical and public health data is justified by the benefits associated with combining data sets.¹ Efficiency can be improved when data are centralized. The County and care providers will be better equipped to plan current and future programming.² Evaluating services and outcomes becomes much easier and more accurate when data from multiple sources, measuring different but related results are combined. To improve future results, more accurate adjustments to existing programming can be made. Scott County could benefit from the implementation of an integrated early childhood database.

Integrated databases bring efficiency to users and systems. Centralizing data creates easier comparisons for researchers and other interested parties. Ease in comparing data allows research, recommendations and changes to be made faster. When system analysis is made more efficient, improvement to system outcomes can be made more efficiently, too. Thus, when early childhood data are collected in an integrated database, efficiency is a benefit to the systems and individuals served.

Service providers are able to improve plans and interventions when they have access to multiple data points. The more a service provider can know about the impact of a particular

¹ Johnny Downs, et al., *Linking Health and Education Data to Plan and Evaluate Services for Children*, ARCH DIS. CHILD, Vol 102 No. 7 (Jul. 2017); Office of the Legislative Auditor, *Early Childhood Programs* (Apr. 2018); Andrew Ho, *Advancing Educational Research and Student Privacy in the "Big Data" Era*, NATIONAL ACADEMY OF EDUCATION, Washington, D.C. (2017); U.S. Dept. of Health & Human Services, U.S. Dept. of Education, *The Integration of Early Childhood Data: State Profiles and A Report* (Nov. 2016); Elizabeth Laird, *Developing and Supporting P-20 Education Data Systems: Different States, Different Models*, Data Quality Campaign (Feb. 2008).

² Johnny Downs, et al., *Linking Health and Education Data to Plan and Evaluate Services for Children*, ARCH DIS. CHILD, Vol 102 No. 7, at 600 (Jul. 2017).

intervention, the more equipped they are to take steps that are specific to a child's needs. Further, when systems are equipped with data that are all-encompassing, broad improvements can be made to interventions.

Probably the most important benefit of integrating data comes from the ability to evaluate services and outcomes. Childhood development, cognitive development, special education needs (hearing/vision screening, emotional behavioral disorders, learning disabilities), social care data, population-based analysis, hospital care and policy initiatives, absenteeism are all useful measures across system types and individual actors within those systems. Local governments can analyze the impact of their services. Researchers can apply academic lenses to results in a particular location or related to a specific population. Local service providers can understand their customer base better. Individual care givers can be more informed of the impact of their approach. These stakeholders would each benefit from the use of integrated data, and would become more informed of the results of services provided.

Similarly, integrated data illuminates gaps in service and allows service providers to make adjustments. Analyzing data from various sources may help users to flag gaps in individual care and system programming. When gaps are recognized, and adjustments are made, outcomes across systems may be improved. The ability to effectively adjust course is enhanced when data are integrated.

In Scott County, home to roughly forty Parent Aware Rated preschools,³ eight school districts,⁴ 320 licensed in-home daycares,⁵ at least ten early childhood initiatives in the Public

³ Minnesota Early Childhood Longitudinal Data System, ECLDS Map (2018) (<https://education.mn.gov/Maps/ECLDS/>).

⁴ Scott County Libraries, (<https://www.scottcountymn.gov/818/SchoolsDistricts>).

Health Department,⁶ and sixteen medical clinics accepting medical assistance,⁷ an integrated system could supply all of these benefits. For example, if the data from the Early Hearing Detection and Birth Defects Program could be shared with the Follow Along or New Beginnings programs, perhaps families experiencing challenges during early life could be flagged for follow up with a program designed for toddler age children.⁸ Then, those programs could share their data with the Child and Teen Check-ups program to ensure those same children are part of a program that promotes their individual health. Upon viewing the accumulated data, the child's practitioner could be alerted to possible residual symptoms or health concerns from early life and could treat them more readily. If this data was shared with daycares, pre-schools, and eventually elementary schools, teachers and school nurses could be better aware and thus equipped to address that child's needs. Each of these systems would benefit from an understanding of their beneficiary's medical and educational experiences, too. If the Early Hearing Detection and Birth Defects Program can access early education data, it can have a better understanding of how its patients retain service benefits later-on in life, for example.

Relevant Laws

The database will store personal data which requires specified treatment under the law. Health, education and government data are each regulated by federal and state laws in regard to use, storage, transmission, access, sharing, and have liabilities attached to violation of these laws.

⁵ Scott County Public Health, *Scott County 2017 Report to the Community* (2017) (<https://indd.adobe.com/view/306a2e24-b2a7-4b84-828c-2ea62ea0c785>).

⁶ Scott County Public Health, *Scott County 2017 Report to the Community* (2017) (<https://indd.adobe.com/view/306a2e24-b2a7-4b84-828c-2ea62ea0c785>).

