2020 Predict Align Prevent Data Sharing Initiative

Capstone Project Team Members:
Jessica Amos
Chris Fletcher
Markett Humphries
Ashley Lichtle
Roy Ragland
Andre' Rogers
Paulette Smith
Hanna Windley

Master of Public Administration, School of Public Affairs
University of Arkansas at Little Rock

May 11, 2020

PADM 7373: Master of Public Administration Capstone
Instructor: Kirk A. Leach, Ph.D.

Team
Jessica Amos, Chris Fletcher
Markett Humphries, Ashley Lichtle,
Roy Ragland, André Rogers,
Paulette Smith, & Hanna Windley

Advisor ***Sponsor***
Kirk A. Leach, Ph.D. **Dr. Dyann Daley M.D.**

Acknowledgements

The completion of this project would not have been possible without the leadership of Dr. Kirk Leach, and the dedication of Dr. Dyann Daley. We appreciate this opportunity to engage with a group of dedicated professionals striving for the betterment of communities. PAP's commitment to the effective prevention of child abuse and neglect is inspriational. The Master's in Public Administration Graduate Capstone Team is also grateful for the time and assistance provided by personnel of the Arkansas Department of Health and the Arkansas Department of Human Services. Our gratitude goes out to each of you for sharing invaluable insights that contributed to this work.

Copyright

"We the team members,

Jessica Amos Chris Fletcher Markett Humphries Ashley Lichtle

Roy Ragland André Rogers Paulette Smith Hanna Windley

Kirk A. Leach, Ph.D.

Hereby assign our copyright of this report and of the corresponding Executive Summary to The School of Public Affairs at The University of Arkansas at Little Rock. We also hereby agree that the video of our Oral Presentations is the full property of the School of Public Affairs.

Table of Contents

Executive Summary

Due to the long-term negative impact that adverse childhood experiences (ACEs) have on individuals and the communities in which they live, it is imperative that public and private strategies and interventions be maximized to prevent ACE-related events and outcomes. Predict Align Prevent (PAP) is a Texas-based 501(c)(3) nonprofit organization founded for the purpose of preventing child abuse and neglect. The mission of PAP is to use geospatial risk prediction to identify high risk areas for child maltreatment and abuse and align community organizations with one another in a unified front to target those areas. However, access barriers to ACE-related data inhibit the ability of PAP to adequately inform research and thereby disrupts achievement of its mission goals. Thus, PAP partnered with the 2020 University of Arkansas at Little Rock Master of Public Administration Capstone Team to determine causation of data sharing barriers within Arkansas and to develop recommendations to effectively overcome those barriers.

To ascertain the barriers and practices that inhibit data sharing between public agencies in the State of Arkansas, the Capstone Team conducted comparative legal and case analysis, semi-structured interviews of state agency personnel, and reviewed policies of public entities to answer research questions regarding information sharing and access to ACE-related data. Analysis revealed that data sharing barriers inhibiting PAP's ability to adequately inform research are common big data issues prevalent across divisional bureaucratic organizational structures. The negative impact of those barriers was found to be exacerbated by inadequate legislation and lack of data sharing agreements that prevent strategic alignment of resources. Because data sharing barriers are spread across systems managed by multiple public and private organizations, elimination of those barriers is a formidable task impossible for PAP to accomplish alone.

The Capstone Team recommends PAP partner with the University of Arkansas Winthrop Rockefeller Institute to facilitate collaborative discussions among public and private stakeholders that lead to transformational change in ACE-related data sharing practices in the State of Arkansas. PAP should specifically advocate for the development of a mandated central record-keeping repository that is managed by the State of Arkansas and allows access to location-based ACE-related data while protecting person specific information. This type of system with the capability to link datasets will eliminate barriers that inhibit PAP's ability to inform research, and identify geospatial and environmental risks associated with other community concerns.

Introduction

Predict Align Prevent (PAP) is a Texas-based 501(c)(3) nonprofit organization, founded for the purpose of preventing child abuse and neglect. Dr. Dyann Daley, M.D. is a pediatric anesthesiologist and Founder/CEO of PAP. Through partnerships with Urban Spatial Analytics, founded by Ken Steif, PhD, Predict Align Prevent offers geospatial machine learning workflow development, analytics, and consulting services. The mission and purpose of PAP is to use geospatial risk prediction to identify locations where risk for child maltreatment and abuse is most prevalent on a geographical grid-level. The goal of PAP is to use these predictions to align community organizations with one another in a unified front to target identified higher risk areas. Through a quality improvement cycle, PAP continues to monitor the effectiveness of these efforts on an on-going basis in order to identify solutions that prevent child maltreatment and abuse.

Transparency and accessibility of information are critical components of Predict Align Prevent's research model. The research conducted and published by PAP is accessible and free to the public. The organization's hope is to make child maltreatment information more accessible to community agencies, coalitions, and organizations in order to enhance the effectiveness, efficiency, and impact of community intervention efforts. However, PAP has experienced difficulty in gaining access to health records and child maltreatment data. The lack of access to data and records has created an information barrier that inhibits the ability of PAP to adequately inform their research as desired. Ultimately, this limits PAP's ability to connect community members with resources and information as a means of disrupting and preventing child abuse and maltreatment. Thus, Predict Align Prevent enlisted the support of a team of graduate student researchers from the University of Arkansas at Little Rock (hereinafter "UA Little Rock") to determine why information sharing is not transpiring across public agencies and to develop recommendations for effectively navigating around these barriers.

In order to pursue these efforts, the Master's in Public Administration Graduate Capstone Team (hereinafter "Capstone Team") interviewed state agency personnel and reviewed agency policies among public entities in the State of Arkansas. The Capstone Team aimed to use this data to inform PAP about the normative and structural barriers that are currently preventing data sharing between state agencies and recommend solutions that maintain privacy and equity while also improving resource allocations. Specifically, the Capstone Team sought to identify federal or state laws, rules, regulations, and/or procedures limiting cross-agency data sharing relating to location of adverse childhood experiences-related risk factors, protective factors, and outcomes in Arkansas for the purposes of strategic planning of prevention resource allocation. The Capstone Team also sought to identify organizational norms limiting cross-agency data sharing associated with the aforementioned factors.

Child maltreatment prevention efforts rely heavily on the accessibility of child maltreatment data. Reducing severe and fatal child maltreatment requires coordination of vital records," which includes but is not limited to vital records, child welfare data, and data pertaining to early intervention (Barth et al., 2015, p. 5). This data helps to inform service providers and specialists about where child maltreatment is happening, and assists in identifying the most effective intervention mechanisms. Unfortunately, this data is often hard to access due to the fact that there is currently no standard, mandated reporting system for child abuse or neglect deaths (Covington, 2020, para. 5). This issue is compounded by the fact that much of the data that does exist is housed within government agencies and these agencies lack the ability to share data across systems (Covington, 2020, para. 9).

Ultimately, this lack of data sharing impedes the research and intervention programming that could lead to better child welfare policies and child maltreatment intervention practices. Thus, the Capstone Team has partnered with PAP to assist in efforts to better understand the normative and structural barriers to data sharing among public agencies. They will conduct a comparative case analysis, interview state agency personnel, and review agency policies among public entities in the State of Arkansas. More specifically, the Capstone Team will engage in these data collection and analytic processes in order to answer the following questions regarding information sharing and access to child maltreatment data:

1. What identifiable federal or state laws, rules, regulation, and/or procedures are limiting cross-agency data sharing regarding location data for adverse childhood experiences (ACEs) related risk factors, protective factors, and outcomes in Arkansas for the purposes of strategic planning of prevention resource allocation?
2. What organizational norms are limiting cross-agency data sharing regarding the above factors?

Literature Review

Administrative data has consistently been used in child welfare research and to shape policy for over a decade. This information is used to educate the public and policymakers on the welfare of children within their communities. Data from one agency, such as the Department of Human Services, can answer many fundamental questions. However, when data is linked across multiple sectors, including schools, law enforcement, death records, census, etc. in addition to child welfare, the impact could be considerably greater. In fact, having a database that includes administrative records from multiple sectors can address many more questions than each could in isolation (Jonson & Reid, 2008). Having complete, real-time data from multiple sectors could give organizations a more thorough understanding of the problems occurring in the communities they serve (Jonson & Reid, 2008). It could also allow agencies to examine how effective and efficient services and referrals are, and whether they are working for specific groups or demographics (Jonson & Reid, 2008). This literature review aims to find a connection between existing data sharing literature and how it can be adapted to shape data sharing in Arkansas. In order to do this, the literature will be evaluated to better understand the impact of data sharing on adverse childhood experiences and the barriers of data sharing among agencies as well as case studies that have been implemented in other states.

Adverse Childhood Experiences and Data Sharing

Adverse childhood experiences (ACEs) have “a greater long-term impact than a number of communicable diseases combined and interoperability should be leveraged to maximize public health strategies to prevent [them]” (Nguyen, 2014, p. 2043). When data is shared across multiple sectors that work with the same children and families, it can provide a more complete picture of circumstances and improve the communication and decision making for a child’s safety. Children that experience ACEs are oftentimes involved with multiple state agencies such as state child welfare agencies and law enforcement; however, these agencies do not always share information with each other, even when laws permit such data sharing. For example, a law enforcement officer responding to a domestic violence call may not know that the family has had multiple reports of suspected abuse or neglect of the children in the home. This lack of information sharing can prevent agencies from making the most informed decision about a child's overall safety in a home. Effective use of public health data sharing across agencies could mean that thousands of deaths and injuries could be avoided.

Barriers in Interagency Collaboration

The literature identifies several barriers to interagency collaboration as it relates to data sharing. Gil-Garcia et al. (2007) found barriers in organizational, political and legal, and technical domains, and van Panhuis et al. (2014) discovered barriers in motivational, economic, and ethical domains. These barriers in interagency collaboration often prohibit dramatic improvements to public health practices and limit the outcomes for children and families because they can cause gaps in research and evidence-based policymaking. Addressing these barriers would mean that "critical information [could] be shared more easily across agencies and systems, improving our ability to support families and keep children safe" (Within Our Reach, 2016, p. 91).

Organizational barriers can be due to explicit or implicit differences among participating organizations and can include conflicting organizational policies, priorities and cultures, limited resources, or misinterpretation or misuse of shared information (Green et al., 2015; van Panhuis et al., 2014). Even when state agencies do have accessible data, they fail to have clear policies regarding access to the data, or interpretation of the laws and regulations are inconsistent for data sharing between various state agencies (Goerge, 2018; Graham et. al, 2016). Vest and Issel (2013) assert that data collection and sharing are not straightforward processes due to the "varying organizational responsibilities among [state] agencies" (p. 358) and this results in multiple data sources that are not integrated effectively. Further, they point out that the "jurisdictional boundaries of [state] agencies do not always completely correspond to actual population locations, jurisdiction overlap, and public health events of interest that can occur elsewhere" (Vest & Issel, 2013, p. 358).

