Fiscal impact reports (FIRs) are prepared by the Legislative Finance Committee (LFC) for standing finance committees of the NM Legislature. The LFC does not assume responsibility for the accuracy of these reports if they are used for other purposes.

Current and previously issued FIRs are available on the NM Legislative Website (<a href="www.nmlegis.gov">www.nmlegis.gov</a>) and may also be obtained from the LFC in Suite 101 of the State Capitol Building North.

#### FISCal IMPaCT REPORT

SPONSOR	SJC		ORIGINAL DATE LAST UPDATED		НВ		
SHORT TITI	LE	Child and Family I	Databank Act		SB	202/SJCS/aSFC	
				ANAI	YST	Courtney/Klundt	

#### **REVENUE** (dollars in thousands)

	<b>Estimated Revenue</b>	Recurring	Fund	
FY19	FY20	FY21	or Nonrecurring	Affected
	See Fiscal	See Fiscal		
	Implications	Implications		

(Parenthesis () Indicate Revenue Decreases)

Senate Bill 202 (SB202) originally duplicated House Bill 173 (HB173). Both bills have committee substitutes and no longer duplicate one another therefore the committee substitute for SB202 (CS202SJC) now conflicts with the committee substitute for HB173 (CS173HJC) as these two substitutes differ from one another.

CS202SJC relates to other bills calling for collection and use of integrated data across state agencies including House Bill 88 (Senate Bill 101 duplicate) and House Bill 267. LFC staff were recently asked to provide additional information on existing proposals for integrated data systems which is included as an attachment (Attachment A)

#### SOURCES OF INFORMATION

LFC Files

#### Responses Received From

Department of Health (DOH) Children, Youth, and Families Department (CYFD)

Human Services Department (HSD)

#### Responses not received from

Office of the Governor

Public Education Department (PED)

Department of Information Technology (DoIT)

Administrative Office of the Courts (AOC)

#### Senate Bill 202/SJCS/aSFC – Page 2

#### **SUMMARY**

#### Synopsis of SFC Amendment

The Senate Finance Committee Amendment to Senate Bill 202 removes the appropriation of \$3.738 million previously contained in this bill.

#### Synopsis of Original Bill

The Senate Judiciary Committee Substitute for SB202 (CS202SJC) appropriates \$3.738 million from the general fund to the Department of Health in FY20 to establish a Child and Family Databank Commission (Commission) for the purposes of creating a commission, mandating data sharing across agencies, and developing a governance process to share and access administrative data for research and evaluation. Unspent money from the appropriation would not revert. CS202SJC creates a 15 member commission, administratively attached to the Department of Health, that would be responsible for selecting a database host, establishing a data management and governance process, managing the databank, and facilitating evaluation and analysis. The commission would consist of agency secretaries, members of the public, advocacy organizations for underserved communities, and others. In addition to establishing a commission, the bill calls for an executive director, staff, or a qualified nonprofit entity to carry out the charge of the committee. The bill provides guidelines for creation of the Commission and for hiring or contracting of staff and services by the Commission. The Commission would also be tasked with promulgating rules, selecting a databank host, charge reasonable fees for various tasks related to data management and analysis, and ensure data provided by agencies can be used and made available to agency staff, researchers, and other public and private partners.

The bill requires data sharing for seven agencies (Department of Health, Human Services Department, Children Youth and Families Department, Public Education Department, Corrections Department, the Administrative Office of the Courts, and the New Mexico Sentencing Commission) absent specific legal prohibitions. Provisions for sharing data would be put forth in memorandum of agreements with agencies that are being required to share data. The bill also identifies specific datasets or programs that must be shared with the databank. The bill also sets forth provisions for treatment of data and data protection. The bill also calls for databank policy officers to be hired by four of the seven aforementioned agencies (DOH, HSD, PED, and CYFD) for the purpose of coordinating with the Commission and addicting with identification of datasets to include in the databank. The Commission would provide funding for these four officers.

The Commission would require that any researcher seeking to use Databank data provide a summary of its findings for publication on the Commissions website. Additionally, state agencies would not be able to prevent publication of findings in the case of disagreement. Agencies retain ownership of their original datasets. In the case sharing of data is prevented by law the bill requires agencies to work with the Commission to work toward supplying a dataset by making edits, deletions or adding additional protections. The bill also does not allow for redisclosure of information that conflicts with law, making such an occurrence a punishable misdemeanor.

#### FISCAL IMPLICATIONS

#### Amendment Impact

The SFC amendment removes the appropriation from the bill.

#### Original analysis

The general fund FY20 appropriation of \$3.738 million would be made to the Department of Health, and any unexpended or unencumbered balance remaining at the end of FY21 would not revert. According to New Mexico Appleseed (see attached) the appropriation would be split evenly between FY20 and FY21. The appropriation contained in this bill is a recurring expense to the general fund assuming the proposed Commission would continue to operate past FY21. The ongoing budget past FY21 would likely be \$1.9 million a year from the general fund.

The executive FY20 budget recommendation includes a \$1.9 million special appropriation for a child services database to the Children, Youth and Families Department whereas the Legislative Finance Committee (LFC) recommendation does not include such an appropriation. Since the bill attaches the Commission to the Department of Health, the special appropriation should also reflect this and not the Children, Youth and Families Department.

The bill gives the Commission authority to charge "reasonable fees" for a number of tasks involving the development of research projects, conducting of research, and data management and analysis. Collection of these fees would likely result in some revenue, however without a fee schedule or assessment of likely use, a revenue estimate for these fees in currently incalculable. Note that entities contributing data to the databank would not be subject to fees. DOH notes that the committee substitute is an improvement over the original bill.

#### DOH states:

"SB202JUS reflects several changes from the original bill that were responsive to issues raised by NMDOH and other agencies."

Some agencies express concerns with the need for additional resources, which is discussed in the next section "SIGNIFICANT ISSUES."

#### SIGNIFICANT ISSUES

Significant issues fall into three categories (although each agency does not voice every concern):

- Concerns with duplication of efforts and coordination;
- Concerns with confidentiality and data sharing; and
- Concerns with existing resources;

Concerns with duplication of efforts and coordination. Regarding duplication, the Databank would focus on the family unit and service usage throughout the system making this a unique effort apart from existing efforts cited by agencies. Other existing integrated data systems such as ECIDS focuses on early childhood data and MMIS focuses on updating the Medicaid system, and does not include all of the agencies proposed for inclusion in the Databank. Moreover, the

#### Senate Bill 202/SJCS/aSFC - Page 4

Databank would contain historic administrative data, which would not be subject to some of the necessary technical support that a live federated database would need. It is likely that work on these existing systems could be leveraged for the Databank effort as both the HSD secretary and CYFD secretary would serve on the council. Additionally, added value of the Databank and the Commission exists for entities who will use these data for analysis and evaluation to further promote evidence-based policymaking. These entities could potentially include LFC, LESC, university researchers, and other entities using data to make policy decisions.

#### DOH states:

"SB202JUS removes language that specifically identified NMDOH as a possible databank host under the Child and Family Databank Act. The bill also updates language regarding applicability of federal and state privacy laws, potential restrictions on data sharing, and allows for situations where agency data are unavailable. Some of the detail regarding specific data sets and how they can be shared will have to be negotiated as part of the contract process between state agencies and the Commission."

However, HSD and CYFD identify concerns with duplication of efforts with existing data systems.

#### HSD states:

"SB202 CS mandates the creation of an integrated data system. Agencies are mandated to transfer data annually to the Child and Family Databank, including the Human Services Department (HSD), Department of Health (DOH), Public Education Department (PED) and Children, Youth, and Families Department (CYFD). All these agencies except PED are participating in the HHS2020 MMIS Replacement project.

At a minimum, the commission will require HSD to transfer the data below in a format yet to be defined no less than annually:

- 1. Demographics relating to recipients of medical assistance;
- 2. Medicaid data, including both fee-for-service and managed care organization data and children's health insurance program claims data; and
- 3. Data from the following programs:
  - a. the supplemental nutrition assistance program (SNAP)
  - b. cash assistance programs
  - c. utility payment assistance programs
  - d. child support enforcement
  - e. behavioral health services

The data must be protected from disclosure and inappropriate use, as much of the information requested is confidential or protected PHI. The substitute calls for data to be anonymized.

For the MMISR Project, a Data Governance Council, consisting of representatives from HSD, DOH, CYFD, and other participating agencies has been chartered and is responsible for establishing the processes by which the HHS2020 modules will link, store, maintain, receive, share and securely protect data. This may be a vehicle to support

#### Senate Bill 202/SJCS/aSFC – Page 5

the Child Data Bank."

#### CYFD states:

"The Early Childhood Services Division of CYFD is already collaborating with the Public Education Department and the Department of Health to align, coordinate, and share early childhood data. The Early Childhood Integrated Data System (ECIDS) incorporates both a unique identifier and a data warehouse with de-identified data for reports, data visualization, and decision-making. This project started with Race to the Top federal funding, and is now in its final stages. Currently, the project is scheduled to be completed in 2019 using Preschool Development Grant Birth to age 5 funds.

The ECIDS duplicates components of the databank described in this bill. At this time, ECS does not have the resources available to develop new data processes or new data sets which may be called for as a result of this bill. There are additional issues about the potential for privacy violations which can lead to participants' concerns for the privacy of their information, and result in families being reluctant to participate in state-funded programs that help keep their families safe, or enroll their children in programs that prepare them for later in life."

Concerns with confidentiality and data sharing. Agency concerns with confidentiality should be taken in the context that some projects using these types of data have been successful in other states. Existing models within the state such as the New Mexico Sentencing Commission could also show promise for cooperation and data storage and use that complies with federal and state law.

However, all three agencies responding (DOH, HSD and CYFD) express concerns about confidentiality and data sharing.

#### DOH states:

"SB202 CS mandates the creation of an integrated data system, the composition of which significantly overlaps the agencies and data sets that are part of the HHS2020 initiative. Agencies are mandated to transfer data annually to the Child and Family Databank, including the Human Services Department (HSD), Department of Health (DOH), Public Education Department (PED) and Children, Youth, and Families Department (CYFD). All these agencies except PED are participating in the HHS2020 initiative.

In Section 6.C.(7) there is a requirement that "Family, Infant, Toddler program participation information" be shared by NMDOH. There is no description or definition of FIT program participation information. Data from other programs is stated as "data," rather than "program participation information." What is meant by "program participation information" requires further definition.

There are ongoing projects among state agencies that involve interoperability of data systems. It will be important to determine how and when data are to be anonymized to ensure protection from disclosure and inappropriate use."

#### Senate Bill 202/SJCS/aSFC - Page 6

#### HSD states:

"The bill states that in cases where data sharing is prohibited, agencies will work with the commission to identify ways the data could be edited, redacted, or protected to allow the data to be provided to the commission in compliance with state and federal law.

HSD has worked with the sponsors and DOH and CYFD on proposed amendments. The changes made by the sponsors that are reflected in the substitute remove most of HSD's previous concerns and much of the ambiguity found in the original bill. The changes also prevent the agencies from being charged for use of their own data and provide more direct authority for the Commission."