⁷ Scott County Public Health, *Scott County Community Health Resource Guide* (2017) (<https://indd.adobe.com/view/c06a8a99-4273-4bb0-aa42-35d7f65fdc4d>).

⁸ Scott County Public Health, *Scott County 2017 Report to the Community* (2017) (<https://indd.adobe.com/view/306a2e24-b2a7-4b84-828c-2ea62ea0c785>).

HIPAA⁹ and the accompanying “Privacy Rules” regulations¹⁰ govern entities handling personal health data.¹¹ FERPA imposes requirements on bodies that hold educational records. Both of these laws supersede state law, however sometimes they rely on state laws. The MGDPA regulates Minnesota government data and fills gaps where FERPA and HIPAA require state law to provide guidance. Each of these laws impose significant requirements on entities using, storing and sharing personally identifiable information, as well as certain forms of aggregated public data.

HIPAA

The Privacy Rules accompanying HIPAA place restrictions on covered entities when personally identifiable information (PII) is used or disclosed.¹² Covered entities fall under three categories: health care providers, health information clearing houses, and health plans.¹³ Although it is not explicit in statutory text, guidance documents suggest that entities, including counties, that disburse Medicaid or Medicare services/funds are likely covered entities for purposes of the HIPAA Privacy Act.¹⁴ Thus, this memo considers Scott County as a covered

⁹ Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 42 U.S.C. & 29 U.S.C. § 1181).

¹⁰ 45 C.F.R. §§ 160, 164 (2002).

¹¹ U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule* (2003); *see also* U.S. Dept. of Health & Human Services, *Summary of the HIPAA Security Rule* (“The Security Act establish a national set of security standards for protecting certain health information that is held or transferred in electronic form.” This memo does not address security requirements.)

(<https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html>).

¹² U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 2 (2003).

¹³ 45 C.F.R. §§ 160.102, 160.103.

¹⁴ 45 C.F.R. §§ 164.103, 164.105 (Scott County could be considered a hybrid entity); U.S. Dept. of Health & Human Services, *Are State, County or Local Health Departments Required to Comply with the HIPAA Privacy Rule?*

entity because it disburses Medicaid services/funds to residents. Scott County must follow certain protocols when using and disclosing PII.¹⁵ PII may not be used or disclosed by a covered entity except in two circumstances: as permitted or required by the Privacy Rules or as the individual who is the subject of the information authorizes in writing.¹⁶ SCALE intends to use the database not only to evaluate systems but also to inform individual service providers.

There are several “permissible” purposes for a covered entity to share PII without an individual’s authorization. The permissible purposes that may apply to this project are “Public Interest and Benefit Activities” and “Limited Data Set” for purposes of research, public health or health care operations.¹⁷ Neither of these permissible purposes would fully enable the database to function as SCALE wants it to. Thus, although these permissible purposes will be described below, inevitably this memo will detail the second circumstance in which PII may be disclosed by a covered entity, by written authorization.

The “Public Interest and Benefit Activities” exception to individual authorization allows disclosure for twelve national security purposes.¹⁸ Some of these national security purposes

(<https://www.hhs.gov/hipaa/for-professionals/faq/358/are-state-county-or-local-health-departments-required-to-comply-with-hipaa/index.html>).

¹⁵ 45 C.F.R. § 160.103. “Personally identifiable information is information, including demographic data, that relates to: the individual’s past, present or future physical or mental health or condition, the provision of health care to the individual, or the past, present, or future payment for the provision of health care to the individual, and that identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual. Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, Social Security Number).” (quoting U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 4 (2003)).

¹⁶ 45 C.F.R. § 164.502(a); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 4 (2003).

¹⁷ 45 C.F.R. § 164.502(a)(1); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 5 (2003).

¹⁸ 45 C.F.R. § 164.512; U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 6 (2003).

include requirement by law, public health activities, research, health oversight activities, and essential government functions.¹⁹ For SCALE, “public health activities” may be the most viable exception to individual authorization. This allows “covered entities to disclose protected health information to public health authorities authorized by law to collect or receive such information for preventing or controlling. . . disability and to public health or other government authorities authorized to receive reports of child abuse and neglect”.²⁰ Before the data could be collected, SCALE would need to identify existing law which authorizes Scott County to collect such information. If there is no existing law, legislation would need to be passed to authorize the release of data to Scott County. Other options like “essential government functions” and “health oversight activities” sound relevant, but they do not address the release of PII to local governments for the purposes of evaluating early childhood interventions.²¹ Thus, neither “essential government functions” nor “health oversight activities” are viable options for this early childhood integrated database. On its face, “Research” also appears to be a plausible exception, but it is intended for “systematic investigation” that contributes to “generalizable knowledge,” thus is not a likely access point for this project since the purpose of release is to inform Scott County and other interested parties.²² The “public health activities” purpose for

¹⁹ The other national security reasons to release PII without authorization under the “Public Interest and Benefit Activities” purpose is: victims of abuse, neglect or domestic violence; judicial and administrative proceedings; law enforcement purposes; decedents; cadaveric organ; eye or tissue donation; serious threat to health or safety; and workers’ compensation. These purposes are not discussed in this memo since they do not reflect the purpose or content of the early childhood integrated database suggested by SCALE. *See*, 45 C.F.R. § 164.512.