Van Panhuis et al. (2014) define political barriers as "fundamental structural barriers embedded in the public health governance system that are grounded in a political or socio-cultural context" (p.5). These barriers are often due to lack of trust, restrictive policies, or lack of guidelines. Lips et al. (2011) also found that protecting personal data and trust in cross-agency information sharing were identified as being very important. Agencies that lack trust among one another are less likely to participate in joint problem solving or offer increased data sharing. Barriers are created when individuals believe that the people receiving the information will not treat the information professionally and use it judiciously. Further, a lack of trust in cross-agency information sharing may deter agencies from sharing due to fear of criticism or potential exposure of fabrication or manipulation of data (van Panhuis et al., 2014). Datasets may reveal results that could "potentially be harmful to the agency or to a particular leader" (Goerge, 2018, p. 125). The potential threat of data being used in a way that exposes gaps in programs is also a threat to agency funding. Goerge (2018) further explains that

> state agencies are often in competition for scarce resources, that their programs are at risk of being cut, that their staff may be reassigned, or that their authority over their operations is diminished as a result of information that is externally compiled. (p. 128)

Graham et al. (2016) discuss these barriers as being “embedded in the larger political environment, which can require policy changes through legislative action to enable, promote, and permit data and technology sharing, information management, and other activities” (p. 573). Further, Graham et al. (2016) found that “when legislation and policy action provide specific guidance on how information should be used and shared, it can help build relationships and trust across agencies and mitigate the risk inherent in sharing data” (p. 573).

Legal barriers are “legal instruments used to restrict data sharing, resulting from the underlying willingness (or not) to share data” (van Panhus et al., 2014, p. 5). These are often laws and regulations or privacy and confidentiality assurances, such as ownership and copyright laws as well as the Health Insurance Portability and Accountability Act (HIPAA). These laws and regulations restrict access and prevent data sharing across agencies. Privacy and confidentiality of child maltreatment records, especially at the individual child or case level, are of great concern and can be particularly difficult to navigate. Another component found in the Lips et al. (2011) study was the distinction between “hard” and “soft” information. “Hard” information, formal information that is written and exchanged in formal processes, can be scrutinized by the media, lawyers, and even clients themselves (Lips et al., 2011, p. 261). “Soft” information, information that is typically exchanged directly between individuals and is unwritten, is often relied on more heavily but is less conducive to data sharing processes (Lips et al., 2011, p. 261). Therefore, the information collected and written down can often be lacking or leave crucial components out, which causes gaps in any data that is accessible.

Privacy and confidentiality are considered ethical barriers in addition to legal barriers. Ethical barriers are normative barriers that involve conflict between moral principles and values. Deliberating the risks and benefits of data sharing compared to the potential impact of its use after collection, also known as proportionality, is the “guiding ethical principle for public health data sharing” (van Panhuis et al., 2014, p. 6). Additionally, data sharing practices can feel unfair or exploitative if there is a lack of reciprocity or uncertainty around valid consent. Other ethical considerations are the impact on public trust, stigma and discrimination, and who is allowed to access the data or be involved in the decision-making process around data sharing policy.

Other limitations in the data are often due to technical barriers. Technical barriers are issues with data that include conflicting data definitions, incompatible database designs, lack of significant or accurate data, and lack of ability to use data at an individual level (Graham et al., 2016; Green et al, 2015; Nguyen, 2014; Teixeira & Boyas, 2017; van Panhuis et al., 2014; Within Our Reach, 2016). Green et al. (2015) acknowledged that while administrative data sets regarding child abuse and neglect have been used successfully for years, the family and socio-demographic variables that are important to understanding the maltreatment are “often not reliably available in admistrative datasets” (p. 41). Goerge (2018) addresses technical barriers by saying that “technical and procedural safeguards must be implemented, maintained, updated, and then communicated to the owners of the data so that data security is no longer a barrier” (p. 130). Vest and Issel (2013) point out that state health agencies and local health departments “do not always possess [information systems] capable of efficiently managing sharing data with other organizations” and this is “further complicated by the usage of different [information systems] between organizations and even the practice of recording different data elements” (p. 358). Barriers are still present even when state agencies have access to an information system because data management is not equal

> in terms of ability to exchange data with other organizations. Systems that are not interoperable, or cannot send or receive information in a standard, structured format, create isolated data silos; the data contained within these systems cannot be easily accessed by other organizations. (Vest & Issel, 2013, p. 358)

Motivational barriers are based on institutional or personal motivations and beliefs that limit data sharing and these barriers often occur due to lack of incentives, opportunity costs, and possible economic damage or criticism (van Panhuis et al., 2014). Graham et al. (2016) says data sharing projects suffer "from the lack of institutional incentives to collaborate, and the power struggles inherent in a multi-agency setting in government" (p. 573). Public health agencies often struggle to have the time and resources to effectively manage data sharing systems, and there are typically no incentives to prioritize data sharing over other duties. When a specific agency is not delegated the responsibility to create datasets, structure, or system, it delays any potential for sharing between agencies even when agreements are in place (Goerge, 2018). Even when agencies want to participate in data sharing, it is difficult to find the workforce and funding "to both acquire and curate high quality data and to analyze the databases once built" (Goerge, 2018, p. 130).

Case Studies

Four case studies were included in the literature review to further explain data sharing from the perspective of other locations. Gasner et al. (2014) found that a range of state and local laws inhibited data sharing within the New York Department of Health and Mental Hygiene (DOHMH). The DOHMH has 5,000 employees and serves 8.3 million New Yorkers. This study found that one major barrier to data sharing was DOHMH's own internal policies. These policies were frequently found to be more strict than required by law. The strict nature of these policies was designed to protect confidentiality of patients, but also prevented functional data sharing. The case study also demonstrates that balancing confidentiality and data sharing become significantly more challenging as the volume of data increases.

In 2015, El Emam et al. examined the growing movement in North America and Europe to share individual patient data for secondary purposes. The authors found that in most circumstances patient data could be shared through two mechanisms: consent of the patient and the anonymization of the data (El Emam et al., 2015). Consent in data sharing would be significantly complicated in the context of child maltreatment, where children would be legally unable to give consent to researchers. While consent is typically more desirable, there is often "systemic consent bias whereby consenters and non-consenters differ on important characteristics," making the anonymization of data a more fruitful practice (El Emam et al., 2015). The El Emam et al. (2015) separated patient data into three distinct categories, with each group requiring different levels of anonymization: public, quasi-public, and non-public data. While the category of data would vary across jurisdiction, each would need to be anonymized. In most North American and European contexts, all three of the above categories are available to qualified researchers. Despite anonymization best practices, re-identification may still be possible in some instances. To circumvent attempts at re-identification of anonymized data, El Emam et al. (2015) recommended that data be generalized and paired with a probability risk assessment, however it may not be appropriate in all contexts.

Graham et al. (2016) identified how important executive leadership was in state-level efforts of data sharing, and that data sharing literature identifies legislation as “an important factor for providing specific guidance on how information should be used and shared and on building relationships” (p. 578). Of the states in Graham et al.’s (2016) study, three adopted the “importance from the top” attitude to make data sharing a priority. The legislatures and governors in Maryland, Texas, and Washington have passed and signed data sharing legislation that serves three purposes: “to mandate which agencies will share data and how; to create an organizational structure, or research center, for the [data sharing] system that supports sustainability of the project; and to address data sharing issues” (Graham et al., 2016, p. 578). Further, Graham et al. (2016) found that alongside the support of executive leadership, states also needed strong and consistent legal advice. Differences in interpretation from state-to-state or agency-to-agency “can cause a ripple effect of doubt” and made it “difficult to secure the between-agency data sharing agreements that had to occur to build the system” (Graham et al., 2016, p. 579). Therefore, “finding consistency in interpretation of the laws governing data sharing was key to making data sharing agreements work” (Graham et al., 2016, p. 581).

Health Management Associates (HMA) (2018), on behalf of the Lucile Packard Foundation for Children’s Health, examined cross-sector collaborations of six interagency programs working with children and youth with special health care needs (CYSHCN). These programs collaborated through interagency councils and task forces, implemented data sharing agreements, and formed new departments or positions focused on interagency communication and coordination. HMA (2018) found that the achievements of these programs were:

> better identification of CYSHCN and more children/families with a shared care plan (Colorado care coordination data sharing pilot); “flagging” of CYSHCN for targeted outreach (Washington’s CYSHCN cross-agency data system); increased health screening and dental visit form completion in public schools (D.C.’s data sharing across Education, Medicaid, and Health departments); a common developmental screening metric for health and early learning systems (Oregon’s alignment of Health and Early Learning), a new interactive website for families of vulnerable children to navigate services across health, education, and human services (New York’s Council on Children and Families), and a cross-sector ten-point plan for improving long term outcomes for young children enrolled in Medicaid (New York’s First 1000 Days on Medicaid initiative). (p. 2)

Research Design & Methods

Ultimately, the lack of data sharing among government agencies impedes research and intervention programming that could lead to evidenced-based ACE-related policies and practices. Thus, the Capstone Team partnered with PAP to assist in ascertaining the barriers and practices that inhibit data sharing between public agencies in the State of Arkansas. The Capstone Team conducted a comparative case analysis, semi-structured interviews of state agency personnel, and reviewed policies of public entities to answer the following research questions regarding information sharing and access to ACE-related data:

1. What identifiable federal or state laws, rules, regulation, and/or procedures are limiting cross-agency data sharing regarding location data for ACEs-related risk factors, protective factors, and outcomes in Arkansas for the purposes of strategic planning of prevention resource allocation?

2. What organizational norms are limiting cross-agency data sharing regarding the above factors?

Semi-Structured Interviews

The Capstone Team utilized semi-structured interviews to gain insight into the perceived norms that may be prohibiting the exchange of data and information between agencies by conducting interviews with state agency personnel (see Appendix 2 for full list of questions). The interviews focused on federal and state laws, rules, regulations, and/or procedures that may prevent cross-agency ACEs-related data sharing. The ten interviewees were from the Arkansas Department of Health (ADH) and the Arkansas Department of Human Services (DHS). The interviewees were chosen based on their insight into the mechanics of their respective agencies and their likelihood to have encountered information barriers in their fields of work. Their insight helped to inform the Capstone Team's knowledge of the factors or issues that are contributing to the information barriers that exist relative to the sharing of child maltreatment and ACEs-related data and information. Additionally, the Capstone Team noted that the information obtained in these interviews may or may not be reflected in the policies of the agencies they represent, instead reflecting the unofficial organizational norms that have been created over time.

The interviews were conducted individually with utmost care to ensure participant anonymity. The range of employee experiences with regard to agency protocol and practice provided invaluable insight relating to the sharing of ACEs-related data across state, city, and community organizations. Meaningful patterns of information were then identified, and coded to build a framework for analysis discussed later in this report. These results were used to inform the Capstone Team about the current status of data sharing in Arkansas and develop recommendations regarding the best practices for sharing data across state, city and with community organizations.

Case Studies

The Capstone Team reviewed a series of case studies in an attempt to determine public health data sharing best practices. These case studies, while not directly related to ACE's policy or the State of Arkansas, provided significant insight into the considerable challenges facing public health data sharing. Reviewing these case studies allowed the Capstone Team to identify common barriers to data sharing at the city, state, and federal level. Identifying these common barriers early in the research process allowed the team to focus the semi-structured interview questions on themes that have repeatedly hindered data sharing in other states. Case studies were selected on their relevant discussion of barriers to data sharing in public agencies and the utility of their findings within the Arkansas context.

The case studies were selected to offer the researchers a variety of examples to draw upon. These case studies ranged from a single municipal agency, albeit a very large one to multi-state programs. Although none of the case studies utilized for this project directly studied Arkansas, the researchers were careful to select studies that included states that have similar demographics and cultural histories to Arkansas. In total four case studies were reviewed. Gasner et al. (2014) discussed the various local laws and regulations that impeded data sharing in the New York Department of Health and Mental Hygiene. Though markedly different in terms of scale, the New York Department of Health and Mental Hygiene delivers insight into large complicated bureaucracies, which could be applied to the Arkansas Department of Human Services. Graham et al. (2016) conducted a longitudinal study across four states. A 2018 study by Health Management Associates (HMA) for the Lucile Packard Foundation for Children's Health examined interagency, cross-sector collaborations of six programs working with children and youth with special health care needs (CYSHCN) in four states and Washington D.C. El Emam et al. (2015) examined the growing movement in North America and Europe to share individual patient data for secondary purposes. In total, these case studies allowed the Capstone Team to draw on examples from numerous agencies, states, and major cities.