#### CYFD states:

"While the bill does make modifications to the Children's Mental Health and Developmental Disabilities Act, it does not make modifications to the NMSA 1978, Section 32A-2-26 statute governing the sealing of juvenile records. All Juvenile Justice cases are subject to automatic sealing either once the youth reaches age 18 or the expiration of disposition is reached, whichever occurs later. As data being submitted to the databank must include individual identifiers so that the data can be accurately linked to other datasets, modifications to 32A-2-26 or 32A-2-32 (Confidentiality), records may be required in order for sealed case data to either be submitted to, or to subsequently remain, in the databank."

Concerns with existing resources. The bill recommends funding four positions at DOH and four databank officers, one each to selected agencies. The bill explicitly states that agencies retain ownership of their original dataset. DOH states the appropriation would be enough to address resources, however HSD and CYFD put forth concerns regarding a lack of specificity of tasks and lack of adequate resources respectively.

#### Regarding resources, DOH states:

"SB202JUS makes the Commission administratively attached to NMDOH. NMDOH has experience in hosting large integrated data systems. It will require a significant amount of resources to administer the Commission for NMDOH to provide data into the databank. NMDOH will have to execute cooperative agreements and privacy agreements related to the Healthcare Insurance Portability and Accountability Act of 1999 (HIPAA).

SB202JUS appropriates three million seven hundred thirty-eight thousand dollars (\$3,738,000) to NMDOH to establish the child and family databank commission, and a child and family databank, and to support implementation of the bill. This funding can be used for the administrative and technical tasks and FTE required to implement the databank.

There will also be a cost associated with paying vendors to create data extracts and reports. For example, FIT KIDS and Families FIRST have vendor-hosted systems that charge a fee for any enhancements, modification, and reporting that is requested.

A significant amount of staff resources would be needed to implement this bill, although the appropriation contained in the bill would cover those expenses for NMDOH."

#### Senate Bill 202/SJCS/aSFC – Page 7

#### HSD states:

"The cost of reporting information to the commission is unknown at this time due to the lack of specificity as to what data are to be transmitted and in what format."

#### CYFD states:

"The administrative impact on CYFD of providing datasets which are already provided to other entities can be absorbed by existing resources. The administrative costs associated with aligning datasets with other requirements, developing new datasets, and increasing the quality of the available data cannot all be absorbed by existing resources."

#### ADMINISTRATIVE IMPLICATIONS

DOH shared the potential value of the effort. DOH states:

"The databank proposed in this legislation has the potential to help NMDOH better serve children and families in New Mexico. It would expand the scope of multi-systems data available to NMDOH administrators, researchers, epidemiologists, program coordinators, and evaluators.

#### CONFLICT, DUPLICATION, COMPANIONSHIP, RELATIONSHIP

Senate Bill 202 originally duplicated House Bill 173. Both bills have committee substitutes and no longer duplicate one another therefore the committee substitute for Senate Bill 202 (CS202SJC) now conflicts with the committee substitute for House Bill 173 (CS173HJC) as these two substitutes are different from one another including the fact that CS173HJC administratively attaches the Commission to the Office of the Governor and CS202SJC administratively attaches the Commission to DOH. Additionally, the Commission is constructed differently in each bill.

CS202SJC relates to other bills calling for collection and use of integrated data across state agencies including House Bill 88 (Senate Bill 101 duplicate) and House Bill 267. LFC staff were recently asked to provide additional information on existing proposals for integrated data systems which is included as an attachment.

There are currently at least three bills proposing integrated data systems or elements of such systems (e.g. data sharing among multiple agencies)<sup>1</sup>:

- House Bill 88 (Senate Bill 101 Duplicate)-Health Care Value & Access Commission Act
- Senate Bill 202 (House Bill 173 Duplicate)-Child and Family Databank Act
- House Bill 267 Criminal Justice Reforms

LFC was recently asked to provide an analysis of collective efforts for data integration (See Attachment). Although each of these pieces of legislation are addressing different policy issues, agency responses to these proposals (for fiscal impact reports) show similar concerns for each effort including duplication with existing efforts, with other proposals being made through

<sup>&</sup>lt;sup>1</sup> Note other bills also have components of integrated data systems but do not represent integrated data system efforts. Senate Bill 370 would require data sharing from eight government entities. House Bill 168 would require PED to share data with CYFD.

#### Senate Bill 202/SJCS/aSFC - Page 8

legislation, concerns about data privacy and compliance with federal and state privacy laws, and agency resource concerns. Additionally, agencies have cited ongoing and future efforts within agencies that need to be considered. For example, New Mexico was recently awarded \$5.4 million from the U.S. Department of Health and Human Services for the Preschool Development Grant – Birth to Five (PDG B-5) to assist in efforts to build a high-quality early learning system for families and young children. The Children Youth and Families Department (CYFD) is designated as the lead agency for the grant, which was applied for collaboratively with the Department of Health (DOH) and the Public Education Department (PED). This initiative reflects another example with potential duplication.

In addition, the Human Services Department's (HSD) HHS2020 initiative is to provide a common technology platform, highly shared data, common tooling, and to implement reusable capabilities that will expand business capabilities and cross-program/cross-organizational sharing of data and results. HSD plans to leverage acquired service capacity for multiple business needs across programs and across population servicing agencies within the State of New Mexico, beginning with the Medicaid Management Information System Replacement (MMISR) project. The MMISR project is primarily federally funded (90/10) and other state agencies such as DOH are also leveraging federal funds for associated projects currently underway. For example, two DOH projects to be integrated with the MMISR project, include the Family First Medicaid Eligibility System, and Children's Medical Services Medicaid Provider Enrollment System.

JRC/KK/al/sb

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February 14, 2019

#### **MEMORANDUM**

TO:

Patricia A. Lundstrom, Chairwoman, HAFC

John Arthur Smith, Chairman, SFC

FROM:

Jon Courtney, Ph.D., Program Evaluation Manager, LFC

Brenda Fresquez, Program Evaluator, LFC

Sarah Dinces, Ph. D., Program Evaluator, LFC

THRU:

David Abbey, Director, LFC

**SUBJECT:** 

**Integrated Data Systems** 

The purpose of this memo is to analyze ongoing and new proposals for building integrated data systems. Integrated data systems link individual level data from multiple agencies, such as schools, law enforcement, and human services. Having a clear purpose for shared data, these systems hold potential for great benefit in improving service delivery in case management and research analysis and evaluation. However, these systems also pose significant risk and New Mexico's record of accomplishment of building such systems is poor. Policymakers should use caution on moving forward with new integrated data systems. Ongoing integrated data system efforts and new proposals need to be considered together to avoid potential duplication and leverage funding opportunities from non-profits and the federal government.

Integrated data systems value and best practices. New Mexico state and local government entities provide valuable services to citizens but often do not coordinate or share data. Integrating data across agencies and data systems is a strategy that can better inform performance management, program evaluation, cost-benefit analysis, and policymaking. State and local integrated data systems in other states have demonstrated ongoing effective and efficient improvements in public administration while improving public trust and protecting personal data. The Actionable Intelligence for Social Policy (AISP)<sup>1</sup> provides several examples of government entities using integrated data systems to identify system issues such as multi-system involved individuals and heavy system utilizers, and to address these issues with tailored solutions such as targeted prevention or evidence-based intervention.

<sup>&</sup>lt;sup>1</sup> Actionable Intelligence for Social Policy. (2017). The Integrated Data System Approach: A Vehicle to More Effective and Efficient Data-Driven Solutions in Government. <a href="https://www.aisp.upenn.edu/wp-content/uploads/2017/09/The-IDS-Approach\_Fantuzzo-et-al.-2017\_Final.pdf">https://www.aisp.upenn.edu/wp-content/uploads/2017/09/The-IDS-Approach\_Fantuzzo-et-al.-2017\_Final.pdf</a>

According to AISP, there are six leading practices for building integrated data systems.

- Strong and inclusive data governance;
- Streamlined legal agreements;
- Data standards;
- Clear and transparent communication and stakeholder engagement;
- Iterative inquiry processes; and
- Sustained investment in capacity and cross-agency coordination.

Strong data governance creates the foundation for using the integrated data system and ensures the system is able to address current problems. Strong governance cannot exist without commitment from executive leadership and leadership must provide the time and resources necessary to create sound data system infrastructure. As part of the governance structure, stakeholders need to determine the purpose and scope of the integrated data system as this will determine the system structure and which agencies to include.

Legal agreements are essential for the system to function and provide privacy protections. These protections minimize risk to all entities and individuals involved. Agreements between state agencies ensure the data system identifies relevant laws and addresses any challenges that these laws may pose to sharing of information.

Data quality is paramount to have a reliable, functioning system - if the data is not reliable, no conclusions drawn from the data can be trusted. Therefore any integrated data system needs to have quality checks to determine the reliability the data.

All stakeholders need to be presented with results from analysis of the data in the data system. Clear communication facilitates stakeholder engagement and allows for an open discussion of how to handle any problems that arise.

Barriers to organizational communication need to be identified and removed to allow coordination between all relevant agencies. All agencies need to have an open and ongoing dialogue, this dialogue may not be possible without continued resources.

AISP also identifies a number of best practices critical for an integrated data system to be successful, including establishing data governance, addressing legal issues and data security, managing data and analytic protocols, and securing long-term support for operations. Sharing of data across agencies also brings ethical concerns around data usage and privacy.

The current situation. There are currently at least three bills proposing integrated data systems or elements of such systems (e.g. data sharing among multiple agencies)<sup>2</sup>:

- House Bill 88 (Senate Bill 101 Duplicate)-Health Care Value & Access Commission Act
- House Bill 173 (Senate Bill 202 Duplicate)-Child and Family Databank Act
- House Bill 267-Criminal Justice Reforms

<sup>&</sup>lt;sup>2</sup> Note other bills also have components of integrated data systems but do not represent integrated data system efforts. Senate Bill 370 would require data sharing from eight government entities. House Bill 168 would require PED to share data with CYFD.

Although each of these pieces of legislation are addressing different policy issues, agency responses to these proposals (for fiscal impact reports) show similar concerns including duplication with existing efforts, with other proposals being made through legislation, concerns about data privacy and compliance with federal and state privacy laws, and agency resource concerns. Additionally agencies have cited ongoing and future efforts within agencies that need to be considered. For example, New Mexico was recently awarded \$5.4 million from the U.S. Department of Health and Human Services for the Preschool Development Grant – Birth to Five (PDG B-5) to assist in efforts to build a high-quality early learning system for families and young children. The Children Youth and Families Department (CYFD) is designated as the lead agency for the grant, which was applied for collaboratively with the Department of Health (DOH) and the Public Education Department (PED). This initiative reflects another example with potential duplication such as the federal Race to the Top grant funding for New Mexico to develop an early childhood data system that has yet to be fully deployed.