²⁰ 45 C.F.R. § 164.512(b); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 7 (2003).

²¹ 45 C.F.R. §§ 164.512(d), (k); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 7, 8 (2003).

²² 45 C.F.R. § 164.514(e); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 8 (2003).

disclosure of PII without individual authorization may be the most viable purpose under the “public interest and benefits” exception to the nondisclosure requirement of the HIPAA Privacy Rule.

The other permissible purpose in the Privacy Rules is the release of a limited data set.²³ A limited data set is PII from which specific identifiers have been removed. Individuals’ information and their relatives, household numbers and employers are removed from limited data sets.²⁴ If a recipient of the limited data set enters into a data use agreement “promising specified safeguards for the information within the limited data set,” then the data may be used for research, health care operations, and public health purposes.²⁵ In the case of the database which SCALE wishes to establish, the use of a limited data set could be helpful for evaluating systems. However, a limited data set would significantly minimize the ability of service providers to evaluate effectiveness of interventions on an individual basis. The effects of only receiving a limited data set on mid-level analysis are probably less restrictive than individual evaluation but more restrictive than larger system evaluation. SCALE seeks to utilize PII to analyze effectiveness from across systems and all the way down to the individual level. Therefore, a limited data set would not be the most helpful way to use HIPAA protected data, but it could have some benefit to an integrated database for early childhood interventions in Scott County.

Authorized release of PII is another option for disclosure under the Privacy Act.²⁶ If a covered entity uses or discloses PII for purposes other than “treatment, payment or health care

²³ 45 C.F.R. § 164.514(e); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 4 (2003).

²⁴ *Id.* at 9.

²⁵ *Id.*

²⁶ 45 C.F.R. § 164.508.

operations or otherwise permitted or required by the Privacy Rule,” then the covered entity must obtain the individual’s written authorization.²⁷ All written authorizations must be in “plain language, and contain specific information regarding the information to be disclosed or used, the person(s) disclosing and receiving the information, expiration, right to revoke in writing, and other data.”²⁸ The authorization “may allow use and disclosure of [PII] by the covered entity seeking the authorization, or by a third party.”²⁹

Scott County should pursue individual written authorization in order to gain access to PII. This is the easiest route to gain the most data, which will help serve SCALE’s goals for the integrated database. Written authorization is the clearest way to demonstrate that the release of PII is allowed on an individual basis. It may be more difficult because parental consent may be challenging to obtain.³⁰ However, meeting the authorization requirements established by the Privacy Rule could lead to legal challenges on the grounds of a failure to use plain language or the use of specific terms. Still, authorization requires the least amount of work up front because it does not require any permitting legislation or research plan. Another significant advantage to authorization is that it is not subject to the “minimum necessary” requirement, which could significantly decrease the amount of data available for entry in the database.³¹ Schools will be required to follow FERPA laws as any medical data that schools possess will become “education records” for purposes of data security.

²⁷ *Id.*

²⁸ See 45 C.F.R. § 164.532; U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 9 (2003).

²⁹ *Id.*

³⁰ However, in nearby Olmsted County, parents were willing to consent to release of health data to schools for purposes of sharing asthma plans with school nurses and teachers.

³¹ 45 C.F.R. §§ 164.502(b) & 164.514(d); U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 10 (2003).

FERPA

FERPA protects PII in education records held by “all educational agencies and institutions that receive funds under any program administered by the Secretary of Education.”³² The disclosure of PII is prohibited unless written consent is obtained or one of the permissible exceptions to the written consent requirement is met.³³ The exceptions are an audit and evaluation by state and local authorities³⁴ or the school official exception.³⁵ Scott County could fall under the audit and evaluation exception, but not the school official exception. At this point, the best route for Scott County is to obtain written consent.

The audit and evaluation by state and local authorities permits access to PII for the purpose of evaluating federal or state supported education programs by establishing linked data.³⁶ This exception to consent may be granted to “state and local educational authorities.”³⁷ Generally, the term “state and local educational authorities” has been interpreted to “refer to an entity that is responsible for and authorized under local, state, or federal law to supervise, plan, coordinate, advise, audit, or evaluate. . . federal- or state-supported education programs and services in the state.”³⁸ “Education program” is defined by FERPA regulations to mean: “any

³² U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 5 (Jan. 2017).