Policy Reviews

In order to identify the significant structural barriers inhibiting PAP's ability to access ACEs-related location information, the Capstone Team conducted legal research and analysis of federal and state laws. The Capstone Team also evaluated regulations of administrative agencies associated with policy and procedures relating to sharing of child maltreatment data across state, city, and community organizations in Arkansas. Analysis outcomes from the policy reviews and semi structured interviews were triangulated to uncover normative and procedural barriers of the agencies. The findings generated from that process informed the Capestone Teams recommendations to enhance ACE-related research and intervention programming.

Interview Analysis & Results

The Team conducted interviews with ten representatives from state agencies including the Arkansas Department of Health (ADH) and the Department of Human Services (DHS). The interviews focused on understanding the importance of data sharing within organizational, political, legal, and technical domains in addition to barriers that inhibit cross-agency collaboration. Throughout the data analysis process, several themes related to data sharing were revealed. Many of the respondents emphasized the importance of internal and external data sharing. Some participants also shared concerns about their agencies' current data sharing and technological capabilities. During the course of the interviews, certain limitations were discovered as it was determined that several of the interviewees were not directly involved with the processes and procedures relating to data collection and data sharing. Overall, the information shared with the Team was very useful in building awareness, future policy recommendations, and closing the gap between "what is possible theoretically and what is possible in practice."

Internal & External Data Sharing

"Data sharing," which includes how data is shared, who it is shared with, and why it is shared, was a central theme throughout the interviews. Interviewees from both the ADH and the DHS voiced that the department they worked for within the larger agencies shared data with the other departments of that agency. Most of the time this data sharing was a normal process or procedure held by the agency through some type of data system or structure. Internal data sharing seemed to have very few, if any, barriers; however, external data sharing was a different matter. Some interviewees mentioned specific outside agencies or organizations, such as Arkansas State Police or Arkansas Children's Hospital, that their agency would share information and data with, but most of that data sharing was limited to high level data aggregations without address level data; agencies and organizations that had specific authorizations, agreements, or MOUs with the agency in question; or the outside organizations or agencies had a similar mission or purpose to the agency providing the data. These stipulations could be a hindrance to smaller nonprofits or research groups who may not have the influence or connections needed to establish agreements with larger state agencies.

Four of the interviewees mentioned the level data had to be at in order to be shared. High level data cannot be connected to or identify a specific person or group. Much of the data that was shared could not disclose locations or addresses. Zip code level or higher were the most common types of data shared outside the agency. Only one interviewee mentioned sharing specific address level data for the purpose of preventing ACEs, and that was due to an agreement between that agency and Predict Align Prevent. If data sharing were to become easier and more prevalent to outside agencies, organizations, or researchers, laws and procedures would need to be reassessed, reevaluated, and changed.

Data Structure, Systems, & Infrastructure

The interview data collected from the Arkansas Department of Health indicated that there is a great need for more up-to-date and comprehensive systems for the storing ACEs data. Representatives from the ADH that participated in this study revealed that the State's current data systems are not sufficient for interagency and external sharing. Perhaps the most critical issue mentioned during the interviews was the need for data systems capable of linking data sets. One interviewee stated that "the greatest value is when you take one data set and you can link it with another… then you all of a sudden can see patterns that you couldn't see just by looking at the data on child maltreatment." The ability to link data sets makes it possible to observe potential patterns related to when, where, and why child maltreatment occurs. This same interviewee mentioned that there may be "different associations and patterns," particularly among demographic data like race, geography, substance use, and criminal records. Creating linkage among this data could offer insights about ACEs risk factors and enable child advocates to address these potential factors to prevent maltreatment in the future.

Another critical takeaway from the interview data was the need for compatible systems, capable of sharing data across agencies and departments. One participant explained that "the law is the biggest impediment to being able to share the information, however, there's a secondary issue [of] being able to properly match up an individual across disparate systems." Currently, state government agencies are operating their own unique systems, which are functional for their individual agency purposes, but do not allow for efficient data sharing. Due to the lack of compatible or singular systems across all state agencies, there are issues with data accuracy that arise, as well as, a lack of effective data tracking. The Department of Health is currently working to establish a data aggregation hub that is able to ensure that the individual(s) being identified are tracked across different data sets. The agency aims to be able to track individuals across different sets of data in order to more effectively observe patterns of behavior, risk factors, etc. associated with the individual. The establishment of a common data system would allow state agencies to work more cooperatively together to track patterns and associations across different sets of data.

Finally, these interviews from ADH revealed the need for improved accuracy of data. The use of disparate data systems has diminished the accuracy of information across data sets. There is currently no way to track an individual across sets of data using the current data systems. Even if there are patterns or associations that appear across data sets, there is no way to verify the accuracy of these observations because each data system is operating under different definitions and functions. Thus, the establishment of an "aggregat[e] data hub would enable [the agency] to aggregate data from different systems and then be able to make that available to researchers."

Personnel from the Arkansas Department of Human Services were also interviewed during this study, and their responses revealed a few similar findings to those of the Department of Health. For example, one DHS interviewee stated:

> I don't think there's been a lot of moving the ball forward and getting all that data in one place where you can do a lot of effective matching and utilize that data to help people and to prevent fraud and to be more efficient.

This statement indicates that creating a mass index or cumulative data sharing system does not seem to be a priority for DHS at this present time. Similarly another interviewee from DHS also commented on the overreliance on outdated data storing mechanisms, jokingly stating, "it's not because of a data sharing issue. It's much more of a, somebody still keeping files and paper type stuff." Based on these statements, it is reasonable to assume that DHS has not yet taken the steps to update their data storage and sharing systems with more advanced technology, capable of more advanced analytics and sharing capabilities. These outdated systems negatively affect the efficiency of data sharing, as illustrated by the previous interviewees comment that "... medical data moves pretty well across the state. Where it doesn't move well is simply because of not having the actual technology and systems in place." Clearly, the agency's current data and sharing structure does not support effective and efficient data sharing and analysis.

While reviewing the responses provided by the DHS interviews, it became apparent that there is a lack of common knowledge about the agency's data systems and sharing capabilities. There were several inconsistencies across the responses collected from the interviewees. One notable inconsistency was the disagreement about whether or not the agency is moving towards making improvements to their systems. While one interviewee, as previously mentioned, stated that they did not perceive any efforts for the agency to update the data systems, another interviewee stated that changes to data systems are "aggressively underway and going on." Although interviewees seem to agree that the agency's current systems are insufficient for data storage and sharing, there appears to be limited communication within the agency regarding whether or not these systems will be updated in the near future.

Another inconsistency of this interview data was the lack of direct response to the interview questions. Many of the interviewees failed to provide direct answers that adequately answered the questions being asked. The Capstone Team specifically discussed the sharing of ACEs related data during the interviews. As previously mentioned, each respondent was given a diagram to illustrate the categories of data and data sharing that the Team was interested in learning more about. Despite the Team's efforts to clarify the focus of the interviews, the respondents still seemed to misunderstand the focus of the interview and/or discuss other unrelated forms of data sharing. When the Team asked the DHS interviewees about the current data sharing capability of their agency, the majority of respondents discussed other technological systems unrelated to data sharing. One respondent mentioned an online DHS performance center, which "tak[es] the organization piece by piece through process mapping… trying to put together operational dashboards." This particular system is useful for tracking the progress towards completions of agency projects, but doesn't actually have any relevance to data sharing. Another interviewee discussed the agency's case management system CHRIS (Child Welfare Information System), which records the information received from the child abuse hotline for accepted allegations. Again, this system does not directly relate to data systems with the capacity to share data with internal or external departments or agencies. While these systems may contain data that can be shared, the interviewees did not specifically discuss the agency's data sharing capability.

There could be several possible explanations for this avoidance of directly responding to the questions asked related to the agency's data structure and its capacity to share data. Based on the details of the interviews and the responses offered by DHS interviewees, it appears that the agency does not have the data systems and technology needed to engage in effective data sharing. Additionally, the agency personnel seem to be unaware of the specific protocols and procedures for data sharing both internally and externally. Instead of acknowledging their lack of common knowledge of DHS data sharing, the interviewees chose to discuss other systems that they possessed more knowledge about. Based on the data collected from these interviews, there appears to be a need for more collective understanding among personnel of the agency's current data sharing capability and the direction of future updates in technology.

The Arkansas Department of Health is currently working toward establishing more efficient data systems capable of sharing data across agencies and with external entities. One interviewee mentioned that the ADH has organized an informatics working group, charged with the task of bettering the use of the agency's larger data sets and linking them. The group is also looking at developing a "master person index" which would allow the agency to track individuals across all governmental data sets. The goal for this master person index, as explained by one ADH representative, would be "that you match up enough elements of information that you receive, whether its address, name, date of birth, cell phone, and previous address, [to] get a matching rate of maybe about 95% or so." In other words, the point of establishing a master person index would be to effectively match data related to the individual, with a high rate of accuracy. An agency employee should, ideally, be able to look across several data sets and identify all the data across those sets that describe one unique individual. While the development of this system is a work-in-progress, the agency is hopeful that the development of this master index will improve data tracking capability and make these data sets more accessible to other agencies and organizations.

The ADH is also interested in developing a tracking system to complement the development of the master index. In order to improve data tracking, one participant suggested the creation of a "unique identifier that's unique across the systems." By providing some common definition or measure for data, these data sets that span across agencies, the data can be translated across the different agencies. Currently, the Department of Information Systems and the ADH transparency panel, are looking at conducting a "statewide longitudinal survey," which the Department of Education has been wanting for some time. This longitudinal study would "track a child all the way through their education and also link it up to other data systems." Long-term data tracking capability will allow the department to compare the risk factors for child maltreatment over time to other sets of data. Access to this type of data could help the development of child maltreatment predictive analytics prior to incidence. In general, representatives from the ADH advocated for a clean-up of their current systems. As one interviewee mentioned, “it doesn’t cost so much money to clean up the old data, but also to properly link it to the individual.” The development of more effective and advanced data storing mechanisms in combination with a general clean-up of existing data are the recommendations for improved data systems offered by the ADH.

With regard to improving data sharing systems at the Department of Human Services, the interviewees failed to provide many suggestions. The previous responses mentioned regarding the agency’s current paper filing system indicate that updated technological systems would improve the agency’s ability to store data. Also, comments relating to the agency’s lack of a consolidated data storage system indicates that the agency would benefit from installation of a new system with capability to compile all the agency’s data into one homogenous code index. Thereby making data user-friendly for all departments and utilization by external agencies and organizations. Furthermore, DHS would also benefit from establishment of a standard protocol for sharing data externally. The creation of a clear protocol would make it easier for external agencies to follow the necessary processes to submit applications to access data and easier for DHS to process these requests.

Current Laws & Policies

One of the largest barriers to data sharing, according to the interviews conducted, are prohibitive federal and state laws. Ninety-percent (90%) of interviewees mentioned that sharing data with outside agencies, organizations, or researchers is limited due to state and federal laws, though only fifty-percent (50%) of interviewees specified the particular law they were alluding to. The lack of specification could possibly be due to absences of interviewee’s law specific knowledge, or the assumption that laws alluded to were commonly known such as HIPAA or FOIA. Particular laws cited during interviews include: Arkansas Annotated Code, Arkansas Act 1818, and HIPAA. Legal analysis of these laws and others that relate to limitations of data sharing in Arkansas is outlined in a following section of this report. The interviews demonstrated that even when specific laws were not mentioned, employees of the two agencies professed awareness of laws that prohibited data sharing.