In addition, the Human Services Department's (HSD) HHS2020 initiative is to provide a common technology platform, highly shared data, common tooling, and to implement reusable capabilities that will expand business capabilities and cross-program/cross-organizational sharing of data and results. HSD plans to leverage acquired service capacity for multiple business needs across programs and across population servicing agencies within the State of New Mexico, beginning with the Medicaid Management Information System Replacement (MMISR) project. The MMISR project is primarily federally funded (90/10) and other state agencies such as CYFD and DOH are also leveraging federal funds for associated projects currently underway. For example, two DOH projects to be integrated with the MMISR project, include the Family First Medicaid Eligibility System, and Children's Medical Services Medicaid Provider Enrollment System.

CYFD's Comprehensive Child Welfare Information System (CCWIS) Modernization project will replace its 20+ year old mission critical client management system to meet current federal regulations and requirements, including data sharing requirements. The project leverages federal funding (50/50), and is currently in the planning phase. An additional appropriation for FY20 is anticipated for CYFD to continue the planning with Federal approval in process.

**Previous or ongoing New Mexico efforts in building integrated data systems.** New Mexico state government have attempted, or are attempting, to build at least four integrated data systems. However, each system has run into problems with implementation.

- P-20 Data System: Data governance established, however the statutorily created Data System Council stopped meeting and the system has not been built.
- Early Childhood Integrated Data System (ECIDS): Funded by a \$2 million Race to the Top grant, the ECIDS effort is behind schedule, is not being implemented as originally intended, and the Department of Information Technology's (DoIT) Project Certification Committee has held off on project closeout pending an update from ECIDS partner agencies.
- Medicaid Management Information System Replacement (MMISR): A \$176 million information technology project utilizing data integration to support the HHS2020 initiative. The MMISR project is currently rated as red by the LFC information technology status report, meaning significant issues limit success of the project<sup>3</sup>.

<sup>&</sup>lt;sup>3</sup>See FY19 Q1 Report

Advanced Data Analytics Project: The Taxation and Revenue Department is in the
process of implementing phase one of an analytics platform to provide increased fraud
detection and audit selection capabilities. With a current investment of \$1.15 million,
results and outcomes will not be realized until sometime next fiscal year.

A potential strategy. One potential strategy is following previous IT project proposals by funding a planning phase. As the State has several information technology (IT) projects underway or currently proposed, associated with integrated data systems, appropriate vetting of these projects is critical to ensure prudent allocation of state IT resources. Any new or proposed projects receiving an appropriation in the General Appropriation Act, require appropriate vetting. DoIT, in collaboration with the Department of Finance and Administration and the Legislative Finance Committee (LFC) have established criteria for reviewing IT funding requests. Because of the complexities and risks associated with multi-agencies projects, implications of data governance, including availability, usability, integrity quality, and security, LFC typically considers integrated data systems complex IT projects. Typically, DoIT and LFC recommend a phased approach for complex, multi-year IT projects. According to AISP, creating the necessary governance structure from which the rest of the integrated data system will be built is the foundation of any sound integrated system. Furthermore, according to a joint report 2016 from the United States Departments of Health and Human Services and Education<sup>4</sup>, effective data governance helps to ensure reliable data are securely available to identified stakeholders, while protecting the privacy of the individuals. The governance is usually determined in the planning phase of the project. As part of the governance structure, stakeholders need to determine the purpose and scope of the integrated data system to define the system structure and which agencies to include. Therefore, until the governance plan is securely in place, fully funding any integrated system may not be appropriate. As a standard, past LFC IT funding recommendations for the initiation and planning phase ranged from \$250 thousand to \$600 thousand.

Cc: Bill Valdes, Chief of Staff, HAFC
Mike Burkhart, Chief of Staff, SFC

<sup>&</sup>lt;sup>4</sup> The Integration of Early Childhood Data: State Profiles and a Report from the U.S. Department of Health and Human Services and the U.S. Department of Education (2016). https://www.acf.hhs.gov/sites/default/files/ecd/intergration of early childhood data final.pdf



# THE NEW MEXICO CHILD AND FAMILY DATABANK

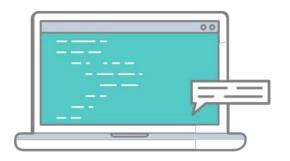


#### 2019 NEW MEXICO LEGISLATIVE SESSION

NEW MEXICO APPLESEED IS A NONPARTISAN, NONPROFIT ORGANIZATION WITH THE MISSION OF ENDING POVERTY THROUGH HIGH-IMPACT, SYSTEMIC CHANGE.



Jeffrey Mitchell, Ph.D. Director, Bureau Of Business & Economic Research (BBER) The University Of New Mexico



### THE CHILD AND FAMILY DATABANK (CFD)

# WILL ENABLE GOVERNMENT AGENCIES AND RESEARCHERS TO:

- Craft data-informed solutions to complex problems;
- Improve the delivery of services;
- Evaluate program effectiveness;
- ► Conduct research at a fraction of the cost of traditional studies, including low-cost randomized control trials (RTC) with administrative data:
- Conduct research faster and with improved accuracy by using historical administrative data rather than imprecise and costly to conduct samples or surveys;
- ► Better manage limited resources, including taxpayer dollars by funding only evidence-based or promising programs and identifying and eliminating wasteful spending;
- ► Establish a business case for state programs and services, including by identifying cost savings downstream;
- ▶ Promote more effective and informed stewardship of agency resources;
- Recognize resource gaps that the state or agency should fill;
- ▶ Increase accountability, including from contracted social service providers;
- ▶ Better identification of risk and protective factors for clients or service utilizers, leading to more targeted and effective case management;
- ▶ Develop predictive risk models and target services to those at highest risk; and
- ► Improve case management.

### Content

**OVERVIEW** Ι. a) The Complex Lives of Families in Poverty b) Stability and Cost-Containment for Multi-System Families Cannot Happen Without Integrating Data c) By Integrating Data Across Agency Systems, New Mexico Will Gain a Critical Tool to Dramatically and Permanently Improve Outcomes for Children and Families. i) The Child and Family Databank (CFD) ii) The Child and Family Databank Commission (CFD Commission) (1) CFD Commissioners (2) CFD Commission Staff (3) Data Linkage Staff (4) State Agency Staff iii) **Budget Narrative DISCUSSION** Ш. A Typical Family in Chaos and Poverty Bounces Between Systems a) i) Many of the hardships of Multi-System Families are correlated and often causal ii) Multi-System Families are the Most Expensive to the Public iii) The Fragmented Data Landscape in New Mexico

III.	THE SOLUTION: THE CHILD AND FAMILY DATABANK			
	i) Administrative Data Draws a Detailed Picture of What At-Risk Children and Families Need to Thrive			
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#### THE COMPLEX LIVES OF FAMILIES IN POVERTY

Every baby's first breaths should be breaths of hope and potential. The first days of a child's life should be filled with the anticipation of life's milestones. Approximately 100 babies are born every day in New Mexico. Yet, even before those babies take those first breaths, we can already predict that many of their lives will have sadness and hardship that no child should face.

# FROM WHAT WE KNOW ABOUT THE CYCLE OF POVERTY IN NEW MEXICO. IT IS FAIR TO PREDICT THAT:



30% will live their lives in poverty [1]



10% will have a parent incarcerated at some point [2].



7% will abuse drugs in high school [3].



Far too many will be abused, neglected and fail to meet even fourth-grade reading standards [4].

The babies most at risk are generally born into families that are poor and chaotic with few tools to give them the hope for the bright future they deserve. They may have little access to cash — pushing diapers and even food out of financial reach. Parents are in and out of corrections, while their children are the victims of abuse and neglect; hopping from one living situation—and school—to the next. Families bounce between social service agencies such as criminal justice, child welfare, and Medicaid. They live day-to-day, fighting against forces threatening to dismantle the little stability they may have. And, worst of all, the cycle is repeated with each generation.

THE SOCIAL SERVICE SYSTEMS
DESIGNED TO SERVE THESE CHILDREN
AND FAMILIES RARELY WORK
TOGETHER OR SHARE DATA AND,
BECAUSE OF THAT, FAIL TO MAKE
PERMANENT AND POSITIVE IMPACTS

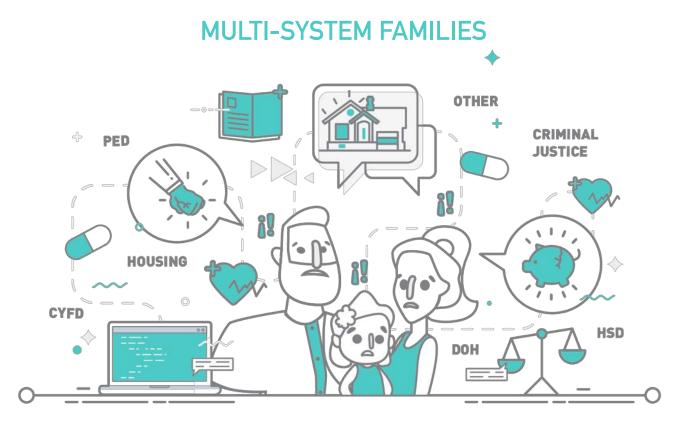
Generational poverty, abuse, neglect, and poor educational outcomes have not been ameliorated despite decades of time and billions of dollars spent trying to end those cycles. State and federal agencies, service providers, and philanthropic efforts have struggled to make even the smallest positive impact on the most at risk children and families.

In addition to having poor life wellbeing outcomes, families that use services from multiple agencies are the most expensive to serve. Hospitals call them "super-utilizers" because they use the most costly triage services, like emergency rooms. If one looks at the records of emergency room regulars, they often look a lot like the children and families defined above. They are in multiple social services and are best described as "Multi-System Families."

For each generation of Multi-System Families, there remains little understanding as to who is getting what services and whether those services even work, and state agencies and families continue to see few positive outcomes from the investment of taxpayer dollars.

#### MULTI-SYSTEM FAMILIES ARE SOME OF THE MOST FRAGILE IN THE STATE

A study of Multi-System Families completed by Chapin Hall at the University of Chicago found that 86 percent of the social services budget was used by 23 percent of Multi-System Families [5]. Please see Appendix A for more information on the calculation for this figure.





Using the figures in this study, New Mexico Appleseed's estimate is that 16,000 families cost the state almost \$900 million dollars, yet we have no idea who these families are, what mix of services they are utilizing, and what their outcomes are [6].

Multi-System Families are some of the most complex and fragile families in the state. They interact with multiple systems and services, including foster care, behavioral health and substance abuse, SNAP, TANF, and Medicaid, corrections and juvenile justice, foster care and child welfare; they may be frequent utilizers of emergency departments; housing insecure; and their children may struggle in school.

The system catches these children and families at the peak of crises — when they need expensive and short-term triage. Because there is no system of identifying risk factors for these crises and preventing them, the families become harder to help and are likely long-term consumers of expensive social services. And, because their children are growing up in poverty amid an abundance of household challenges, the cycle is likely to perpetuate itself in the following generation.