³³ 20 U.S.C. §§ 123g(b)(1), (b)(3), (b)(5), (b)(6) & (b)(7), (h), (i) & (j); 34 C.F.R. §§ 99.30(a) & 99.31; U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 5 (Jan. 2017).

³⁴ 20 U.S.C. §§ 1232g(b)(1)(C), (b)(3); 34 C.F.R. § 99.31(a)(3), 99.35.

³⁵ 20 U.S.C. § 1232g(b)(1)(A); 34 C.F.R. 99.31 (a)(1).

³⁶ 20 U.S.C. § 1232g(1)(C), (b)(3), (b)(5); 34 C.F.R. §§ 99.31(a)(3), 99.35; U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 7 (Jan. 2017).

³⁷ *Id.*

³⁸ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 8 (Jan. 2017).

program that is principally engaged in the provision of education, including, but not limited to, early childhood education, elementary and secondary education, postsecondary education, special education, job training, career and technical education, and adult education, and any program that is administered by an educational agency or institution.”³⁹ There are several requirements which make this option uniquely challenging for Scott County.

Scott County would need to first establish whether it is a local educational authority under FERPA. Scott County is not a local educational authority, so it would have to be an IDS Lead for purposes of this exception. An IDS Lead (lead) is the body that controls access, security, and data maintenance. This requires infrastructure, legislation, staff, security, and more, which will not be covered by this memo. The bigger concern for SCALE in considering this exception is that the data are released only for the purposes of evaluating federal and state programming. This significantly limits the purposes of data use and practical applications sought by SCALE.

Written consent is a better option for Scott County than the audit and evaluation exemption under FERPA. Parental buy-in appears to be strong in nearby counties like Dakota and Olmsted, which have gained significant parental consent to share PII between schools, medical providers, and county agencies.⁴⁰ Aside from the apparent ease of obtaining consent, the programmatic demands of facilitating the audit and evaluation exception under FERPA appear to be much greater than the efforts necessary to gain and maintain consent. The audit and evaluation exceptions are generally permitted when the local authority designates an authorized

³⁹ 34 C.F.R. § 99.3.

⁴⁰ E-mail from Bonnie Brueshoff, Director, Dakota County Public Health Department, to author (Oct. 4, 2018 10:56 CST) (on file with author); E-mail from Lisa Klotzbach, Lead Nurse Health Informaticist, to author (Nov. 14, 2018 2:27 CST) (on file with author).

representative for the purposes of auditing or evaluating the education program on its behalf. Thus, another entity would be conducting the evaluation of data. The exception needs more than just a representative, the local education authority should enter into a written agreement with the IDS lead and the agreement, at a minimum must: designate the IDS lead as the local educational authority's authorized representative, specify the PII from education records to be disclosed, specify the purpose for which the PII from education records is disclosed to the IDS lead to carry out an audit or evaluation, specify whether the IDS Lead is authorized to redisclose the PII from education records to a third party, and if so the circumstances under which such redisclosure is permissible and the recordation requirements applicable to such redisclosure, etc.⁴¹ On the other hand, consent is obtained once per year⁴² and could easily be included in back-to-school documentation which parents are accustomed to.⁴³

The School Official Exception probably does not apply to Scott County since the language is exclusively "school district."⁴⁴ Further, the data system lead must perform a function for the school district.⁴⁵ For example, the data system could link and store education data and

⁴¹ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 8, 9 (Jan. 2017).

⁴² This does not appear to be codified in state law but is customary practice by local and national parental consent forms for release of PII to integrated databases. This is an opportunity for Scott County to decide whether it can withstand the risk of pushing customary practices in this area, or if it would prefer to forgo the efficiency benefits and remain within the usual practice of consent expiring after one year.

⁴³ E-mail from Lisa Klotzbach, Lead Nurse Health Informaticist, to author (Nov. 14, 2018 2:27 CST) (on file with author).

⁴⁴ 20 U.S.C. § 1232g(b)(1)(A); 34 C.F.R. § 99.31(a)(1).

⁴⁵ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 9 (Jan. 2017).

maintain security and access. The lead must be under control of the school district.⁴⁶ There are eight school districts that would participate in the proposed data system, but not all of the students in those school districts would be residents of Scott County.⁴⁷ It is unlikely that the County will find it a valuable use of resources for an entity that cannot be under its control and serves non-residents. Thus, the second exemption to parental consent under FERPA will not likely be well suited to Scott County's preferences. Again, written consent seems to be the best option for Scott County in comparison to the school official exception.