Five interviewees stated that the agency with which they were associated also had internal policy and procedures that prevented, or severely limited data sharing. Specific areas of limitation mentioned related to data that contained protected health information (PHI), personally identifiable information (PII), and address level data. Due to lack of specificity of interviewee responses in regard to laws and rules pertaining to data sharing, the content and purpose of internal policies and regulations referenced could not be determined. Interviewees expressed that agency data containing the aforementioned limitations could only be accessed through legal authorizations or agreements similar in form and content to memorandums of understanding.

Adverse Childhood Experiences

While ADH and DHS acknowledged the importance of ACEs-related data, neither collected nor shared this data consistently. Throughout the interviews, the relevance of ACEs-related data was inconsistent. One interviewee stated, “a lot of the adverse childhood experiences have to do with things beyond data sharing.” Similar statements demonstrated a lack of understanding regarding the relationship between ACEs and data sharing. Additionally, respondents also seemed confused with how ACEs prevention and mitigation efforts could benefit from data sharing. Due to this lack of understanding, state agencies are not actively sharing or collecting ACEs-related data as effectively or consistently as prevention and mitigation efforts require.

Limitations to the Interviews

During the interview process, certain limitations became apparent related to collection of information associated with data sharing processes and structure within the respective agencies in which interviews were conducted. Several possible reasons exist for why information from the interviews did not reach the depth desired by the Capstone Team. One possible explanation for the limited interview responses may be attributed to an overall lack of data sharing among state agencies. If data sharing is not occurring or happening only on a small scale within these agencies, then there may be little insight for agency personnel to offer on the subject matter. Another potential explanation for the lack of in-depth responses may be related to fear or anticipation of repercussions from state employers. Many of the interviewees appeared resistent or hesitant to share information about the processes and procedures of their agencies. This lack of desire to share in-depth information may be attributed to the risk of losing employment or the possibility for some other negative consequence.

The Capstone Team also considered that the bureaucratic nature of these agencies may have also impacted interviewee responses. For some agencies there may be information that requires administrative authorization for public release or information that is just simply confidential. The interviewees may have also avoided responding directly to the Capstone Team's questions in order to avoid misrepresenting or negatively commenting on the operations and data-sharing capacity of their agencies. Interviewees could have also reasoned that providing only surface level information would be a more secure alternative than admitting that the data sharing capabilities of these agencies, both technological and procedural, are lacking. Additionally, many of the respondents seemed uninformed about the specific policies and protocols for sharing data with external entities. Governmental personnel often become siloed in their job tasks and responsibilities, limiting their exposure and understanding of agency operations outside their immediate job classification. Thus, the interviewees may not have possessed the knowledge and insight needed to offer an informed response to the interview questions. While there is no way to definitively explain the lack of in-depth interview responses, the Capstone Team acknowledges that limitations exist and recognizes the possible benefits of conducting further research.

Legal Analysis

Federal and state privacy acts protect the personal privacy of an individual's information provided to the government, and such acts are created to limit the public's access to personal data maintained by government entities. Analysis of regulations relevant to ACE-related information associated with the successful achievement of PAP's mission reveals the following:

Freedom of Information Act (FOIA)

Freedom of Information Act (FOIA) requests are major instruments for obtaining information otherwise deemed private, and are a primary means for assuring government transparency and accountability with respect to the information it collects. While no constitutional right for access to government records exists, the United States Supreme Court has recognized "the paramount public interest in a free flow of information to the people concerning public officials" (*Garrison v. Louisiana*, 1964). Congress and state legislatures have established such a right through public access and public record laws (See, e.g., 5 U.S.C.A. § 552; Ark. Code Ann. §§ 25-19-101 *et seq*.). Clearly, a balance must be struck between what information is subject to disclosure under FOIA and what falls under an exemption concerning privacy of an individual's personal information. Congress has long recognized a need to strike a balance between the public's right to know and the government's legitimate interest in keeping certain information confidential through enactment of these public record laws. These procedures were created to open the administrative processes to the scrutiny of the press and the general public, which echoes a general philosophy of full disclosure unless clearly defined, statutory language excepts such disclosure, not privacy, as the primary objective of the FOIA.

Every state has enacted its own freedom of information law, which is modeled after and reflects the principles of the federal FOIA. Under the federal FOIA, 5 U.S.C.A. §§ 552, 552a, individuals are permitted to request documents and records not generally prepared for distribution and dissemination to the public. Similarly, state FOIA statutes are an essential device for disclosure of public records. The Arkansas FOIA has been a means for its citizens to access public records. The following policy statement can be found in the Act, which states:

> It is vital in a democratic society that public business be performed in an open and public manner so that the electors shall be advised of the performance of public officials and of the decisions that are reached in public activity and in making public policy. Toward this end, this chapter is adopted, making it possible for them or their representatives to learn and to report fully the activities of their public officials. (Ark. Code Ann. § 25-19-102)

To effectuate the policy underlying the Arkansas FOIA, the courts liberally interpret it "to accomplish its broad and laudable purpose that public business be performed in an open and public manner," and broadly construe FOIA in favor of disclosure (*Fox v. Perroni*, 2004). The Arkansas FOIA establishes a general policy for all public records to be open to inspection unless they are specifically exempt (Ark. Code Ann. § 25-19-101 *et seq*.; *Hyman v. Sadler for Ark. State Police,* 2018).

The Act opens all "public records" for public inspection and copying. The Act provides that "[e]xcept as otherwise specifically provided by this section or by laws specifically enacted to provide otherwise, all public records shall be open to inspection and copying by any citizen of the State of Arkansas" (Ark. Code Ann. § 25–19–105(a)(1)(A)). Section 25–19–105(a)(2)(A) permits Arkansas' citizens authority to request to "inspect, copy, or receive copies of public records" from a covered entity's custodian of records (Ark. Code Ann.). Section 25-19-105(d)(2)(A) requires that the custodian within a covered entity "furnish copies of public records upon receipt of a proper request and payment of a statutorily prescribed fee" (Ark. Code Ann.). For access to public records through FOIA, those records "must (1) be possessed by an entity covered by the Act, (2) fall within the Act's definition of a public record, and (3) not be exempt by the Act or other statutes" (Nabholz Constr. Corp. v. Contractors for Pub. Prot. Ass'n, 2007).

Under FOIA, a "covered entity" includes most government entities and some private entities where that private entity receives public funding in combination with an intertwining of a government entity. A public entity can be the custodian of public records even if it does not have physical possession of them, if it has "administrative control" of the records (*Fox v.*

Perroni, 2004). Records of a "public official or employee" and a "governmental agency" are covered by the FOIA (Ark. Code. Ann. § 25-19-103(5)(A)). The Arkansas FOIA requires each state agency to prepare and make available certain information to the public, including records maintained by the agency (Ark. Code Ann. § 25-19-105). Therefore, the Department of the Arkansas State Police (ASP), the Arkansas DHS, and the ADH are entities covered by the Act, in which PAP could seek data related to adverse childhood experiences.

Under FOIA, "public records" are subject to disclosure upon appropriate request. A covered entity must either be required to keep or has otherwise kept data for it to constitute being a "public record," which is independent of who keeps the record or the location of where the record is stored (*Fox v. Perroni*, 2004). Public records are:

> writings, … , electronic or computer-based information, or data compilations in any medium required by law to be kept or otherwise kept and that constitute a record of the performance or lack of performance of official functions that are or should be carried out by a public official or employee, a governmental agency, or any other agency wholly or partially supported by public funds or expending public funds. All records maintained in public offices or by public employees within the scope of their employment shall be presumed to be public records. (Ark. Code Ann. § 25-19-103(5)(A))

The presumption is that it is a public record if it is (1) maintained in public offices or by public employees (2) within the scope of their employment, which can be rebutted if the record does not reflect the "performance or lack of performance of official functions" (Ark. A.G. Op. 2005-095).

State child protective services agencies, including the DHS, are required to maintain records of the reports of suspected child abuse and neglect that they receive. Arkansas maintains a centralized database for the statewide collection and maintenance of child abuse and neglect investigation records referred to as the Child Maltreatment Central Registry. The Child Maltreatment Central Registry contains records of cases on all true investigative determinations of child maltreatment; however, it does not include records of all cases in which allegations are determined to be unsubstantiated (Ark. Code Ann. §§ 12-18-902, -906). Records within the Child Maltreatment Central Registry maintained by DHS constitute public records under FOIA, and are subject to disclosure absent exemptions.

Information on unsubstantiated reports are included in and retained indefinitely in the automated data system or child welfare information system – Children's Reporting and Information System (CHRIS). CHRIS was developed to comply with federal criteria for a statewide automated child welfare system. In addition to utilizing CHRIS to meet its obligations to maintain all reports of child abuse and neglect, DHS also uses CHRIS to manage its cases, staff, providers, and the records. The information in CHRIS is crucial to DHS's ability to achieve its stated purpose of protecting children. Electronic records and data maintained in CHRIS, the electronic case management system maintained by the DHS, makes CHRIS a public record under FOIA. As such, these records are accessible by the public unless otherwise exempt from disclosure.

By statute, the ADH has authority to create a state health data clearinghouse through the "State Health Data Clearinghouse Act," codified at Arkansas Code Annotated §§ 20-7-301 *et seq*. ADH must prescribe rules, including "the manner in which data are collected, maintained, compiled, and disseminated" from state agencies and other sources that promotes confidentiality of data reported to the ADH (Ark. Code Ann. §§ 20-7-303(a) and 305(a)). All state agencies responsible for the collection, maintenance and distribution of health data, including the Arkansas Medicaid Program, must provide the ADH any data necessary for its operations (Ark. Code Ann. § 20-7-303(c)(1)). Statutory provisions prevent unnecessary duplication of efforts in that health data reported to another "governmental agency in the same manner, form, and content or in a manner, form, and content acceptable to the department" is not required to be resubmitted by that organization (Ark. Code Ann. § 20-7-303(c)(2)). Records maintained by the ADH are public records subject to disclosure absent statutory exemptions. The data or records requested by PAP are public records within the FOIA. The issue is whether data requested is subject to, or exempt from, disclosure.

FOIA provides for full disclosures absent either constitutional or statutory exemptions. Statutory exemptions include those listed within the FOIA, or those referenced in another state or federal statute. The FOIA contains exemptions to access or disclosure of public records within its statutory provisions (Ark. Code Ann. § 25-19-105(b)). Those exemptions include, but are not limited to medical or vital records, specifically records containing information relating to the treatment or diagnosis of a medical condition; adoption records; records relating to DHS risk or security assessments, or regarding compliance with the Federal Health Insurance Portability and Accountability Act (HIPAA) (Ark. Code Ann. § 25-19-105(b)).

While FOIA requires each state agency to prepare and make available certain information to the public, including records the agency maintains, data maintained by the ADH which identifies, or could be used to identify, any individual is exempt from disclosure under FOIA (Ark. Code Ann. § 20-7-304 and 305(b)). Similarly, child maltreatment records maintained by the DHS are exempt from disclosure under FOIA (Ark. Code Ann. § 12-18-104).