NEW MEXICO ALREADY HAS ALL OF THE DATA ABOUT MULTI-SYSTEM FAMILIES, BUT BECAUSE IT IS NOT SHARED ACROSS SYSTEMS, WE CANNOT SEE THE FULL CONSTELLATION OF RISK FACTORS AND PROBLEMS THEY FACE

New Mexico will never be able to see changes in its dismal child outcome statistics without the ability to prevent problems in at-risk children and evaluate the social service programs it provides to those children. It is difficult, if not impossible, to truly pull a child or family from the grip of generational poverty and chaos without the systems that serve that child or family working together.

While the state agencies, philanthropy and social service providers are desperate to see better outcomes for children and families, they lack the tools to answer three questions that are critical to family stability:

- 1. Who needs supportive services?
- 2. Which services do they need?
- 3. Are those services effective?

Because the social service systems with which Multi-System Families interact do not share and analyze integrated data or collaborate across systems, state agencies, schools and social service providers do not have the ability to identify who is at risk for what and intervene before problems occur.

They are unable to know what services the child and/or whole family are receiving and whether or not those services even work. Service providers and public servants become frustrated because their efforts to serve their communities are thwarted by systemic inefficiency.

If a risk factor for failed third grade reading scores is a parent in prison, the state will never know that because it has not compared those two data sets of reading scores and parental incarceration. If a program to help parenting foster youth keep their own children out of foster care has been funded for years, but nobody has integrated the data to see if it was effective, then the program may be failing families and providing no benefit to the children.

#### BY INTEGRATING DATA ACROSS AGENCY SYSTEMS, NEW MEXICO WILL GAIN A CRITICAL TOOL TO DRAMATICALLY AND PERMANENTLY IMPROVE OUTCOMES FOR CHILDREN AND FAMILIES

In the 2019 New Mexico Legislative Session, New Mexico Appleseed is spearheading legislation that could transform New Mexico's broken system of service provision to address the problem of persistently negative indicators of child wellbeing and life outcomes. The legislation will mandate data sharing across agencies through the establishment of the Child and Family Databank (CFD) and Child and Family Databank Commission (CFD Commission) to oversee ethical and privacy-driven data use.

The CFD and CFD Commission's mission is to improve the lives and opportunities of New Mexican families by working with agencies to discover and deploy evidence-based, data-informed and scalable solutions to common challenges facing vulnerable children and families. The CFD and CFD Commission will support state agencies in improving, developing, and evaluating services for children and families and provide insight into policy changes needed to end the cycle of poverty for Multi-System Families.

The CFD will be a comprehensive system of deidentified individual data that has been linked across agencies with the goal of improving child health and wellbeing in New Mexico. The CFD Commission will govern the CFD and in collaboration with agencies, determine how the data is used.

The CFD Commission's primary duty is to ensure that any data integration and use helps and never harms New Mexican children and families, improves upon existing state data privacy and security practices, and ensures that federal and state privacy laws are faithfully followed. The CFD Commission will also work to support cross-sector collaboration, and ensure the right parties are at the table to foster a culture of evidence-based policymaking and effect meaningful change.



# The Child and Family Databank (CFD) and CFD Commission's mission

is to improve the lives and opportunities of New Mexican families by working with agencies to discover and deploy evidence-based, data-informed and scalable solutions to common challenges facing vulnerable children and families.

#### MULTI-SYSTEM FAMILY DATA BEFORE THE CFD

Because the agencies that serve these complex families share limited data and do not collaborate across sectors, they are unable to accurately assess the constellation of needs a child or family may have, know which services they are receiving, or determine whether any of those services are effective.

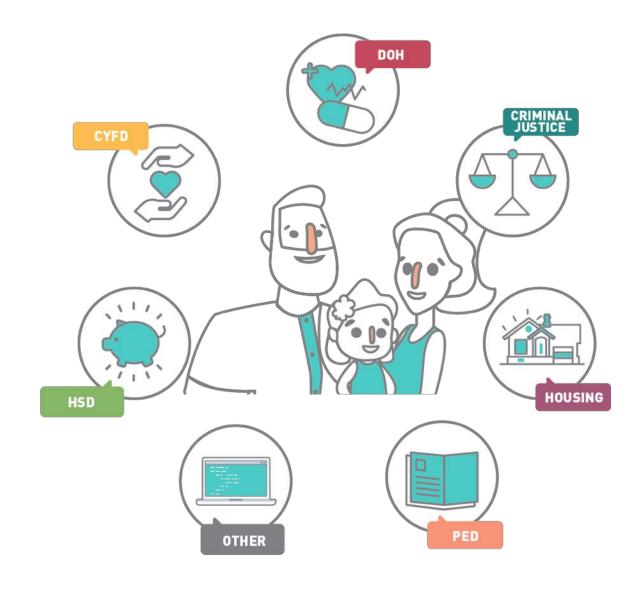


# THE CFD WILL ENABLE GOVERNMENT AGENCIES, SOCIAL SERVICE PROVIDERS, AND RESEARCHERS TO:

- ▶ Identify risk and protective factors to help predict and prevent problems;
- ► Target evidence-based programs and interventions to high risk groups;
- ► Evaluate programs, policies, and interventions for efficacy and cost;
- Improve case management based on the whole family picture.

#### MULTI-SYSTEM FAMILY DATA AFTER THE CFD

Linking existing administrative data across state agencies creates a clearer picture of how a program may have affected participants, including access to housing, employment, educational attainment, utilization of social and human services, and health care.





# THE CHILD AND FAMILY DATABANK (CFD) & CFD COMMISSION

The Child and Family Databank (CFD) and CFD Commission will link historical, individual, birth to death administrative data across agencies, which will be de-identified before it is shared with researchers or agency staff. The CFD Commission will establish privacy protections to ensure that only the appropriate parties may access the data, a secure framework for storing the data, and a robust mechanism to evaluate the ethical implications of any use of the data.

In compliance with state and federal regulations, the CFD will include data from the following sources [7]:

#### Department of Health ("DOH")

Vital records, including birth and death information. Inpatient hospitalization data and emergency department usage. Emergency medical service ("EMS") data. Family Infant Toddler ("FIT") program data. Environmental health and injury data.

#### ► Human Service Department ("HSD")

Medicaid (fee-for-service and MCO) and CHIP claims data. SNAP, TANF and other information from the Income Support Division. Child support enforcement and behavioral health services data.

#### Children, Youth and Families Department ("CYFD")

Juvenile justice data. Children's behavioral health data. Early childhood data (pre-k, home visiting, head start, daycare, family nutrition). Protective services division data, such as foster care, adoptions, reports and investigations for maltreatment/child abuse and neglect. Permanency planning and youth services.

#### ► Public Education Department ("PED")

Data regarding students statewide.

#### Courts

Future data integration may include:

- Homelessness Management Information System ("HMIS").
- Department of Workforce Solutions ("DFW").
- City and County data sources.
- Other data sources.

#### THE CFD COMMISSION

The CFD Commission will be made up of appointed agency officials, issue area experts, community leaders and community members. The Commissioners will help guide research priorities by soliciting input during quarterly meetings, report to both the executive and legislature on progress, and ensure that a diverse mix of executive leadership, researchers, practitioners, and representatives from the public are involved in the process.

Ultimately, the work that the CFD Commission does is a benefit to all New Mexicans, not just vulnerable and struggling families. It is paramount to the success of this program that agency partners feel engaged, encouraged, and that this project enhances their work. For this reason, including them on the CFD Commission and creating a broad coalition to drive the process forward is a critical part of the developing the governance process for the CFD. The ultimate goal is to foster a culture of data-sharing and evidence-based policymaking, and promote capacity-building among state agencies.

#### **CFD Commissioners**

The statutory requirements of eligibility for CFD Commissioners will provide for a wide breadth of expertise in areas from technology to ethics to child wellbeing. They will be appointed by the governor and legislature for staggered terms to maintain a nonpartisan environment across gubernatorial elections. The board will be culturally and geographically diverse with about thirteen CFD Commissioners providing representation from the following areas:

- ▶ Agency secretaries or their designee from CYFD, PED, HSD, DOH, and Corrections.
- A representative from the courts.
- ▶ Representation from the following domains:
  - One person representing persons whose data may be received, maintained, or transmitted by the CFD Commission.
  - One person with experience in human subjects research and a demonstrated understanding of the ethical considerations in such research, who is affiliated with a research university in New Mexico.
  - An individual with legal expertise in the privacy, security and ethical use of individually identifiable information.
  - An individual with technical expertise and experience in the creation, design, and maintenance of large data systems and data security.
  - An individual with an expertise in civil rights.
- Social service providers and child advocacy organizations.

#### **CFD Commission Staff**

The work of the CFD Commission will be executed by a staff of five at the Commission, a staff of four at the Department of Health or other entity, and supported by four CFD Policy Officers placed at CYFD, HSD, DOH, and PED. The commissioners will oversee the work, help guide research priorities, and regularly report to both the executive and legislature on progress.

The staff are the data experts who can move the agenda of the CFD Commission forward, ensure ethical and legal data use, and provide data access and analytics as needed. The staff will support the state agencies in refining their research agendas and providing the data analytics.

The initial staff of the CFD Commission will consist of five FTEs for the following positions:

- 1. Executive Director. This person is responsible for the operations and strategic direction of the CFD Commission. He or she will have the expertise to oversee the staff, familiarity with integrated data systems, extensive management experience, and an in-depth understanding of research and analysis using administrative data.
- 2. Data Scientist. This person will understand how to integrate and organize complex and varied data. This person will also have the ability to communicate complex technical concepts to different audiences and understand research methodologies on administrative data.
- 3. Two Data/Policy Analysts. This position will be comfortable working with linked and de-identified data, be able to undertake statistical analysis and assist researchers and analysts in obtaining the appropriate data to meet needs. This position requires the expertise to undertake the initial research questions of the CFD Commission, including on Multi-System Families, evaluate

agency programming, and assist in evidence-based policymaking.

4. Legal/Privacy/Ethics Expert. This FTE will have legal expertise in drafting and negotiating MOUs, an understanding of the historical, cultural, and ethical implications surrounding data use, and an interest in protecting the privacy and security of individually identifiable information.

#### **Data Linkage Staff**

Secure data linkage and de-identification is critical to ensure data is protected. The Department of Health has experience in data linkage and the secure systems to store, clean and link the data from the state agencies.

Proposed legislation will place this responsibility, as well as assisting with compiling data for research requests, with the Department of Health or other qualified entity experienced in data linkage with the highest levels of data security. This work will be handled by four employees.

#### **State Agency Staff**

The most profound barrier to agencies using their own data to evaluate programs or identify the most at-risk children may be the lack of staff to guide them through the process of identifying a research agenda. Questions such as "what are the top three risk factors for repeat infant or child maltreatment" and "does the program the agency funds have the desired outcomes," are left unanswered due to a lack of time and/or the appropriate skillset among existing staff members.