Under FERPA, the written consent must meet certain requirements.⁴⁸ Before an educational agency discloses PII, the parent or student must provide a signed and dated written consent.⁴⁹ The written consent must specify the records that may be disclosed, state the purpose of the disclosure, and identify the party or class of parties to whom the disclosure may be made.⁵⁰ "Signed and dated written consent" may include a record and signature in electronic format that can identify and authenticate a particular person as the source of consent and indicate that person's approval of the information contained in the consent.⁵¹ If a disclosure is made using written consent, then upon request, the parent or student must be provided with a copy of the records disclosed.⁵²

⁴⁶ *Id.* See also, U.S. Dept. of Education, *The Family Educational Rights and Privacy Act Guidance for Reasonable Methods and Written Agreements*, 2-4 (June 2015) (<https://studentprivacy.ed.gov/resources/guidance-reasonable-methods-and-written-agreements>).

⁴⁷ Scott County Libraries, (<https://www.scottcountymn.gov/818/SchoolsDistricts>).

⁴⁸ See generally, 34 C.F.R. § 99.30.

⁴⁹ *Id.* Unless an exception has been utilized, as previously described. See, 34 C.F.R. § 99.31.

⁵⁰ 34 C.F.R. § 99.30(b)(1), (b)(2), (b)(3).

⁵¹ 34 C.F.R. § 99.30(d)(1), (d)(2).

⁵² 34 C.F.R. § 99.30(c)(1), (c)(2).

Considerations must be made for students who fall under the Individuals with Disabilities Act (“IDEA”). Students who are “referred to, eligible for, or receive services under either Part C or Part B of the IDEA must comply with the applicable confidentiality regulations in Part C or Part B of the IDEA in addition to the requirements identified by FERPA.”⁵³ Part B applies to children with disabilities ages three to 21 and Part C applies to “infants and toddlers with disabilities, from birth to age three (and at the state’s option until the child enters kindergarten).”⁵⁴ Generally, these parts require parental consent prior to disclosing PII unless a specific exception applies.⁵⁵ However, there are differences between Part B and Part C in terms of integrated data system participation.⁵⁶ IDEA protected data are not addressed further in this memo, thus further research must be conducted to ensure any future integrated database in Scott County is in compliance with this law.

Some providers will be exempt from FERPA because they are permitted access by other state and federal laws. For example, child welfare caseworkers may not be subject to consent requirement because of the Uninterrupted Scholars Act.⁵⁷ Private schools at the elementary and secondary levels receive no federal funding, and therefore, are not subject to FERPA.⁵⁸ Individual consultation with their privacy rules is required if they are an intended participant in the database.

MGDPA

⁵³ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 7 (Jan. 2017).

⁵⁴ *Id.* at 15.

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ Uninterrupted Scholars Act (USA) 20 U.S.C. § 1221 (2013).

⁵⁸ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy* (Jan. 2017).

The MGDPA requires government entities to follow state and federal laws regarding collection, creation, storage, maintenance, dissemination, and access to data.⁵⁹ A “government entity” includes schools, county governments, state governments, local government bodies, which are often involved in providing data to early childhood integrated databases.⁶⁰ The scope of the law in terms of covered entities and laws create a complicated but viable landscape for integrated databases.

Collection

The government may collect private data about individuals. This data is not considered public information for purposes of public access to government data or records. However, this data is accessible to the subject of the data.⁶¹ In the case of minors, parents and guardians have access to these records with a few exceptions.⁶² Parents and guardians may not access data if the minor provides written documentation that they do not want their data released to the requesting parent/guardian. This data is also releasable to government entities by informed consent, in this case by the parents and guardians of the minor subject of the data.⁶³

Informed consent is written permission from an individual to allow a government entity to release the individual’s private data to another government or non-government entity or person, or to use the individual’s private data within the entity in a different way.⁶⁴ A government entity must obtain an individual’s informed consent when the entity wants to release

⁵⁹ Minnesota Government Data Practices Act, MINN. STAT. § 13 (2018).

⁶⁰ Minn. Dept. of Administration, Data Practices, *Minnesota Government Data Practices Act* (https://mn.gov/admin/assets/DPO_datapractices2018_tcm36-310509.pdf).

⁶¹ *Id.*

⁶² MINN. R. 1205.0500 (2013).

⁶³ MINN. R. 1205.14 (2013).

⁶⁴ MINN. STAT. § 13.05(4) (2018).

the individual's private data to another entity or person.⁶⁵ The informed consent requirements apply to Minnesota governmental entities subject to the Data Practices Act⁶⁶ and, in some cases, to third party contractors.⁶⁷ Valid informed consent requires that individuals giving informed consent have sufficient mental capacity to understand the consequences of their decision to give consent.⁶⁸ A valid informed consent must: be voluntary and not coerced, be in writing, explain why the new use or release is necessary, include any known consequences for giving informed consent, and if the individual is a minor, the entity may also need the signature of the individual's parent or guardian depending on the situation or the entity's policy.⁶⁹

Dissemination

Private information may be released with informed consent of the data subject.⁷⁰ If the data subject is a minor, the informed consent of a parent or legal guardian is required. This is true for education data, public health data, and medical data.⁷¹ These types of data may also be released for more system-wide evaluations and inventories. However, to serve the purposes of the integrated database, the focus of this analysis will be on individually identifiable information, which is only available in Minnesota through informed consent.