Health Insurance Portability and Accountability Act (HIPAA)

The United States Department of Health and Human Services (HHS) issued the Standards for Privacy of Individually Identifiable Health Information ("Privacy Rule") establishing a set of national standards for the protection of certain health information (HIPAA, Pub. L. 104-191). The Privacy Rule safeguards the use and disclosure of "protected health information" (PHI) by limiting use and disclosure of PHI by covered entities (45 C.F.R. § 164.502(a)). The Privacy Rule balances an individual's interest in keeping his or her health information confidential with other social benefits, including health care research. The general rule is that a covered entity may not use or disclose protected health information except as permitted or required by the rules (45 C.F.R. § 164.502(a)).

The Privacy Rule applies to health plans, health care clearinghouses, including public health authorities (i.e. ADH), and health care providers, as covered entities, which transmit protected health information (45 C.F.R. § 160.102). The Privacy Rule extends to hybrid entities, such as DHS, whose activities involve functions that are covered by the Privacy Rule to the extent that it performs covered functions and contains designated health care components (45 C.F.R. § 160.105; Department of Health, 2019, #4002, pp.1-2). The Privacy Rule protects all "individually identifiable health information," including demographic data, collected by a health care clearinghouse that "relates to the [individual's] past, present, or future physical or mental health or condition. . .that identifies the individual; or with respect to which there is a reasonable basis to believe the information can be used to identify the individual" (45 C.F.R. § 160.103).

PHI includes individually identifiable health information held or disseminated by a covered entity regardless of form (45 C.F.R. § 160.103).

Generally, state laws that are "contrary," as defined by part 160.202, to the Privacy Rule are preempted by the federal requirements, which means that the federal requirements would apply (45 C.F.R. § 160.203). The Privacy Rule provides exceptions to the general rule for contrary state laws that (1) relate to the privacy of individually identifiable health information and provide greater privacy protections or privacy rights, or (2) provide for the reporting of disease or injury, child abuse, birth, or death, or for public health surveillance, investigation, or intervention (45 C.F.R. §§ 160.203 and 160.204). The Arkansas Health Insurance Portability and Accountability Act of 1997 codified at Ark. Code Ann. §§ 23-86-301 *et seq.* does not include language regulating disclosure of PHI. The Privacy Rule of the federal HIPAA governs disclosure of ACE related data containing PHI sought from ADH and DHS by PAP. The ADH and DHS, as a covered entity, are generally subject to the privacy regulations found within HIPAA.

The Privacy Rule limits the circumstances in which covered entities may use or disclose PHI. A covered entity may not use or disclose PHI, except (1) as the Privacy Rule permits or requires; or (2) pursuant to written authorization by the individual, or his or her representative, who is the subject of the information (45 C.F.R. § 164.502(a)). A covered entity must disclose PHI only to an individual that has requested access when disclosure is required and in compliance with HHS (45 C.F.R. § 164.502(a)(2)). A covered entity must make reasonable efforts to restrict the disclosure of PHI to that minimally necessary to accomplish the intended purpose of such (45 C.F.R. § 164.502(b)(1)).

The Privacy Rule does not prohibit the use or disclosure of de-identified health information, which is technically not PHI by definition (45 C.F.R. §§ 164.502(d)(2), 164.514(a) and (b)). The health information must neither identify nor provide a reasonable basis to identify an individual to be classified as de-identified (45 C.F.R. § 164.514(a)). Information can be de-identified in one of two ways, either by (1) a formal determination by a qualified statistician that the risk of identification through the information, alone or in combination with other accessible information, is very small; or (2) the removal of enumerated identifiers of the individual and of the individual's relatives, employers, and household members in such a manner that the covered entity has no actual knowledge that the remaining information could be used to identify the individual (45 C.F.R. § 164.514(b)). Part 164.514(b)(2)(i)(B) requires the removal of geographical identifiers below the state level, unless a geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people, whereby the first three digits of the zip code may remain. DHS's policy is to de-identify PHI in response to a request under FOIA (Department of Human Services, 2010, #4007.1.2, p. 1). De-identified information would not be beneficial for PAP, which seeks location data for ACEs-related risk factors, protective factors, and outcomes in Arkansas.

Similarly, a covered entity also may use or disclose, without an individuals' authorization, a limited data set of PHI for research purposes if the individual's, his or her relatives, employers, and household members direct identifiers have been removed (45 C.F.R. §§ 164.514(e)(1)-(3)). A limited data set may be used and disclosed for research provided the recipient enters into a data use agreement promising specified safeguards for the PHI within the limited data set (45 C.F.R. § 164.514(e)(1)). Limited data sets would be more beneficial for PAP than de-identified PHI, however, even this data requires the removal of geographical identifiers below the town or zip code level (45 C.F.R. § 164.514(e)(2)(ii)).

The Privacy Rule recognizes certain permissible purposes and important uses of PHI outside the purview of the health care context (*See* 45 C.F.R. § 164.512). The Privacy Rule establishes specific conditions or limitations for each public interest purpose to balance the individual privacy interest and the public interest needs for PHI. A covered entity may use and disclose PHI without an individual's authorization (45 C.F.R. § 164.502(a)(1); *See* 45 C.F.R. § 164.512). Covered entities may disclose PHI to public health authorities authorized by law to collect or receive such information for preventing or controlling disease, injury, or disability and to public health or other government authorities authorized to receive reports of child abuse and neglect (45 C.F.R. §§ 164.512(a)-(c)).

The Privacy Rule permits a covered entity to use and disclose, without authorization, PHI for research purposes provided the covered entity obtains either (1) an Institutional Review Board or Privacy Board approval of a waiver to the required authorization to disclose PHI pursuant to part 164.508; (2) researcher's representation that the use or disclosure of the PHI is solely for review to prepare a research protocol, that the researcher will not remove any PHI from the covered entity during review, and that PHI sought is necessary; or (3) researcher's representation that research is solely on the PHI of decedents, that the PHI sought is necessary, and documentation of the death of the individuals whose PHI is sought upon request by a covered entity (45 C.F.R. §§ 164.512(i)(1)(i)-(iii)).

The ADH's policy for the release of health data, including PHI, for research projects follows federal HIPAA guidelines and statutory requirements (Ark. Code Ann. § 20-7-305(c)(2); 45 C.F.R. § 164.512(i) and 45 CFR § 164.514(e); Arkansas Department of Health, 2009, pp. 13-15). The data that the ADH shares must be handled in compliance with "all state and federal privacy requirements, including, without limitation, the federal Health Insurance Portability and Accountability Act of 1996 privacy rule, specifically 45 C.F.R. § 164.512(i)" (Ark. Code Ann. § 20-7-305(c)(2)). Any authorized medical provider may provide data relating to the condition and treatment of any person to ADH "for use in the course of studies for the purpose of reducing morbidity or mortality," and all data of the ADH used for such purposes "shall be strictly confidential and shall be used only for medical research" (Ark. Code Ann. §§ 20-9-304(a) and (b)).

Child Abuse Prevention and Treatment Act (CAPTA)

States must preserve the confidentiality of all child maltreatment records to protect the privacy rights of the child, and his or her parent or guardian, except in certain limited circumstances to receive federal funding under the Child Abuse Prevention and Treatment Act (CAPTA) (42 U.S.C.A. §§ 5106a(b)(2)(B)(viii)-(x)). Arkansas has provisions that protect child maltreatment records from public scrutiny and public view. The Arkansas Child Maltreatment Act, codified at Arkansas Code Annotated §§ 12-18-101 *et seq*., identifies who is considered a child and defines child maltreatment as abandonment, abuse, neglect, sexual abuse or sexual exploitation. Section 12-18-104 further statutorily prescribed confidentiality of records, such as when data related to child maltreatment investigations can be disclosed, by and to whom, and for what purposes (Ark. Code Ann.). Specifically, section 12-18-104 provides that:

> Any data, records, reports, or documents that are created, collected, or compiled by or on behalf of the Department of Human Services, the Department of Arkansas State Police, or other entity authorized under this chapter to perform investigations or provide services to children, individuals, or families shall not be subject to disclosure under the Freedom of Information Act of 1967, §§ 25-19-101 *et seq*. (Ark. Code Ann.§12-18-104)

Under most circumstances, information from child maltreatment records may not be disclosed to the public. Conforming with section 106(b)(2)(B)(viii)(II) and (VI) of CAPTA, states are authorized to release child maltreatment records to researchers either through a direct contract with the child protective service agency in that state as its agent, or through an authorizing statute permitting release of child maltreatment records as a legitimate state purpose in furtherance of a policy-making or program development for the state (42 U.S.C.A. § 5106(b)(2)(B)(viii)).

Arkansas has statutorily authorized release of such information to researchers (Ark. Code Ann. § 12-18-909). While true reports of child maltreatment are confidential, these records may be otherwise disclosed to certain persons or entities, including "a person, agency, or organization engaged in a bona fide research or evaluation project" (Ark. Code Ann. § 12-18-909). As such researchers are not only entitled to access to true, confidential reports, but also any other information obtained and in the possession of the DHS or ASP related to the true report (Ark. Code Ann. § 12-18-909). Such public records include any PHI otherwise protected by HIPAA, the administrative hearing decision, reports written, and photograph or radiological procedures taken concerning a true report (Ark. Code Ann. § 12-18-909). Notwithstanding PAP's access through statutorily prescribed means for research purposes, PAP has a direct contract with DCFS.

Section 106(b)(2)(B)(x) of CAPTA requires states to allow for public disclosure of the findings or information of the case of child abuse or neglect that results in a child fatality or near fatality (42 U.S.C.A. § 5106a(b)(2)(B)(x)). In compliance with CAPTA, DHS must provide public notice, including certain individual identifiers, on the department's website when a child fatality or near fatality is reported to the Arkansas Child Abuse Hotline under the Child Maltreatment Act, §§ 12-18-101 *et seq*. (Ark. Code Ann. § 9-28-120(a)). The general public may request and DHS must provide certain information involving reports to the hotline involving children in the custody of the department, and reports of child deaths occurring in out-of-home placements resulting from removals. Ark. Code Ann. §§ 9-28-120(b)-(c). PAP, along with other entities, could access information concerning such events through these means.

Specified State Laws Permitting Interagency Collaboration

While a subtle balancing act between confidentiality and data analysis exists, agencies can navigate cross-agency data sharing given such restrictions. Arkansas has already provided mechanisms for cross-agency data sharing between the DHS and other state agencies, including the ADH, in statutorily specified contexts.

DHS has the discretionary power to enter into cooperative agreements with other state agencies "to provide direct online access to data information terminals, computers, or other electronic information systems" and power to obtain information from other state agencies in spite of laws that otherwise may deem information confidential to locate individuals (Ark. Code Ann. §§ 9-28-119(b)(2)-(3)). Any information obtained through any cooperative agreement for placement of children in DHS custody becomes the confidential record of the DHS, however, such information may be disclosed pursuant to other provisions of law necessitating cooperative agreements (e.g. Multidisciplinary (MDT) Interagency Agreement, Ark. Code Ann § 12-18-106(a)) or to an entity engaged in a bona fide research project deemed of value by DHS for the development of policies or programs within DCFS (Ark. Code Ann. §§ 9-28-119(e); 9-28-407(h)(1)(C), (W)(i)).

Arkansas has identified the unexpected death of infants and children as an important public health concern resulting in cross-agency data sharing agreements of ACE-related information between ADH and DHS, along with other state agencies, review panels (e.g. Arkansas Child Death Review Panel), and multidisciplinary committees (e.g. Child Death and Near Fatality Multidisciplinary Review Committee), to assist in investigation of causes, and the methods of prevention of infant and child deaths (Ark. Code Ann. §§ 9-25-101 *et seq*.; Ark. Code Ann. §§ 20-27-1701 *et seq*.).