A CFD Policy Officer will be placed at four state agencies to ask the important questions and find the answers. Agency staff is already stretched thin trying to meet current deliverables and there is not any single position responsible for evaluating the overarching goals and outcomes of each agency. CYFD, PED, DOH, and HSD will all receive CFD Policy Officers with the goals of defining research agendas and changing agency culture to one of evaluating outcomes, versus outputs. The CFD Policy Officer would be responsible for liaising with the CFD Commission, including assisting with data-sharing and evaluating research requests,

assisting the agency in critically evaluating its work, and helping connect research findings with the appropriate policy-maker.

A critical component of this position is to foster a culture of both evidence-based policymaking and data sharing at each agency to promote cross-sector collaboration. In conjunction with the CFD Commission staff, the CFD Policy Officer will hold workshops for agency staff to foster a culture of data sharing with small pieces of existing data. This will help state agencies become more comfortable with the process of data sharing and increase data literacy, identify areas for cross-sector collaboration, and promote a more outcomes-focused approach to providing social services.

#### **Budget Narrative**

Developing evidence-based policy and programs and moving towards an outcomes-oriented approach to providing services will require an initial modest investment from the state of \$1,869,000 per year for the first and second years. We expect that this investment will pay dividends, however. The state will have the ability to ascertain which programs are effective and thus determine which ones provide the most significant return on investment. State agencies can better understand the Multi-System Families they are serving and shift their focus to prevention and stabilizing services, as opposed to desperately triaging critical problems.

We already know that incarceration, child abuse and neglect, behavioral health issues, and other pressing problems have long-term physical and emotional repercussions on families, as well as a huge financial and social cost to the state.

Understanding who Multi-System Families are and ensuring they are served by effectual programs on the front-end will generate long-term cost savings for the state. For a more detailed budget, please see Appendix B.



IN ORDER TO STOP THE INTERGENERATIONAL POVERTY, THE STATE MUST BE ABLE TO ANSWER THREE CRITICAL QUESTIONS:

- 1. Who needs services?
- 2. What services are they getting?
- 3. Are those services effective at achieving their desired outcomes?

New Mexico has no capacity to do this and this lack of capacity means that few children and families get the quantity and quality of services they need to stabilize and thrive.

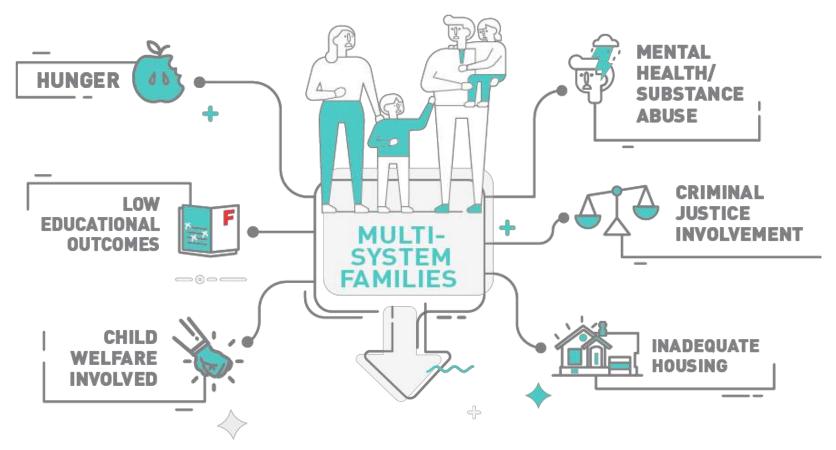
Each year New Mexico is at the bottom of the list for child welfare, educational outcomes, poverty levels, and food security. The Annie E. Casey Foundation's Kids Count Databank ranked New Mexico 48th in economic wellbeing and 50th in education for children [8]. In 2015, New Mexico had the highest percentage of public school fourth graders not proficient in reading, at 77 percent [9]. In 2016, 30 percent of children in New Mexico were living in poverty and in 2015, 28 percent of households were food insecure [10]. The state also has one of the highest child abuse rates in the country [11].

The children who live these statistics often belong to the most complex, expensive, and difficult to serve families who cycle through multiple social services systems. These Multi-System Families may experience mental health or substance abuse disorders, inadequate housing, food insecurity, and poor educational outcomes.

With rare access to the full spectrum of resources these individuals and families need to address their often complex and co-occurring problems, they bounce among multiple social service systems such as child protective services, corrections, and emergency departments with little to no improvement.

A typical family that seems incapable of exiting the cycle of chaos and poverty has many co-occurring problems and interacts with different state agencies and systems. A child's mother may have substance abuse issues that lead to frequent trips to the ER and her eventual arrest. His father may be unstably housed and food insecure, thus unable to provide a stable home environment or even meals for his children.

# MANY OF THE HARDSHIPS OF MULTI-SYSTEM FAMILIES ARE CORRELATED AND OFTEN CAUSAL



Inadequate housing puts children more at risk for child maltreatment and poor educational outcomes [12]. Having a parent in prison increases a child's risk for trauma and toxic stress [13]. Children who spend time in foster care are at a higher risk for mental and physical health problems [14].





Cases of child neglect are more correlated with poverty than other forms of child maltreatment. Neglect is more likely to be recurring than physical or sexual abuse and can have much more devastating long-term effects [15]. As a result, many adults who were victims of neglect struggle with un-/under-employment, behavioral health issues, and/or substance abuse. As factors compound, they can become more inclined to neglect their own children.



### SUBSTANCE ABUSE IS CORRELATED WITH CHILD MALTREATMENT

One-third to two-thirds of child welfare cases involve parental substance abuse as a contributing factor [16]. One study concluded that children living in a home with a substance-abusing mother were more likely to suffer from neglect and maltreatment than those with a mother who has depression, or even co-occurring substance abuse with depression [17]. Without intervention, the risks to these children remain high over time.



IF A CHILD HAS NO STABLE AND SAFE PLACE TO LIVE, THEY ARE MORE LIKELY TO ENGAGE WITH CHILD PROTECTIVE SERVICES

According to a report from the University of Chicago, homeless or insufficiently housed families are more consistently subject to child welfare services involvement than low-income families that are stably housed.

In 2012, 11 percent of children in foster care nationally had been placed there due to issues related to homelessness.

While poverty and neglect are often poorly delineated and do not necessarily precipitate one another, it is likely that the additional stress of housing instability on parents can lead to child abuse or neglect [18]. This proves true in New Mexico: among mothers with children in state custody, approximately 72 percent are homeless or lack adequate housing and 76 percent are unemployed or have inadequate resources to meet their family's needs [19].



IF A CHILD HAS NO STABLE AND SAFE PLACE
TO LIVE, THEIR MOTHERS ARE MORE LIKELY
TO HAVE MENTAL HEALTH PROBLEMS

Housing instability is also correlated with cooccurring mental health and/or substance abuse
among parents. A study in Massachusetts found
the occurrence of mental health disorders to be
three times higher among homeless mothers
than mothers who were adequately housed.
Further, homeless mothers have been found to be
twice as likely to have substance abuse issues,
with 41.1 percent of that population dealing with
substance abuse versus 20.3 percent of housed
mothers from all socioeconomic backgrounds
[20].



HOMELESSNESS AND HOUSING INSTABILITY
IN EARLY CHILDHOOD CORRELATE WITH
DELAYS IN CHILDREN'S LANGUAGE, LITERACY,
AND SOCIAL-EMOTIONAL DEVELOPMENT [21]

Pregnant women experiencing homelessness are less likely to receive adequate prenatal care than stably housed mothers, and their children are at increased risk for low birth weight, which can negatively affect a child's cognitive, physical, and social-emotional development [22]

# MULTI-SYSTEM FAMILIES ARE THE MOST EXPENSIVE TO THE PUBLIC



New Mexico Appleseed's very rough estimate, based on the Chapin Hall study, is that 16,000 Multi-System Families use almost 900 million dollars in public services, with about \$53,000 spent annually on each of these families [23]. There is a confluence of factors that may affect the high cost of Multi-System Families.

Agencies may provide services that fail to address the root cause of problems, leading to an ongoing need for services that are never tailored to a particular family's situation.

Overlapping service needs may be an indicator of complex and seemingly intractable problems, yet there is no coordination among agencies to ensure that comprehensive and cost-effective (yet not redundant) services are being provided.

Agencies consider only individual issues rather than the whole family picture, thus missing the intergenerational component present in many Multi-System Families and the likelihood that involvement in one system, such as corrections, may lead to involvement in another, such as foster care.

Problems may only be dealt with on an emergency basis and utilize the most expensive forms of care: emergency department visits instead of a visit with a primary care provider, inpatient behavioral health treatment rather than treatment in a community setting. Furthermore, agencies are unable to meaningfully use data to identify service gaps that could aid in preventing problems or steering families towards less expensive but effective alternatives. Because there is very little data sharing or collaboration among agencies, families and children may be receiving ineffective services, paid for with taxpayer dollars, which result in continued problems for Multi-System Families.

"New Mexico Appleseed's rough estimate, based on the Chapin Hall study, is that 16,000 Multi-System Families use almost 900 million dollars in public services, with roughly \$53,000 spent annually on each of these families [23]."

#### THE FRAGMENTED DATA I ANDSCAPE IN NEW MEXICO

#### SILOED SYSTEMS FAIL MULTI-SYSTEM FAMILIES



# A FAILURE TO SEE RISK FACTORS MEANS AN INABILITY TO PREVENT PROBLEMS

Because the agencies that serve these complex families have limited data sharing and collaboration across sectors, they have no ability to understand the constellation of needs a child or family may have, know what services they are receiving, and determine whether any of those services are effective.

Failure to share data means an incomplete understanding of the complex and multiple forces that shape the lives of these most fragile New Mexicans and frustration among the public servants whose life work it is to help these families.

Risk factors for a child abuse problem may be found in corrections data. Risk factors for failure to read at a third grade level may be found in the mother's health data.

A caseworker at CYFD may be investigating a homeless family that has an allegation of child neglect, yet have no idea that homelessness is a risk factor for future abuse. HSD may be evaluating why it has unusually high neonatal intensive care costs in one part of the state, but have insufficient access to data to reveal with any real granularity the cohorts utilizing the neonatal intensive care units, thus making it difficult to improve outcomes for those infants and reduce Medicaid costs

Agency staff, teachers, physicians and service providers alike can never adequately serve Multi-System Families and improve their outcomes without a meaningful understanding of the full spectrum of problems and risk factors those children and families face.

# NO STATEWIDE EFFORT TO INTEGRATE DATA

New Mexico's fragmented data systems sow confusion about who "owns" the data and what the parameters around access are. While there have been and continue to be scattered attempts to integrate our data for one-off projects, there has been no prior effort to create a statewide integrated data system or clearinghouse.

Each disconnected endeavor to share data has come about through individually negotiated data sharing agreements that can take years to execute and never lead to ongoing data integration for multiple purposes.

The herculean effort it takes to carry out even a limited data integration project discourages agencies and policymakers from pursuing them. Most concerning, none of the previous efforts to integrate data have created a governance system that clarifies the parameters of data access and use for agencies, researchers, service providers, and other stakeholders.

Who can see and use what data remains opaque, thus discouraging researchers, stakeholders, and even agency staff from attempting to integrate data for evaluation and analysis. As a result, New Mexico continues to operate in the dark about what works, for whom, and why.