Access

Each government entity is required to have two policies about access to government data. One policy is an explanation of the right of the public to access of data, and the other policy is an

⁶⁵ *Id.*

⁶⁶ Minnesota Government Data Practices Act, MINN. STAT. § 13 (2018).

⁶⁷ MINN. STAT. §§ 13.02(11), 13.05(2), (11) (2018).

⁶⁸ MINN. R. 1205.1400(3), (4) (2013).

⁶⁹ MINN. R. 1205.1400(4) (2013).

⁷⁰ MINN. STAT. § 13.05(4)(d) (2018).

⁷¹ MINN. STAT. §§ 13.32(1)(c), 3a, 13.3805(1)(a), 13.384(1)(b) (2018).

explanation of the rights of data subjects.⁷² This memo does not analyze access policies; however, this is a consideration for future stakeholder decisions.

Current Practices

There are several approaches to integrating early childhood data. Some states have seen local governments benefit from enacting legislation that permits the use and release of government data. Other local governments, like Dakota County, are utilizing parental consent to comply with privacy regulations. Overall, different types of access have implications for use and redisclosure.

San Diego utilizes parental consent to share personal data from preschool providers to a state-funded program, but only de-identifiable data is shared back with those entities. The First Five program in San Diego also uses an authorization by legislation/government research justification for release. Although the legislative approval appears to give more validity to the city's collection of data, they are restricted by re-sharing of only de-identified information. First Five San Diego is a way for schools to get grant-based funding through participating in the research the group conducts. It only shares out de-identified family-centered information. For example, First Five compares measures between families living in different areas of the city.

Olmsted County, Minnesota utilizes a combined consent form to share children's asthma plans with teachers and school nurses to improve care for students. This narrow purpose provides for more transparency and a greater sense of security for participating families. In Olmsted County, families were part of the process and were concerned with releasing too much medical information to schools. Thus, the narrower approach was adopted but that restricts the use of the

⁷² Minn. Dept. of Administration, Data Practices, *Policies: Right of Access to Government Data*, (<https://mn.gov/admin/data-practices/data/rules/policies/>).

information to strictly practical application, improving adherence to student asthma plans. Had Olmsted County released more information, it may have been able to gain more insight into the health of students in different locations and tailor more than just asthma treatments to meet the needs of its students. A broader purpose is appealing to entities looking to make improvements at systemic levels.

Dakota County has taken a broader approach to sharing early childhood data in order to reach its goals for children from birth to age eight. There is less transparency about exactly which data are going where, the purpose is broad which allows for multiple agencies to improve practices and publicize success. Compared to Olmsted County, Dakota County has a broader purpose that diminishes transparency but enables more flexibility with data use. Unlike San Diego, neither Dakota nor Olmsted Counties utilize explicit legislation to enable data sharing. Regardless, both Counties have been able to establish data sharing agreements and in Dakota County an integrated database.

SCALE and Scott County should determine specific uses for the data and adapt the consent form to convey those purposes. The consent form is designed to apply to all possible contributors and all possible data points. However, this approach in practice is not advisable. Dakota County can be used as an example for how to implement a broad purpose that enables wide-spread applications. Olmsted County could be a model if interested parties decide to share data for very specific uses. An example of a more long-term approach to operating an integrated database is in San Diego, where legislation established a path for data sharing between agencies and schools. SCALE and Scott County should consider the specific purpose of data integration and consider how broad or narrow the application of data should.

Justification of Consent Form Details

Pursuant to federal and state laws, consent can be obtained to allow release of PII.⁷³ Under HIPAA, covered entities may release PII if the individual subject of the data provides signed, written consent.⁷⁴ Similarly, FERPA allows the release of PII if a parent or guardian signs a written consent form.⁷⁵ Minnesota privacy law requires a more robust form of consent because it demands informed consent.⁷⁶ Thus, this consent form is intended to meet the requirements of HIPAA, FERPA and MGDPA by providing an opportunity for parents of children in Scott County to sign a written consent form.

HIPAA and FERPA have similar requirements for written consent forms.⁷⁷ The consent must be in writing with a signature and date. For compliance with FERPA, the written consent must specify the records that may be disclosed, state the purpose of the disclosure, and identify the party or class of parties to whom the disclosure may be made.⁷⁸ HIPAA requires that all written authorizations must be in plain language, and contain specific information regarding the information to be disclosed or used, the person(s) disclosing and receiving the information, expiration, right to revoke in writing, and other data.⁷⁹ Authorization for medical records “may

⁷³ 45 C.F.R. § 164.508; U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 5 (Jan. 2017); MINN. STAT. § 13.05(4) (2018).

⁷⁴ 45 C.F.R. § 164.508.