The Child Death and Near Fatality Multidisciplinary Review Committee reviews all deaths of children who had contact with the DCFS within the two years preceding that death, which requires a record comparison capacity between the ADH Division of Vital Records with information maintained in DHS's CHRIS (Ark. Code Ann. § 9-25-105(c)). The Child Death and Near Fatality Multidisciplinary Review Committee produces an annual report that is presented to the appropriate House Committee, and publishes the report on the DHS child deaths and near fatalities website (Ark. Code Ann. § 9-25-105(m)).

Similarly, the Arkansas Child Death Review Panel (Review Panel) provides a multidisciplinary and multi-agency review of sudden and unexpected infant and child deaths with the aim of facilitating a better understanding of its causes, the methods of prevention, and identifying gaps in services (Ark. Code Ann. §§ 20-27-1701(a)(2)-(3)). The Review Panel has access to child death investigation reports from various state, county and local agencies, including law enforcement, coroners, fire departments, medical providers, or any other entity with information related to the death investigation (Ark. Code Ann. § 20-27-1705(a)(1)). Additionally, the review panel may access medical and vital records, including PHI, in the custody of physicians, hospitals, clinics, other healthcare providers, and the ADH concerning the unexpected death of the child under investigation, which is compliant with HIPAA's permissible disclosures (Ark. Code Ann. §§ 20-27-1705(b)(1) and 20-27-1706(e); 45 C.F.R. §§ 164.512(a)-(c)). Although the Review Panel has been granted statutory access to these reports, the law does not require that the reports contain standard definitions or coding. Data provided to the Review Panel is confidential, and can only be statutorily disclosed to law enforcement or prosecutors (Ark. Code Ann. §§ 20-27-1706(a)(1)-(3)). However, the Review Panel may publish de-identified statistical compilations and reports reflecting factual information pertaining to the reviewed unexpected deaths of children (Ark. Code Ann. §§ 20-27-1707(a)-(b)).

Arkansas Child Welfare Public Accountability Act, codified Arkansas Code Annotated §§ 9-32-201 *et seq.*, mandates that the Division of Youth Services (DYS), the Division of Aging, Adult, and Behavioral Health Services, and the Division of Children and Family Services (DCFS) issue quarterly and annual reports on the performance of the child welfare system, which must include "(1) Client outcome information; (2) Case status information; (3) Compliance information; (4) Management indicators; and (5) Other data agreed to by the Senate Interim Committee on Children and Youth and the aforementioned divisions of DHS." As part of it's quarterly report, DCFS must include reports of child deaths and near fatalities reported to the hotline, including those deaths occurring in out-of-home placements, reports involving a child in the custody of DCFS made to the hotline, the number of children with multiple foster care placements, and the number of foster care children who have runaway (Ark. Code Ann. § 9-32-203). The annual report includes the same information as the quarterly report except that it does not require inclusion of the total runaway foster children, or total number of foster children having multiple placements (Ark. Code Ann. § 9-32-204). These reports are made accessible on the DHS's website.

The DHS' Division of Youth Services (DYS), a DYS community-based provider, or a juvenile detention facility's confidential records, including PHI, can be disclosed, as permitted by law, to a MDT coordinating a child maltreatment investigation pertaining to a juvenile, or to an entity engaged in a bona fide research project deemed valuable by DYS for the development of policies to advance juvenile justice (Ark. Code Ann. §§ 9-28-217(a)(16) and (18)). This further suggests that Arkansas promotes cross-agency data sharing and facilitates research advancing policy within the state.

Other Considerations

States must safeguard against the unauthorized use and/or disclosure of information regarding children served by title IV-E foster care, and records maintained under both title IV-E and IV-B (42 U.S.C.A. §§ 671(a)(8)). Records maintained under both title IV-E and IV-B are subject to the HHS's confidentiality provisions, which safeguards against unauthorized disclosure of information concerning individuals applying for or receiving assistance under either title (45 C.F.R. § 205.50). Information collected and maintained under both title IV-E and IV-B can be released to certain persons or agencies that require it for specified purposes (45 C.F.R. § 205.50). Authorized recipients of otherwise confidential child maltreatment information are bound by the same confidentiality restrictions as the child protective agency from which it received the information (42 U.S.C.A. § 5106(a)). Therefore, recipients of such information must use the information only for purposes related to the prevention and treatment of child abuse and neglect, and any further disclosure is permitted only in accordance with the CAPTA standards (42 U.S.C.A. § 5106(a)).

In instances where child maltreatment information is subject to both disclosure pursuant to CAPTA and the confidentiality requirements under title IV-E and 45 C.F.R. § 205.50, confidentiality requirements may yield to disclosure based on the date of legislative enactments. To the extent that the CAPTA provisions require disclosure (e.g. section 106(b)(2)(B)(ix) to other governmental entities and section 106(b)(2)(B)(x) in the case of a child fatality or near fatality), the CAPTA disclosure provision would prevail in the event of a conflict since the CAPTA confidentiality provisions were most recently enacted. However, where the CAPTA provision is permissive (e.g. sections 106(b)(2)(B)(viii)(I), (V) & (VI)), states are permitted to disclose such information without violating CAPTA, but it does not make such disclosure permissible in other programs if it is not otherwise allowed under the other program's governing statute or regulations.

Recommendations

The Capstone Team recommends that PAP partner with the University of Arkansas Winthrop Rockefeller Institute to facilitate collaborative discussions to effect transformational change in ACE-related data sharing practices in the State of Arkansas. PAP should specifically advocate for the development of a mandated central record-keeping repository that is managed by the State of Arkansas and allows access to location-based ACE-related data while protecting person specific information. This type of system with the capability to link datasets will eliminate barriers that inhibit PAP's ability to inform research, and identify geospatial and environmental risks associated with other community concerns. The role of the Winthrop Rockefeller Institute will be to facilitate collaboration between PAP, state agencies, and other stakeholder organizations.

Collaborative transformational change requires strategic planning, partnerships, and expertise in facilitating discussions across and among entities with divisional bureaucratic organizational structures. Winthrop Rockefeller believed in combining diversity of opinion, engaging in respectful dialogue, and practicing collaborative problem solving to create transformational change. The University of Arkansas Winthrop Rockefeller Institute continues that approach by engaging resources and employing the "Rockefeller Ethic" in the search for solutions to the most monumental of challenges (University of Arkansas Winthrop Rockefeller Institute, n.d.). Internal and external data sharing barriers inhibiting PAP's ability to adequately inform research are spread across systems managed by multiple public and private organizations making strategic alignment of stakeholders and resources a formidable task impossible for PAP to accomplish alone.

Bolman and Deal (2017) explain that the structure of an organization is a blueprint of expectation and exchanges that guide internal and external stakeholders. Community organizations that PAP desires to align in targeting child maltreatment and abuse are a combination of public and private divisional bureaucratic entities that illustrate principles of classical management theory. Although shared synergy and stability exists in the organizations/agencies, each serves a specific and distinct market. Literature review reveals that "organizations are thought to imitate decisions that are viewed as highly legitimate and deemed acceptable by others in the same organizational community" (Gerlach et al., 2012, p. 219). Despite being divisional and having administrative policies and procedures specific to each organization/agency, all entities fall under the purview of state and federal legislative authority. Data sharing barriers inhibiting PAP's ability to adequately inform research are common big data issues prevalent in divisional bureaucratic organizational structures. The negative impact of those barriers is exacerbated by inadequate legislation and lack of data sharing agreements that prevent strategic alignment of resources. Goal achievement is the determining factor of success for any organization including PAP. A mandated central record-keeping repository that is managed by the State of Arkansas and allows access to location-based ACE-related data while protecting person specific information is needed to align resources and stakeholders in preventing child abuse and neglect. This type of system with capability to link data sets will eliminate barriers that inhibit PAP's ability to inform research and enhance achievement of its mission goals. In order to successfully implement this system, PAP should advocate for third party collaboration, interagency collaboration, and legislative and administrative amendments through a partnership with the University of Arkansas Winthrop Rockefeller Institute.

Third Party Collaboration

Goerge (2018) discusses recommendations for data sharing based on state agencies as the "primary decision makers around access and researchers as the primary user of state administrative data," and his recommendations are aimed at "moving toward optimizing the benefits of increased access for all stakeholders" (p. 124). This perspective is especially important to consider since "governors and state agencies other than that of the state agency holding the data also have a stake in that they may need administrative data to evaluate and improve other state programs" (Goerge, 2018, p. 124). In his experience, sharing data with a third party, such as a research institution, is oftentimes easier to navigate than sharing among other state agencies. Additionally, trust must be built in these relationships. In fact, Goerge (2018) states that agency leadership and staff members "must trust researchers (and other external entities) to protect data from breaches, to not disclose data or preliminary findings to other organizations (researchers, media, advocacy groups) without explicit permission, and to pursue research that is unknown to the agency" (p. 127). Goerge's (2018) recommendations are as follows:

> Encourage ongoing collaborations among state and local agencies and researchers to jointly address the barriers in using administrative data across programs and agencies; build collections of data in secure facilities with the proper controls to ensure that only those individuals with the proper permission have access to data in a quick, manageable fashion; develop and hire agency leadership that understands the need for evaluation and research; train state and local government staff in the use of administrative data for program management and evaluation; train researchers not only in the techniques necessary to process and analyze administrative data, but also in state information system contents and database technologies that will allow them to facilitate the physical transfer of data from state agencies. (p. 136)

Collaboration with third party organizations and trust will be essential to successful implementation of a mandated data sharing model in Arkansas. The University of Arkansas Winthrop Rockefeller Institute will assist in building trust through respectful dialogue and collaborative problem solving.

Interagency Collaboration

Bolman and Deal (2017) suggest that power and conflict are the center of decision making because organizational coalitions are composed of individuals and groups with enduring differences and scarce resources (p. 199). They explain that power is a key resource in organizational life and state that it is "the capacity to make things happen" (Bolman & Deal, 2017, p. 186). Although goal achievement is the determining factor of success for any organization, the productivity of an organization is controlled by its workforce. As such, it is also essential that staff throughout all stakeholder organizations be knowledgeable and engage in data sharing collaborations. Institutional isomorphism, the constraints of resembling other institutions for legitimacy and political power, further impedes organizational changes because it requires change in the homogeneous nature of the organization and "decisions formulated along an isomorphic pathway do not always offer optimal solutions" (Gerlach et al., 2012, p. 219). This makes changing internal policies, cultures, and behaviors very challenging. Organizations will have to work on changing culture and norms through collaboration to address current data sharing barriers.

In addition to dismantling data sharing barriers, collaborating with other agencies will generate a common system beneficial for all organizations. The benefits of internal and external collaboration across stakeholder organizations will increase agency motivations by cultivating participation incentives, such as streamlined data collection, a more robust analysis of data, and an enhanced understanding of the whole picture. Gerlach et al. (2012) finds that collaborative approaches that help agencies achieve legitimacy, are beneficial in reducing operating costs, assist in institutionalizing the use of data-sharing processes, and help foster community-based initiatives. Dawes et al. (2009) point out that interagency collaboration is a valuable tool for innovation, both professionally and organizationally. Data sharing can "help agencies better define and solve joint problems; coordinate programs, policies, and services; and prompt improvements in both IT infrastructure and information content" (Dawes et al., 2009, p. 392). Expertise of the Winthrop Rockefeller Institute in facilitating discussions across bureaucratic organizational structures will assist in reaching collaborative transformational change.