### A COMPLEX DATA MAP AND LACK OF ACCESS

In addition, these limited data sharing attempts have added to the complexity of New Mexico's data map by creating yet another detached dataset in a state where there are already numerous and overlapping datasets.

The Bureau of Business and Economic Research (BBER) at the University of New Mexico mapped the different New Mexico datasets available at the state and federal level. It is a complex and complicated map rife with duplicative data collection efforts and failed or incomplete data sharing efforts.

Even within a single agency, there may be numerous datasets, making case management and data integration within the agency unnecessarily complicated. For example, CYFD has twenty-five different datasets. After attempting to merge its twenty-five different databases into a single database called EPICS, the agency was thwarted by cost overruns, delays, and mismanagement.

Justice data is also scattered. State corrections information is housed in one database, while county jails maintain their own information, which is not automatically shared with the state. Some state data is shared with the federal government, which then collates the data into a separate dataset. Sometimes, one dataset may be made available to researchers, while an agency or division holding the same information in a separate dataset may render it unavailable, despite the fact that there are no clear legal or ethical hurdles prohibiting access.

Agencies have reported that even when they have a clear legal mandate to access certain data, their requests may be rebuffed and there is little recourse available. Some of this reluctance to share data may stem from uncertainty about what is legally permissible under state and federal privacy laws, concerns about what the data will be used for, and a lack of agency leadership that promotes a culture of data sharing.

Regardless of the reason, however, it contributes to the confusion about what is available and who may access it, and makes it difficult to use data to develop actionable intelligence.

## EXISTING DATA-SHARING EFFORTS IN NEW MEXICO

There are data sharing efforts in New Mexico, some in the very nascent stages, including the following:

- New Mexico Community Data Collaborative
- ► Early Childhood Integrated Data Systems (ECIDS)

- New Mexico Human Services Department's Medicaid Management Information System Replacement Project (MMIS Replacement Project)
- ► Bernalillo County's Data Driven Justice project
- ► CYFD's Comprehensive Child Welfare Information System (CCWIS).

These efforts recognize the value of shared data in developing policy and improving the delivery and coordination of services. Until now, however, there has been no effort to create a statewide, integrated data system.

### FRAGMENTED EFFORTS AT CROSS-SYSTEM COLLABORATION

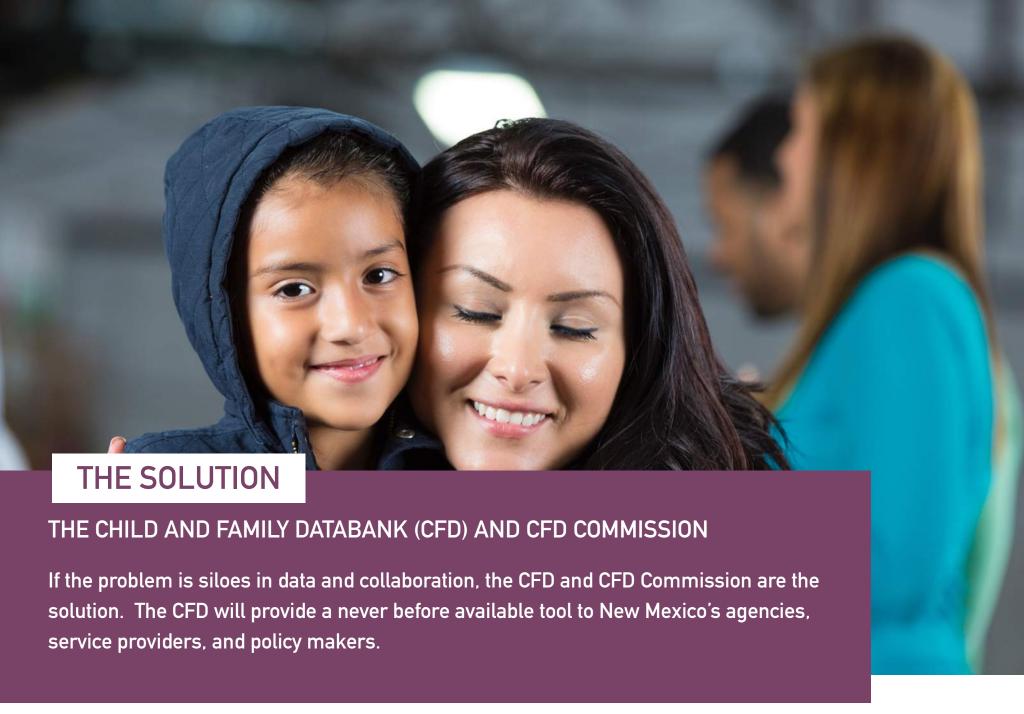
There have also been efforts to facilitate cross-system collaboration that focus on the needs of families and children, in particular the most vulnerable who are often interacting with multiple systems. These include the Children's Cabinet under Governor Richardson, which focused on child welfare and early education, the Early Childhood Funders Group, and the J. Paul Taylor Task Force.

These initiatives have taken a multi-disciplinary approach to tackling the issues New Mexico children face, but are limited in their access to and use of data to assist in their analysis and have had varying degrees of success in translating their recommendations into concrete policy actions

They have also focused more on the children and less on the issues facing the whole family unit.

Furthermore, the attempts at cross-sector collaboration are limited and none were connected to or fueled by an asset such as the CFD. For example, the Children's Cabinet only had representation from agency secretaries and not service providers or issue area experts.

The Early Childhood Funders Group is only comprised of foundations. And even to the extent these entities were able to promote cross-sector collaboration in the identification of problems and proposed solutions, for the most part this has not carried over into how agencies evaluate programs or deliver services to children and families. Without a mechanism to encourage collaboration and strong, multidisciplinary leadership to oversee it, for the most part state agencies continue to think and operate in silos.



Using this data, the CFD Commission can create a comprehensive representation of the issues facing New Mexico's most vulnerable children and families. Policymakers and researchers will have actionable intelligence to develop better policy and evaluate programs.

New Mexico Appleseed is spearheading legislation for the 2019 legislative session that will establish and outline the duties of the CFD Commission, mandate that agencies share their data with the CFD, and appropriate funds to implement the act [24]. New Mexico Appleseed has obtained broad support for the legislation from a diverse group of stakeholders, including the leadership and highlevel staff of the Legislative Finance Committee, Legislative Health and Human Services Committees, CYFD and DOH, UNM, and many legislators.

Administrative data, which is data collected by the government for registration, transaction, record keeping and other administrative purposes, is a treasure trove of information. Linked administrative data at the individual and family

level can provide state and local agencies and their partners a more robust understanding of the population they are serving, including comprehensive information on the full spectrum of services families are using. Agency staff, researchers, and their other partners, assuming all privacy and confidentiality safeguards are met, could have access to data across someone's life span and be able to better understand how programs affect people at different points in their life, and how one intervention or service may have a ripple effect in different areas.

Linking existing administrative data across state agencies creates a clearer picture of how a program may have affected participants, including access to housing, employment, educational attainment, utilization of social and human services, and health care, and the length of time a program has measurable beneficial effects on participants. This evidence-based analysis [25] also provides a more comprehensive measurement of the cost savings downstream (or lack thereof) that can be tied to a program.



# HOW THE CHILD AND FAMILY DATABANK (CFD) AND CFD COMMISSION ARE BUILT FOR SUCCESS

New Mexico has been slowly moving in the direction of sharing data and promoting cross-sector collaboration. The CFD and the CFD Commission build upon these efforts and will create a comprehensive system to continue this work.

1. A Governance System that Creates Clear Parameters Around Data Storage, Access and Use

The CFD Commission, in cooperation with agencies and with staff support from the CFD Commission, will establish a governance system for the linking and sharing of agency data for program evaluation and policy development. The governance infrastructure will provide for ongoing data sharing among agencies and with outside researchers through legal, ethical, secure, and transparent procedures. Sharing historical and contemporaneous data [26] across agencies,

not simply within an agency or between two agencies for purposes of case management, will bring unity and efficiency to what has been a piecemeal and fragmented movement.

There will be a clear process for how data must be securely stored and for controlling data access, including what data may be shared, how it may be accessed, agreements that must be executed, and any fees to cover the CFD Commission's costs of linking or scrubbing the data for outside researchers.

Having a governance system for continuous data sharing will save agencies and researchers time and cost, as they will no longer need to negotiate and draft new MOUs for each data sharing effort.

The CFD and CFD Commission will also have the expertise to understand what data may need to be de-identified or shared in aggregate form to address the legal and ethical concerns of sharing protected



information. Rather than continue to expend finite state resources on myopic or one-off data sharing efforts, the CFD Commission will develop an ethics-informed and transparent governance process to determine which data may be shared with agencies, researchers, and other stakeholders.

## 2. Creating a Culture of Transparency

Because the heads of state agencies will serve on the CFD Commission, the highest leadership will understand the value of using data to develop actionable intelligence and promoting collaboration across sectors.

Moreover, part of the job of the staff at the CFD Commission is to support agencies in their own evaluation and analysis efforts.

Agencies will be permitted and encouraged to use the CFD Commission staff to better understand the services they are providing, the population they are serving, and what is working. This will demonstrate first hand the value that integrated data and the CFD Commission provides.

### 3. Cross-Sector Collaboration to Effectuate Meaningful Change

The CFD Commission will bring together high-level experts and people on the ground. A mix of agency representatives, researchers, and subject matter experts comprise the CFD Commission, the right people will be at the table to share the information with legislators and policymakers and effectuate meaningful change.

Data can illuminate risk factors, preventative factors, demonstrate what programs and policies are working, and provide a more complete picture of vulnerable families. The actionable intelligence derived from data, however, also needs to be informed by the qualitative stories on lived experiences. Only then can effective and culturally sensitive policies be implemented.

# 4. Feedback Loop From Research to Policy Change

Too often, good research ends up on the shelves of the researchers and the findings are never woven into improved policies. One of the strengths of the CFD Commission is to bridge this gap between research and action.

The CFD Commission is equipped to support the translation of information into concrete actions and policy changes that benefit New Mexico's most vulnerable children and families.

The CFD Commission will have mechanisms to do the following:

- Disseminate findings,
- Assist agencies with determining their research priorities, program assessment and deciding best policies to pursue, and
- Support ongoing evaluation and cost analysis.



When fully operational, the CFD should ultimately save and more effectively use significant public dollars. The sections below illustrate a few examples of how data integration can be transformative both to child and family outcomes and to public budgets.

# PREVENTION OF COMPLEX AND EXPENSIVE PROBLEMS

One of the first tasks of the CFD will be to use integrated data to study Multi-System Families to enable prediction and prevention of problems. This will allow the state to understand with much more granularity the composition of these families, the services they utilize, and the cooccurring risk factors. It will permit state agencies and service providers to design a system that holistically addresses the needs of these vulnerable children and families, rather than providing uncoordinated and ineffective services that consume the majority of the social services budget. The state could prioritize access to services on data-driven risk factors, rather than haphazard guesses. The goals of agency programming will be to reduce child abuse and neglect, improve educational outcomes among atrisk children, promote family stability, and end the cycle of intergenerational poverty. Agencies could also evaluate the cost-benefit ratio of their programming, to understand how agencies dollars are being spent and promote better stewardship of resources.