⁷⁵ 20 U.S.C. §§ 123g(b)(1), (b)(3), (b)(5), (b)(6) & (b)(7), (h), (i) & (j); 34 C.F.R. §§ 99.30(a) & 99.31.

⁷⁶ MINN. STAT. § 13.05(4) (2018).

⁷⁷ Compare 34 C.F.R. § 99.30(b)(1), (b)(2), (b)(3), with 45 C.F.R. § 164.532.

⁷⁸ 34 C.F.R. § 99.30(b)(1), (b)(2), (b)(3).

⁷⁹ See 45 C.F.R. § 164.532; U.S. Dept. of Health & Human Services, Office of Civil Rights, *Summary of the HIPAA Privacy Rule*, at 9 (2003).

allow use and disclosure of [PII] by the covered entity seeking the authorization, or by a third party.”⁸⁰ FERPA allows the signed and dated written consent to be in electronic format.⁸¹

This consent form must go further than the requirements of HIPAA and FERPA due to the slightly higher demands imposed by MGDPA that the release of government data may be obtained by written, *informed* consent.⁸² In Minnesota, informed consent requires that individuals giving informed consent have sufficient mental capacity to understand the consequences of their decision to give consent.⁸³ Valid informed consent must also be voluntary and not coerced, be in writing, explain why the new use or release is necessary, include any known consequences for giving informed consent, if the individual is a minor, the entity may also need the signature of the individual’s parent or guardian depending on the situation or the entity’s policy.⁸⁴

This consent form is unique because it combines consent to use and release, with consent to re-release across participating parties. Discussed earlier, Olmsted County of Minnesota has implemented a similar, combined consent document with success. However, the Olmsted County’s purpose for release of data is much narrower than in the case of Scott County. The specificity of the Olmsted document, a required feature,⁸⁵ is much stronger. For this reason, and others discussed below, this consent form should be reviewed by legal counsel for validity in terms of each individual entity’s legal obligations to their data subjects.

⁸⁰ *Id.*

⁸¹ 34 C.F.R. § 99.30(d)(1), (d)(2).

⁸² MINN. STAT. § 13.05(4) (2018).

⁸³ MINN. R. 1205.1400(3), (4) (2013).

⁸⁴ MINN. R. 1205.1400(4) (2013).

⁸⁵ MINN. R. 1205.1400(4) (2013).

Therefore, this consent form is a foundation for the beginning of conversations around creating the database and is not a long-term solution. Gaining advice from counsel relating to this consent form could serve as a beginning step toward parties seriously considering their obligations in the event that they decide to participate in an integrated database. This consent form was created before any of these considerations have been made and will necessarily be altered to reflect the specific purposes, participants, and disclosures that are agreed upon by parties through internal and cross-party discussions. Thus, this consent form should serve as the beginning of considerations in participation in the integrated database and should not constitute a long-term solution to accessing data.

Directions for Use

An individual may sign this consent form at any time or in any location. Signature may be obtained online if it is verifiable and authentic for education data. However, it is unclear whether consent, specifically informed consent, may be obtained online. Parents or legal guardians must sign the consent form before data can be shared. In San Diego, the consent form also included a way for parents to communicate that they did *not* want to participate in data sharing. Although not required by law, this could be a clear way to understand whether parents consented, did not consent or did not complete the form. This information could be used to contact non-consenting parents or parents who did not complete the form for an interview or question and answer session to help the county better understand the families it serves. Although there appears to be no legal requirement for accompanying information for parents, in Dakota County and San Diego the infographics and easy to read hand-outs probably makes parental consent easier to obtain.

Conclusion

All parties interested in contributing to and gaining access to the early childhood integrated database proposed by SCALE for Scott County should consult with legal counsel before participating.⁸⁶ Determining the best course for obtaining data disclosure will be a multi-level decision making process that will require significant consideration of tolerable levels of risk, compliance, and privacy interest. Planning for database governance and security remain critical areas for development before this project can be implemented. Approval from the legislature or developing a research plan could justify the legitimacy of the database. Further research and deliberation are required on planning and implementation issues broadly.

This memo is intended to give a broad overview of the applicable exceptions to the federal and state legislation protecting PII in medical, education and government data. Obtaining individual, written consent is an option for all three types of data, it is in some ways the surest way to ensure disclosure is valid and can offer a prompt start to data collection. This memo provides justification for use of a consent form. It is recommended that the use of a consent form continue throughout the course of data collection to promote transparency with parents and families and to demonstrate the legitimacy of the sharing and redisclosure of PII. However, this is not necessarily the best or only option that should be considered. Parties should evaluate the validity of the consent form for their own purposes. Parties should consider the other, more robust options available to them when contemplating participation in the early childhood integrated database proposed by SCALE for Scott County.⁸⁷

⁸⁶ U.S. Dept. of Education, Privacy Technical Assistance Center, *Integrated Data Systems and Student Privacy*, at 1 (Jan. 2017).