Legislative and Administrative Amendment

Legislative amendment and changing administrative policy and practices associated with the sharing of ACE-related information across agencies and disciplines is imperative to the prevention of child maltreatment and abuse in the State of Arkansas. Although PAP falls within legislative exemptions of research and should be granted access to ACE-related data through direct contract with DCFS, the information collected by agencies in Arkansas is problematic due to the manner and form in which it exists. Rather than location based, all information is person specific and stems from reports associated with present or past child maltreatment/abuse. In their 2016 report, Within Our Reach: A National Strategy to Eliminate Child Abuse and Neglect Fatalities, the Commission to Eliminate Child Abuse and Neglect Fatalities recommends national and local system abilities that include real-time data sharing, increasing the interoperability and system capacity of child welfare data across federal systems, and creating legislation for accessibility of that data by state agencies. Teixeira and Boyas (2017) proposes additional recommendations for areas in which the federal government could aid in lessening the challenges faced by entities engaging in cross-agency data sharing. Those recommendations include developing uniform templates for legal documents such as MOUs, specifying common data definitions, establishing a secure central repository, and supporting agency efforts in data sharing collaborations through funding or other opportunities (Teixeira & Boyas 2017). The Commission's 2016 report also suggests that states and counties implement a cross-notification system for state agencies, law enforcement, and child protection agencies. Inclusion of additional ACE-related features and community challenges within a system capable of linking data sets would enhance PAP's ability to bridge medical and spatial epidemiological aspects of their work. Legislative and administrative amendments implementing the above recommendations as they relate to establishing a data sharing system in Arkansas will require support of policymakers and executive leaders.

Organizational cultures, policies, and behaviors are established by time, tradition, and politics, and can be extremely hard to change. This is especially true in Arkansas; a state grounded in long-standing traditions and values, whose policymakers and policies reflect those. Therefore, the organizational culture and identity of public health institutions, state agencies, and other organizations largely reflect that of the policymakers because their decisions shape what is considered legitimate and acceptable. Data sharing in public health is most successful when a perceived need is directly addressed, and it can be effectively articulated to policymakers through the use of personal narratives. It is vital that policymakers understand the importance of data sharing because lack of legislative support and funding are more detrimental than laws restricting data sharing (Dawes et al., 2009). The Winthrop Rockefeller Institute's expertise in employing the "Rockefeller Ethic" will facilitate thorough examination of data sharing issues in Arkansas and provide a neutral space for all voices to be heard.

Conclusion

Due to the long-term negative impact that adverse childhood experiences (ACEs) have on individuals and the communities in which they live, it is imperative that public and private strategies and interventions be maximized to prevent ACE-related events and outcomes. Although PAP was founded for the purpose of preventing child abuse and neglect, access barriers to ACE-related data inhibits the ability of PAP to adequately inform research and thereby disrupts achievement of its mission goals. Data sharing barriers inhibiting PAP's ability to adequately inform research are common big data issues prevalent in divisional bureaucratic organizational structures. In Arkansas these barriers are spread across systems managed by multiple public and private organizations making strategic alignment of stakeholders and resources a formidable task impossible for PAP to accomplish alone.

The Capstone Team recommends PAP partner with the University of Arkansas Winthrop Rockefeller Institute to facilitate collaborative discussions among public and private stakeholders that will lead to transformational change in ACE-related data sharing practices in the State of Arkansas. A mandated central record-keeping repository that is managed by the State of Arkansas and allows access to location-based ACE-related data while protecting person specific information is needed to align resources and prevent child abuse and neglect. This type of system with capability to link datasets will eliminate barriers that inhibit PAP's ability to inform research, and identify geospatial and environmental risks associated with other community concerns.

References

ARK. A.G. Op. 2005-095

Arkansas Child Welfare Public Accountability Act, ARK. CODE ANN. §§ 9-32-201 *et seq*. (West 2019)

Arkansas Child Maltreatment Act, ARK. CODE ANN. §§ 12-18-101 *et seq*. (West 2019)

Arkansas Department of Health (2009). *HIPAA privacy/security policy disclosure of protected health information (PHI)*. (TN# 09-29). https://www.healthy.arkansas.gov/images/uploads/pdf/HIPAA_PRIVACY.pdf

Arkansas Health Insurance Portability and Accountability Act of 1997, ARK. CODE ANN. §§ 23-86-301 *et seq.* (West 2019)

ARK. CODE ANN. § 9-25-105(m) (West 2019)

ARK. CODE ANN. § 9-28-120(a) (West 2019)

ARK. CODE ANN. §§ 9-28-120(b)-(c) (West 2019)

ARK. CODE ANN. §§ 9-28-119(b)(2)-(3) (West 2019)

ARK. CODE ANN. §§ 9-28-119(b)(2)-(3) (West 2019)

ARK. CODE ANN. §§ 9-28-217(a)(16) and (18) (West 2019)

ARK. CODE ANN. §§ 9-28-407(h)(1)(C) and (W)(i) (West 2019)

ARK. CODE ANN. § 9-32-203 (West 2019)

ARK. CODE ANN. § 9-32-204 (West 2019)

ARK. CODE ANN. § 12-18-104 (West 2019)

ARK. CODE ANN. § 12-18-106(a) (West 2019)

ARK. CODE ANN. § 12-18-902 (West 2019)

ARK. CODE ANN. § 12-18-906 (West 2019)

ARK. CODE ANN. § 12-18-909 (West 2019)

ARK. CODE ANN. §§ 12-18-1101, -1108 (West 2019)

ARK. CODE ANN. § 20-7-303(a) (West 2019)

ARK. CODE ANN. § 20-7-303(c)(1) (West 2019)

ARK. CODE ANN. § 20-7-303(c)(2) (West 2019)

ARK. CODE ANN. § 20-7-304 (West 2019)

ARK. CODE ANN. § 20-7-305(a) (West 2019)

ARK. CODE ANN. § 2-7-305(b) (West 2019)

ARK. CODE ANN. § 20-7-305(c)(2) (West 2019)

ARK. CODE ANN. § 20-9-304(a) (West 2019)

ARK. CODE ANN. § 20-9-304(b) (West 2019)

ARK. CODE ANN. §§ 20-27-1701 *et seq*. (West 2019)

ARK. CODE ANN. §§ 20-27-1701(a)(2)-(3)) (West 2019)

ARK. CODE ANN. § 20-27-1705(a)(1) (West 2019)

ARK. CODE ANN. § 20-27-1705(b)(1) (West 2019)

ARK. CODE ANN. § 20-27-1706(e) (West 2019)

ARK. CODE ANN. §§ 20-27-1706(a)(1)-(3) (West 2019)

ARK. CODE ANN. §§ 20-27-1707(a)-(b) (West 2019)

Barth, R. P., Putnam-Hornstein, E., Shaw, T. V., & Dickinson, N. S. (2015). Safe children: Reducing severe and fatal maltreatment (Grand Challenges for Social Work Initiative Working Paper No. 17). Cleveland, OH: American Academy of Social Work and Social Welfare.

Child Abuse Prevention and Treatment Act, 42 U.S.C.A. §§ 5106a (Westlaw through Current through P.L. 116-140)

Commission to Eliminate Child Abuse and Neglect Fatalities. (2016). *Within our reach: A national strategy to eliminate child abuse and neglect fatalities.* Washington, DC: Government Printing Office.

Covington, T. (2019, November 22). *We won't improve maltreatment prevention without better data sharing*. The Chronicle of Social Change. https://chronicleofsocialchange.org/fostercarecapacity-org/we-wont-improve-maltreatment-prevention-without-better-data-sharing/39181

Bolman L. & Deal, T. (2017). Reframing Organizations: Artistry, Choice, and Leadership (6th Edition ed.). San Francisco: Jossy-Bass.

Department of Human Services (2019). *DHS privacy sanctions.* (# 4002). https://humanservices.arkansas.gov/resources/policy

Department of Human Services (2010). *De-Identified protected health information/Freedom of Information Act.* (# 4007). https://humanservices.arkansas.gov/images/uploads/policies/DHS%20Policy%204007.pdf

El Emam, K., Rodgers, S., & Malin, B. (2015). Anonymising and sharing individual patient data. *BMJ (Clinical research ed.)*, *350*, h1139. https://doi.org/10.1136/bmj.h1139

Fox v. Perroni, 358 Ark. 251, 188 S.W.3d 881 (2004)

Freedom of Information Act, 5 U.S.C.A. § 552 (Westlaw through P.L. 116-140)

Freedom of Information Act of 1967, ARK. CODE ANN. §§ 25-19-101 *et seq*. (West 2019)

Garrison v. Louisiana, 379 U.S. 64 (1964)

Gasner, M. R., Fuld, J., Drobnik, A., & Varma, J. K. (2014). Legal and policy barriers to sharing data between public health programs in New York City: A case study. *American Journal of Public Health*, *104*(6), 993-997. https://doi.org/10.2105/ajph.2013.301775

Gerlach, J. D., Williams, L. K., & Forcina, C. E. (2013). Data selection for making biodiversity management decisions: best available science and institutionalized agency norms. *Administration & Society, 45*(2), 213-241.

Gil-Garcia, J. R., Chengalur-Smith, I., & Duchessi, P. (2007). Collaborative e-Government: impediments and benefits of information-sharing projects in the public sector. *European Journal of Information Systems*, *16*(2), 121–133. https://doi.org/10.1057/palgrave.ejis.3000.673

Goerge, R. (2018). Barriers to accessing state data and approaches to addressing them. *The Annals of the American Academy, 675*(1), 122-137.

Graham, F. S., Gooden, S. T., & Martin, K. J. (2016). Navigating the transparency-privacy paradox in public sector data sharing. *American Review of Public Administration, 46*(5), 569-591.

Green, B. L., Aoub, C., Bartlett, J. D., Furrer, C., Von Ende, A., Chazan-Cohen, R., Klevans, J., & Nygren, N. (2015). It's not as simple as it sounds: Problems and solutions in accessing and using administrative child welfare data for evaluating the impact of early childhood interventions. *Children and Youth Services Review, 47*, 40-49.

Hyman v. Sadler for Ark. State Police, 2018 Ark. Ct. App.82, 539 S.W.3d 642 (2018)

Jonson-Reid, M., & Drake, B. (2008). An indispensable tool for evidence-based policy for maltreated children and their families. *Child Maltreatment, 13*(4), 392-399.

Lips, A., Miriam, B., O'Neill, R., & Eppel, E. A. (2011). Cross-agency collaboration in New Zealand: An empirical study of information sharing practices, enablers and barriers in managing for shared social outcomes. *International Journal of Public Administration, 34*(4), 255-266.

Nabholz Constr. Corp. v. Contractors for Pub. Prot. Ass'n, 371 Ark. 411, 266 S.W.3d 689 (2007)

Nguyen, L. (2014). A public health response to data interoperability to prevent child maltreatment. *American Journal of Public Health*, *104*(11), 2043-2048.

Privacy Act, 5 U.S.C.A. § 552a, (Westlaw through P.L. 116-140).

Social Security Act, 42 U.S.C.A. §§ 671 (Westlaw through P.L. 116-140)

State Health Data Clearinghouse Act, ARK. CODE ANN. §§ 20-7-301 *et seq*. (West 2019)

Teixeria, C., & Boyas, M. (2017). *Predictive analytics in child welfare: An assessment of current efforts, challenges and opportunities.* U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

United States. (2004). *The Health Insurance Portability and Accountability Act (HIPAA)*. Washington, D.C.: U.S. Dept. of Labor, Employee Benefits Security Administration.

van Panhuis, W. G., Paul, P., Emerson, C., Grefenstette, J., Wilder, R., Herbst, A. J., & Burke, D. S. (2014). A systematic review of barriers to data sharing in public health. *BMC Public Health, 14*(1144). https://doi.org/10.1186/1471-2458-14-1144

Vest J. R., & Issel L. M. (2013). Data sharing between local health and state health departments: Developing and describing a typology of data gaps. *Journal of Public Health Management and Practice, 19*(4), 357–365.