#### PROGRAM EVALUATION

The CFD will also be instrumental in determining the efficacy of all programs in New Mexico. There has been growing support for program evaluation and the implementation of evidence-based policies in New Mexico. The LFC has worked with the Pew Macarthur Results First Initiative ("Results First") to inventory and encourage the use of evidence-based programs in New Mexico. To date, this work has focused on child welfare, corrections, early education, and adult and child behavioral health programs [27].

While this outcome-focused analysis is commendable, the Results First approach does not use New Mexico specific data to determine whether any programs achieve their stated objective. The determination as to whether a program is evidence-based is almost entirely based on research conducted in other states [28].

While other states use their data to complete randomized controlled trials on program efficacy, New Mexico has no mechanism to do this. Instead, funding is often tied to how many people are served and not how effectively they are served. With the CFD, researchers could use New Mexico data to inventory existing New Mexico programs and determine whether programs are achieving their stated objective. The CFD will help determine which programs are ineffective or most cost-effective, and generate cost savings for the state.

# EVALUATING EARLY CHILDHOOD PROGRAMS TO CLOSE ACHIEVEMENT GAPS

Even with the Results First initiative, there are still many programs in place that are not evidencedbased or for which the effectiveness is uncertain, not to mention the programs that continue to receive funding even in light of evidence that they are ineffective. The state of New Mexico has identified early childhood care and education as a state priority, in no small part because New Mexico lags behind in almost every child welfare indicator. In a 2017 report, the LFC noted that home visiting programs in New Mexico "are not tied to evidencebased programming, and specific outcomes and return on investment are uncertain [29]." Many home visit models are evidence-based and shown to have positive returns for each dollar invested. Yet the state, even in an area designated as high priority, does not have the means to conduct the research and analysis to ensure tax dollars are invested wisely.

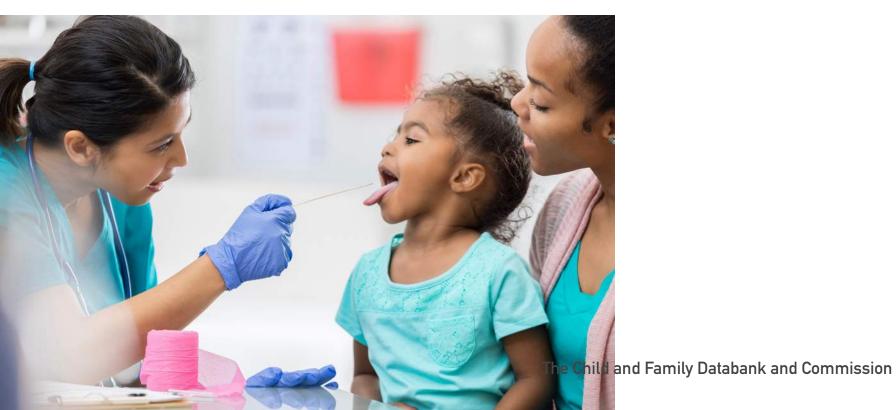
Understanding early childhood and school readiness, and later in life, the educational achievement gaps among various cohorts of students, is not achieved through reductionism. Factors such as access to prenatal care and medical care, health of the birth mother, involvement of the parents, housing instability or homelessness, interaction with the child welfare system or other adverse childhood events, behavioral health and substance abuse issues, and many other elements play a role in determining the well-being of a child. The CFD can help policymakers determine an evidence-based path forward for early childhood programs.

# IMPROVING HEALTH CARE DELIVERY AND ENSURING COST EFFECTIVE USE OF MEDICAID DOLLARS

The CFD will help improve the delivery of healthcare and reduce costs. South Carolina launched a telepsychiatry program to address the critical shortage of mental health professionals at rural hospitals. Patients and emergency room physicians could consult with psychiatrists who accessed the statewide electronic health record system and information on substance abuse and criminal justice. Researchers used administrative data to conduct a low-cost randomized control trial and found that telepsychiatry patients were more likely to receive follow-up care, less likely to be admitted as an inpatient from the emergency room, had a shorter length of stay if admitted to inpatient treatment, and had lower overall thirty day costs associated with their episode of care [30].

Indiana analyzed its administrative data to determine why it had a high infant mortality rate. The researchers found that young mothers on Medicaid were not receiving the recommended number of prenatal visits, and this high-risk population comprised only 1.6 percent of all births in Indiana but nearly 50 percent of deaths. This led the Department of Health to commence targeted outreach to this high-risk cohort and commence a statewide education campaign.

In a state with frequent budget crises and alarming statistics on child welfare, New Mexico can no longer afford to operate in the dark when serving our children and families.





### PRIVACY AND ETHICAL CONCERNS

Of paramount concern to the CFD Commission is the privacy safeguards surrounding the data, and developing a process to ensure that any use of the data is subject to stringent ethical review.

Administrative data is a valuable asset that can provide powerful knowledge and be used to improve the lives of vulnerable children and families. Any use of such data, however, must be subject to the highest standards of confidentiality.

The CFD Commission has a duty to protect the privacy and security of administrative data, and to be thoughtful in how any information is used and shared. Administrative data is a type of public good, entrusted to the government for safekeeping, and the government has a duty to uphold the trust placed in it.

#### PRIVACY PROTECTIONS OF DATA

Any integrated data system will have the challenging, but manageable task of protecting the privacy and addressing the legal issues surrounding the sharing of administrative data.

Successfully overcoming these challenges entails providing agency attorneys with accurate and up-to-date information on the legality of data-sharing arrangements, education on how data can be shared securely (and updated systems if necessary), and creating a top-down culture of transparency and trust that data-sharing is permitted and can improve the ability of the agency to carry out its mission.

Many agencies take an overly cautious position and err on the side of not sharing data even when it is permissible, citing for example, the Health Insurance Accountability and Portability Act (HIPAA) or Family Educational Rights and Privacy Act (FERPA) as justification for their refusal to share certain information. Yet both HIPAA and FERPA permit individually identifiable information to be used for research provided certain safeguards are in place.

An integral safeguard in any data sharing arrangement is having upto-date and legally compliant MOUs in place that clearly explain each entity's obligations with respect to the data, how it may be used, and how it must be protected.

The number of individuals that will actually view identifiable data shared with the CFD Commission will be quite small and DOH (or another designated entity) is well-equipped to securely use, store, and transmit data. Many of the other integrated data systems around the country have only a handful of individuals, or sometimes a single individual, who link the data and see information with intact identifiers. Information released to researchers and agency staff will be deidentified, meaning all identifying information such as names, social security numbers, and addresses have been removed, or the information will be aggregated.

Any data that is released should also be reviewed to ensure that it does not violate anyone's right to privacy or that the data may not be re-identified, either through extrapolation due to small sample size or by combining the data with another source of information.

For example, if a study on substance abuse among recent correctional parolees in each county only included two individuals in one rural county, the information from that county would not be released because of the risk that the individuals could be re-identified. In addition, myriad security features will be in place to protect any information transmitted or stored in the CFD and it will adhere to the most stringent security practices.

These features are standard in a system that stores, uses, or transmits sensitive and confidential data. This will include limits on who can view or use the data, the encryption of computers and networks, the secure and encrypted transmission of data, and special protocols and limits on accessing the data for research.



#### ETHICAL USE OF DATA

As part of its work, the CFD Commission will develop a process to evaluate the ethical implications of any proposed study. Any use of the data must only be to help, never to harm. The CFD Commission will promulgate guidelines on the approval process for research. Any research requests from outside researchers will need to be approved by an Institutional Review Board (IRB).

Agency research requests will either need to go before an IRB or be subject to a similarly stringent internal ethics review. When drafting the guidelines, the CFD Commission will include a mechanism to determine whether any unintended

consequences might ensue from a study and ensuring the data use and policy recommendations are free of any discrimination (even if unintended).

The CFD Commission will also operate in a culturally competent manner and have Commissioners representing groups whose data is likely to be used, as historically many of these vulnerable groups have experienced a long history of discrimination and misuse of their information.

Respectfully and safely sharing and using data can reveal which programs do and do not work and engender informed, evidence-based discussions on policy. This can help ensure that taxpayer and philanthropic dollars are used efficiently and that our most vulnerable communities benefit from thoughtful, effective and targeted programs and assistance.

### PROPOSED TIMELINE FOR IMPLEMENTATION

# FY 2019

- ▶ Develop stakeholder support for the CFD and meet with agency staff, the executive branch, and policy makers. Begin fostering an open dialogue and broad support for a data sharing environment.
- ► Prepare a comprehensive legislative package for the New Mexico 2019 legislative session.
- ▶ Hire and train all CFD Commission staff and CFD Policy Officers.
- ► Identify appropriate data sources for incorporation in the CFD and continue outreach efforts to data owners or holders.
- ► Continue outreach with existing data integration efforts and determine collaborative strategy.
- ▶ Begin developing a training program for agency staff, in conjunction with agencies.
- ► Assist state agencies in preventing children from entering foster care with a focus on prevention using funding streams under the Family First Act.

## FY 2020

- ▶ Begin the work of convening the CFD Commission and developing a stakeholder informed governance process to facilitate ongoing data sharing across agencies.
- ► Convene with existing agencies to make use of the data they have already collected, including developing a snapshot of children utilizing each agency's services.
- ▶ Work with NM child advocates and agencies to develop indicators of child wellbeing through an open data strategy.
- Promote greater availability of granular child-wellbeing indicators and evaluate best method of dissemination, such as through a data dashboard.
- ▶ Work with state agencies to determine how data will be linked and data privacy and security will be maintained.
- ▶ Develop a process for managing metadata.
- ▶ Promulgate legal and ethical guidelines as to who may use the data and for what purposes.
- ▶ Negotiate and draft MOUs with state agencies.

# FY 2020

- ► Continue work with agencies and CFD Policy Officers to develop research priorities.
- Continue to develop training program for agency staff on data use and literacy and evidence-based policymaking.
- ► Create protocols to clean and organize data for maximum effectiveness and ease of use.

## FY 2021

- ► Finalize governance structure for the CFD.
- ► Execute legally compliant MOUs.
  - Once MOUs are in place, begin process for linking data.
- ▶ Use data to evaluate resource gaps and begin determining sufficiency of service provision.
- ▶ Use data to obtain unduplicated count of families served and begin identifying duplicative or redundant programs.
- ▶ Perform first round of data analysis.
  - Focus on determining co-occurring risk factors.
  - Randomized control trials to determine program effectiveness.
- ▶ Evaluate results from data analysis and make methodological adjustments.
- ► Continue outreach and engagement with agencies on value provided by CFD Commission.
- ▶ Identify areas for improved data collection and/or management.
- ► Continue review of research proposals.
- ► Continue data analysis and development of policy recommendations with a focus on clients that are shared across agencies.
- ► Evaluate effectiveness of communication of programmatic evaluation and policy recommendations to interested parties.
- ► Evaluate early effectiveness of policy and programmatic changes at the state and agencies, including any improved outcomes and cost savings through elimination of duplicative or ineffective programming.