⁸⁷ Specifically, parties should consider the “Audit and Evaluation” exception available through FERPA and the “Public Interest and Benefit Activities” exception under HIPAA.

Appendix A: Consent Form

Consent to Release and Rediscover Health, Education and Government Records

I, _____, authorize the below written entities, to release personally identifiable information and all health and all education records and data to Scott County.

School: _____ initials _____
Health Agency: _____ initials _____
Health Clinic: _____ initials _____
Other: _____ initials _____
Other: _____ initials _____

I understand that after Scott County collects these records, they will be combined and then redisclosed to the school districts, health providers, and Scott County agencies below.

School: _____ initials _____
Health Agency: _____ initials _____
Health Clinic: _____ initials _____
Other: _____ initials _____
Other: _____ initials _____

I understand that the purpose for the release and redisclosure of my child’s information is to evaluate programs in Scott County, to provide access to specific schools and health providers so they may evaluate their work, and to provide access to individual teachers, care givers, practitioners at schools, health providers, and county employees so they may improve specific interventions and work with my child.

I understand that the consequences involved in releasing my child’s personally identifiable information and all health and all education records and data include:

- Security breach
- Less privacy for my family

I understand that if I do not authorize the release of this information, it will not affect my child’s eligibility for medical assistance or any other health, education, or social service program.

On behalf of my child, _____, I authorize the release of the above stated records and data to the above stated parties for the above stated reasons while understanding the risks involved in releasing these records and data.

Parent/guardian Signature: _____ Date: _____

I understand that I can request copies of all of the records released per this consent agreement by written request to, X person, X email, X address.

This consent will expire in one year from signature, _____.

Appendix B: Annotated Consent Form

Consent to Release and Rediscover Health, Education and Government Records⁸⁸

I, _____, authorize the below written entities, to release personally identifiable information and all health and all education records and data to Scott County.⁸⁹

School: _____ initials _____
Health Agency: _____ initials _____
Health Clinic: _____ initials _____
Other: _____ initials _____
Other: _____ initials _____⁹⁰

I understand that after Scott County collects these records, they will be combined and then redisclosed to the school districts, health providers, and Scott County agencies below.

School: _____ initials _____
Health Agency: _____ initials _____
Health Clinic: _____ initials _____
Other: _____ initials _____
Other: _____ initials _____⁹¹

I understand⁹² that the purpose for the release and redisclosure of my child’s information is to evaluate programs in Scott County, to provide access to specific schools and health providers so they may evaluate their work, and to provide access to individual teachers, care givers, practitioners at schools, health providers,⁹³ and county employees so they may improve specific interventions and work with my child.⁹³

I understand that the consequences involved in releasing my child’s personally identifiable information and all health and all education records and data include:⁹⁴

- Security breach
- Less privacy for my family

⁸⁸ 45 C.F.R. §§ 164.508, 164.532 (plainly describing the document).

⁸⁹ 34 C.F.R. §§ 99.30 (specifying the records that may be disclosed); 45 C.F.R. § 164.508 (containing specific information regarding the information to be disclosed or used).

⁹⁰ 34 C.F.R. §§ 99.30 (identifying the party or class of parties to whom the disclosure may be made); 45 C.F.R. § 164.508 (containing specific information regarding the person(s) disclosing and receiving the information).

⁹¹ *Id.*

⁹² MINN. STAT. § 13.05.4 (using “I understand” reflects the voluntary and not coerced requirement).

⁹³ 34 C.F.R. §§ 99.30 (stating the purpose of the disclosure); MINN. STAT. § 13.05.4 (explaining why the release is necessary).

⁹⁴ MINN. STAT. § 13.05.4 (listing known consequences for giving consent).

I understand that if I do not authorize the release of this information, it will not affect my child's eligibility for medical assistance or any other health, education, or social service program.⁹⁵

On behalf of my child, _____, I authorize the release of the above stated records and data to the above stated parties for the above stated reasons while understanding the risks involved in releasing these records and data.

Parent/guardian Signature: _____ Date: _____⁹⁶

I understand that I can request copies of all of the records released per this consent agreement by written request to, person, email, address.⁹⁷

This consent will expire in one year from signature, _____.⁹⁸

⁹⁵ *Id.*

⁹⁶ 34 C.F.R. §§ 99.30 (requiring consent in writing that is signed and dated); 45 C.F.R. § 164.508; 34 C.F.R. § 99.30; MINN. STAT. § 13.05.4 (requiring authorization in writing); MINN. STAT. § 13.05.4 (requiring the signature of the individual minor's parent or guardian).

⁹⁷ 45 C.F.R. § 164.508 (including the right to revoke in writing).

⁹⁸ 45 C.F.R. § 164.508 (requiring expiration of written authorization).