University of Arkansas Winthrop Rockefeller Institute. (n.d.). *Winthrop Rockefeller Institute about us*. http://rockefellerinstitute.org/about-us

45 C.F.R. § 160.102 (2013)

45 C.F.R. § 160.103 (2013)

45 C.F.R. § 160.105

45 C.F.R § 160.202 (2013)

45 C.F.R. § 160.203 (2002)

45 C.F.R. § 160.204 (2002)

45 C.F.R. § 164.502(a) (2013)

45 C.F.R. § 164.502(a)(1) (2013)

45 C.F.R. § 164.502(a)(2) (2013)

45 C.F.R. § 164.502(b)(1) (2013)

45 C.F.R. § 164.502(d)(2) (2013)

45 C.F.R. § 164.508 (2013)

45 C.F.R. § 164.512 (2016)

45 C.F.R. §§ 164.512(a)-(c) (2016)

45 C.F.R. § 164.512(i) (2016)

45 C.F.R. §§ 164.512(i)(1)(i)-(iii) (2016)

45 C.F.R. § 164.514(a)-(b) (2013)

45 C.F.R. § 164.514(b)(2)(i)(B) (2013)

45 C.F.R. § 164.514(e) (2013)

45 C.F.R. §§ 164.514(e)(1)-(3) (2013)

45 C.F.R. §§ 164.514(e)(2)(ii) (2013)

45 C.F.R. § 205.50 (1996)

Appendix 1 - Evidence for Data-Sharing Barriers Among Public Agencies

Category	Barrier	Data Excerpt [exact quotes]
Organizational: Barriers due to explicit or implicit differences among participating organizations, i.e. conflicting organizational policies, priorities and cultures.	Organizational priorities	“We are always going to be protecting privacy and confidentiality, so we're always looking through that lens.”[2]
	Organizational policies	“We, well, as part of that, we do share a lot with, we have so many entities that come into the state and help us sort of formulate policies and protocols.” [4] “...with delinquency cases is everything that happens is it's supposed to be sealed.” [4] “All of our policies and procedures that would prevent sharing are all driven by a law. We have no additional policies or procedures that prevent, that are not driven by a law.” [5] “...a big element of what we shift out publicly is going through the privacy review…. We are trying very hard to make as much data public as possible. At the same time, we have to protect the identity of the kids” [9] “That’s the challenge. So we have a massive review we go through that involves legal and all kinds of pieces of the organization to review our internal dashboards before making them public and figure out what we need to pull out because it would allow you to go down to a level where you could potentially identify the family or something.” [9] “...each division has policy and procedures in place for sharing information, and they do that in consultation with a general counsel. Normally each division has an attorney assigned to them to advise them of a law.” [10]
Political: Barriers that are fundamental structural barriers embedded in the public health governance system that are grounded in a political or socio-cultural context, i.e. lack of trust, restrictive policies, or lack of guidelines.	Restrictive policies	“I strongly agree that there are state laws that prohibit us from sharing that information across those entities. Now, there is a public health exception to HIPAA. And that allows us to reach in and get information as we need it if it's in response to a public health issue. But that is also limited to being able to on an individual basis and how we share that information out.” [1] “If you're talking about data, aggregate data under Act 1818, we share child mortality data… there are probably things that we could do to share that data more widely.” [3] “So, there are no laws that prohibit us from sharing de-identified data, but if you're talking about identifiable data, then yeah, we’re limited on what we can share.” [3] “...and you will find that the problem that comes into play is that when it becomes identified data, the ability to share it under the federal restrictions that you have cannot be overcome just by an MOU.” [9] “One [issue with data sharing] is ensuring compliance with federal laws around protecting the information of the individual...” [9]

		“We had something recently that went on… where there was an effort by a third party who wanted to have several different agencies share data with that third party. That third party was then going to aggregate the data and give everybody back some good high level information. Wonderful. Until we all started to work and then the problem became very simply the outside entity would not agree to the restrictions on the data.” [9] “...depending on what the law says we can share, and I say that because there are laws in place that say we cannot share certain information with certain individuals.” [10]
	Lack of guidelines	“...there are some provisions within those privacy laws and within HIPAA that would allow data sharing for particular purposes, and so there are times that maybe you, you get a no, when you could have gotten, if we get these, these agreements in place, we'll share the data for this particular purpose. So I think, I think there's a way to share data more readily than we may have been doing in the past.” [1]
	Lack of trust	“It's not like, well, now once I have the data I can use it. No, you would use the data for this purpose. Then the data is destroyed, returned, etcetera. You cannot then just take information on people's private lives and go do what you want to do with it.” [9]
Legal: Barriers that are legal instruments used to restrict data sharing, resulting from the underlying willingness (or not) to share data, i.e. ownership and copyright or protection of privacy.	Protection of privacy	“...there's legal barriers to sharing information at [the address] level that's personal and you know, if it's medical such as abuse or something like that, that might preclude sharing that information.” [1] “For other more specific data, it is by county [rather than address level]. You know because of the numbers, it would tend to identify folks. So, there's only a certain level that we can go to.” [2] “We are able to share data, de-identify data, but our policies protect confidentiality. We don't release data that can identify a person and we release it only for statistical purposes.” [3] “...we've got over 200 different datasets registries... the real power is when we're able to link...as many as possible, still making sure that they're de-identified, that that linkage doesn't suddenly identify individuals. But that way we can explore different associations and patterns…” [3] “We don't have a lot of direct feeds with other systems because our information is confidential since it's child-specific. So most of the data that we are sharing is at a high level. Not identifiable per kid.” [5] “I think we have to be very cautious and respect that individual child and family, and figure out a balance of information sharing that helps us make policies that keep children safe, but also protect the privacy of kids.” [5]

		“It's more of the privacy of that individual. So we do redact very specific individual information, but there is sharing.” [8] “There's a lot of laws that are involved, a lot of requirements that we have around protecting: protecting that data and protecting the information on a child specific level.” [9]
	Ownership of data	“We have to show that that project is for the [agency's] benefit. So we, we are funding that project because we believe that we will then use that to work with communities and we will fund prevention efforts and those, so that, that is the one exception in the law that allowed us, in fact, there was a ton of pushback on whether I could share, but because I said no, it's our project, we’re funding it, it’s our project. Then I was allowed to share that data.” [5]
Technical: Barriers that are part of challenges in health information system capacity that continue to form major obstacles to the availability and use of public health data, i.e. data not being collected, data not being preserved, language barriers, restrictive formats, technical solutions not available, or lack of metadata and standards.	Technical solutions not available	“...there's a secondary issue into the data structure issue of being able to properly match up an individual across disparate data systems.”[1] “We collect a lot of data that may indicate abuse or something of that, of a child, but... it is a medical record so it’s still embedded within that system and it's not shared outside that system cause there's not, hasn't been, there's not a thing that connects all this information up yet.” [1] “We're looking into that right now, what's the best model for Arkansas in order for us to make sure that we have the structure and the validity of the data and the, and the security of the data, too, is very critical.” [1] “Probably the biggest thing [to improve data sharing] is our data systems informatics. We have an informatics work group… that is working to help us to better use our large datasets and to link them. Oftentimes the biggest lessons to be learned, the greatest value is when you take one data set and you can link it with another then suddenly things become more obvious if you have de-identified data on child maltreatment. For example, races and you can link that with datasets that talk about socioeconomic factors or geographic factors or substance use disorder data or criminal records. Then you all of a sudden can see patterns that you couldn't see just by looking at the data on child maltreatment.” [3] “It [is] hard to look at our populations across, like, Medicaid and child welfare cause we don't have standard data systems. And another one is the court system. So missing a lot of kids who are delinquency kids, but maybe have had some contact with the child welfare system because there's not a standard system or data, data sharing agreement.” [5] “...we do a lot of data exchange back and forth again around both of those populations... but at the same time, there are places that we don't have, I would say, fully integrated data structure.” [9]

	Language barrier	“[We don’t have common language] when it comes to, like, education, so a lot of times we don't have standard data the same that education has, so it's hard to do cross population comparison.” [5] “...where it doesn't move well is simply because of not having the actual technology and systems in place…. It's not because of a data sharing issue. It's much more of somebody still keeping files and paper type stuff.” [9]
	Restrictive data format	“The only data that we receive at this point on possible maltreatment information would be from death certificates. So we do receive that, but not in a systematic and certainly not in a complete way.” [3]
	Data not collected/ complete	“...there's a lot of systems that are not collecting the data that we need at the local level.” [5]
Motivational: Barriers that are based on personal or institutional motivations and beliefs that limit data sharing, i.e. no incentives, opportunity costs, or possible criticism.	No incentives	“All these agencies have so much data. But I don't think there's been a lot of moving the ball forward and getting all that data in one place where you can do a lot of effective matching and utilize that data to help people and to prevent fraud and to be more efficient.” [4]
	Possible criticism	“It was like all of a sudden, ‘what do you mean you got these other people questioning our data’, but we're all going, ‘hey y’all were saying the same things you’ve been saying for years and that data doesn't actually show that.’ And so we had a whole lot of other folks looking at the data” [9]
	Disagreement on data use	“ …[another issue with data sharing] is probably just agreement on the purpose for which the data will be used.” [9]
Economic: Barriers that concern the potential and real costs of data sharing, i.e. possible economic damage or lack of resources.	Lack of resources	“...we need to have a data structure in place, so it doesn't cost so much money to clean up the old data, but also to make proper link it to the individual.” [1] “Linking data sets and having really more individuals involved in those areas who have a background training in informatics so that they can actually make these connections [would improve data sharing].” [4]
	Economic damage	“...therefore, when you start even in an MOU sharing, agreeing to share the data inside the state agencies. If we share data [and they have] a breach, then who is responsible for paying the millions of dollars?” [9]

Categorical definitions as defined in van Panhuis et al. (2014).

Appendix 2 - Interview Questions

Likert Scale Questions: On a scale from 1 to 4, 1 being Strongly Disagree and 4 being Strongly Agree, please rate and explain the following questions.

1. Your agency actively shares data relating to adverse childhood experiences with other local, state, and/or federal agencies and organizations. Explain your reasoning.

2. Your agency actively receives data relating to adverse childhood experiences from other local, state, and/or federal agencies and organizations. Explain your reasoning.

3. There are laws or mandates across local, state, and/or federal levels that prevent or inhibit your agency from sharing data related to adverse childhood experiences with other public or private entities. Explain your reasoning.

4. There are organizational policies or procedures that prevent or inhibit your agency from sharing data related to adverse childhood experiences with other public or private entities. Explain your reasoning.

5. Data sharing across local, state, and federal agencies and organizations is beneficial to the prevention of adverse childhood experiences. Explain your reasoning.

Interview Protocol Questions (Continued):

6. a. With whom does your agency share and receive adverse childhood experiences data? What is the nature of this data?

   b. Does this include non-state agency entities such as non-profits or researchers?

7. Does the data your agency shares/receives contain standard definitions and coding common across local, state, and/or federal agencies?

8. Does the data your agency shares/receives include the specific address data?

9. a. In your opinion, what inhibits the sharing of data and information across local, state, and federal agencies?

   b. What about sharing with non-profit organizations or researchers?

10. a. In your opinion, what would improve data sharing and accessibility across local, state, and federal agencies?

    b. What would improve data sharing and accessibility among non-profit organizations or researchers?