# FY 2022

# FY 2022

- ► Continue to negotiate and execute any outstanding MOUs.
- ► Consider inclusion of additional data into the CFD, such as county or federal data.
- ► Continue exploring creative avenues for continued funding of the CFD and the CFD Commission such as through philanthropy, work with the state to appropriate funds as necessary.

**FY 2023** & BEYOND

▶ Maintain ongoing operations of the CFD.



### CONCLUSION

As long as data about individuals and families from various state agencies is housed in siloes with no mechanism to integrate and evaluate it, New Mexico cannot distribute its services methodically, evaluate the efficacy of those services, identify the risk and protective factors of complex families in New Mexico, and develop policies informed by rigorous research.

This contributes to the long-term failure in addressing poverty and its symptoms in New Mexico. Government has an ethical obligation to ensure that effective programs and policies serve constituents. The establishment of the Child and Family Databank (CFD) and CFD Commission is

critical to improve the lives of children and families in New Mexico.

The main thrust of the CFD Commission's work will be to formalize and operationalize the sharing and linking of data for research and policy development. The CFD Commission will oversee the CFD, a repository of administrative data that will likely, under the auspices of a Cooperation Agreement, be stored at a state agency such as DOH that already has the capacity to maintain and protect sensitive data. Agencies will have a formal mandate to regularly share their data with the CFD Commission. Resources permitting, the data will be linked on an on-going basis to maintain a core linked dataset

### THE CFD COMMISSION, IN COLLABORATION WITH AGENCIES, WILL DEVELOP THE GOVERNANCE **INFRASTRUCTURE TO DO THE FOLLOWING:**

- ▶ Identify relevant data to carry out the CFD Commission's work;
- Link and share administrative data in accordance with legal, ethical, and privacy safeguards;
- De-identify any shared data:
- Evaluate, assist with, and approve research requests,
- Routinize cross-sector collaboration: and
- Assist agency staff, researchers, and legislators to develop effective policy solutions for our state's most vulnerable families.

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Elements of the CFD Commission's work include establishing a secure framework for the CFD, drafting legal and ethical guidelines to oversee data access and review research requests, executing MOUs with the appropriate agencies and preparing data access agreements for researchers, creating data security and usage policies, having a mechanism for ongoing community and stakeholder engagement, reviewing research results, and having effective plans to disseminate findings from examinations and enquiries.

A strong and transparent governance system for data linkage and sharing is at the heart of the CFD Commission. The Commission is not

creating a new IT system with the CFD, in fact, much of the technology to store and link the data already exists at state agencies, and there are also open source data linkage programs available. The purpose of the CFD Commission is to institutionalize cross-sector collaboration and learning across state agencies, and leverage the capacity and knowledge of issue area experts, service end users, and service providers to develop better policy to serve children and families in New Mexico.



### **APPENDIX A**

In 2010, Chapin Hall at the University of Chicago published the results of a study that identified the cost and service usage of Multi-System Families in Illinois [35]. The study showed that a relatively small percentage of families consumed a significant portion of the social services budget. To determine family units that used multiple services, researchers linked agency records of families that had (1) at least one substantiated abuse and neglect case, and (2) were recipients of TANF payments or food stamps.

Once the researchers had identified the family units, they searched for any family members that received mental health care, substance abuse treatment, foster care, or were involved with corrections or juvenile justice. The researchers looked at Medicaid paid claims and data from Children & Family Services and Adult and Juvenile Corrections. The researchers found that 23 percent of Illinois families in this study population used two or more services and these Multi-System Families accounted for 86 percent of the resources spent by the agencies.

There has not been a similar effort in New Mexico to use existing administrative data to quantify service usage and cost of Multi-System Families. To develop an estimate of how our social service agencies may be allocating resources, we applied the same percentages that the Chapin Hall study determined for the Illinois population to the New Mexico costs for comparable services [36].

We believe this to be a reasonable methodology to derive a rough approximation of the costs of Multi-System Families in New Mexico, first, due to the rigorous approach applied by the Chapin Hall researchers, and second, because New Mexico's families are considerably worse off by several measures (poverty, child maltreatment, etc.) than those in Illinois. As such, it is reasonable to expect that families in New Mexico will also have overlapping needs, as the Illinois families did.

Table 1 – Chapin Hall Comparison USD\$ Millions

	FY12	FY13	FY14	FY15	FY16*
CYFD Protective	109.9	124.6	130.4	135.1	142.3
Medicaid Behavioral Health	283.6	290.3	343.3	448.1	485.8
Behavioral Health Services	57.2	60.0	61.4	62.5	60.3
CYFD Behavioral Health Services	0	0	0	15	17.2
Juvenile Justice Facilities	39.5	67.7	73.8	73.2	73.7
Inmate Management and Control	234.2	242.0	244.0	250.9	258.8
Total	724.4	784.6	852.9	984.8	1038.1
86 percent	622.984	674.756	733.494	846.928	892.766

Using this methodology, we estimated that in 2016 there were approximately 16,700 multi-service families [37] in New Mexico consuming roughly \$900 million worth of select social services provided by the state [38] [See Figure 1]. That equates to roughly \$53,000 spent annually on each Multi-System Family [39].

The overall spending represents a 43 percent increase over the 5-year fiscal period beginning in 2012, although some of this is due to rising Medicaid expenditures from the implementation of the Affordable Care Act. The specific services measured include juvenile and adult incarceration [40], Medicaid and CYFD behavioral health spending, and protective services for abused and maltreated children. [See Table 1]. These figures represent a combination of both federal and state money.

Figure 1 – Multi-Service Family consumption of services in New Mexico (USD\$ millions)



### **APPENDIX B**

Figure 2 – The Child and Family Databank and CFD Commission Budget (USD\$)

Category	Description	Year 1	Year 2
CFD Commission S	staff Salaries		
	Executive Director	\$105,000	\$105,000
	Lead Data Scientist	\$100,000	\$100,000
	Two Data Analysts (\$85,000 each)	\$170,000	\$170,000
	Legal/Privacy/Ethics Expert	\$95,000	\$95,000
	Benefits @ 30 percent	\$141,000	\$141,000
	CFD Commission Staff Total	\$611,000	\$611,000
CFD Policy Officers			
	Four CFD Policy Officers (\$85,000 each)	\$340,000	\$340,000
	Benefits @ 30 percent	\$102,000	\$102,000
	CFD Policy Officers Total	\$442,000	\$442,000
Department of Hea	lth (or other entity) for hosting the	e CFD	
	Supervisor	\$85,000	\$85,000
	Two Linkage Analysts (\$80,000)	\$160,000	\$160,000
	IT System Administrator	\$75,000	\$75,000
	Benefits @ 30 percent	\$96,000	\$96,000
	Total Budget	\$416,000	\$416,000
Operating Budget fo	or CFD Commission		
	Supplies, Computers, Printers, Overhead Expenses, Rent	\$180,000	\$180,000
	Travel	\$20,000	\$20,000
	Total Commission Operating Budget	\$200,000	\$200,000
Materials and Syste	em		
	The CFD Design and Build (software licensing, etc.)	\$150,000	\$150,000
	Storage Area Network	\$50,000	\$50,000
	Total Materials and System Cost	\$200,000	\$200,000
		\$1,869,000	\$1,869,000

### **APPENDIX C**

#### **CASE STUDIES**

#### **CHILD WELFARE**

#### 1. CHILD SUPPORT PAYMENTS DELAY FAMILY REUNIFICATION [41].

- Wisconsin pursued child support payments to offset the cost of a child's out of home placement.
- An analysis showed child support payments increased the time a child spent in foster care, and a \$100 increase in a monthly child support order was estimated increase time a child spent out of home by 6.6 months.
- After analysis, Wisconsin will only send a referral for child support payments if the child has been out of the home for over 6 months and the parent is not making strides towards reunification.

#### 2. CONCURRENT TANF BENEFITS SUPPORT FAMILY REUNIFICATION [42].

- Washington officials evaluated the effect of maintaining TANF benefits when a child was removed from their home.
- ▶ Officials found that families that were able to maintain benefits had higher rates of reunification and spent less time out of the home.
- Concurrent TANF benefits were mainly cost neutral, supported family reunification, and remained in place.

#### 3. DIVERTING CHILDREN FROM CONGREGATE CARE SETTINGS [43].

- West Virginia had a high rate of children placed in congregate care settings, such as group homes, psychiatric institutions, or emergency shelters, which is costly and not best practice in child welfare.
- ► The data showed majority of children in congregate care were between the ages of 12-17, had multiple interactions with the child welfare system from a young age, and could be better served in a community or family setting.
- ► The state established Safe at Home, a program that took children who might end up in congregate care, and placed them in a foster home or with family and provided wraparound services, such as therapy, public benefits, and other supportive services.
- An analysis of the Safe at Home program showed a reduction in child needs (such as school behavior issues) and children referred to program experienced fewer and shorter stays in congregate care.

#### 4. CALL-SCREENING TOOL TO AID IN PROCESSING REFERRALS [44].

Allegheny County used administrative data to develop a predictive risk model designed to improve call screening decision-making in the county's child welfare system.

- ► The model helps determine whether a referral should be screened in for more investigation or screened out.
- Model expected to increase accuracy and consistency in decision-making process on follow up of referrals.

#### 5. IDENTIFYING FAMILIES MOST AT RISK FOR SERIOUS RECIDIVISM IN CHILD WELFARE [45].

- ► Texas created a statistical model of high-risk cases in its family preservation program, which provides short-term services within a family's home.
- ► The model helped identify cases that were most at risk for serious recidivism, defined as confirmed physical or sexual abuse, a fatality due to abuse or neglect, or a child removed from the home and taken into state custody.
- Once a case is flagged as high-risk, staff will look for any outstanding safety issues and notify case managers of needed action.
- ► This helps the state efficiently allocate limited resources and the pilot program showed a 30 percent reduction in serious recidivism when compared with cases from the previous year.

#### **EDUCATION**

#### 1. IMPROVING ATTENDANCE TO IMPROVE SCHOOL PERFORMANCE [46].

- ► Charlotte-Mecklenburg County in North Carolina used integrated data to reveal a strong connection between chronic absenteeism and school performance.
- Local United Way agencies developed targeted programs to improve school attendance and engaged in special outreach to homeless children who may struggle with attendance.

#### 2. STOP FUNDING INEFFECTIVE IN-SCHOOL SUPPORTS PROGRAM [47].

- Analysis in San Antonio, TX found that in-school supports such as peer mentoring and other classroom supports were not effective at the elementary school level and enrollees actually showed decline in educational achievement.
- Funding for this program at the elementary school level stopped but continued for middle school and high school where it was found to be effective.

#### SYSTEM INVOLVED YOUTH

#### 1. FOCUS ON PREVENTING YOUTH FROM BECOMING SYSTEM INVOLVED [48].

- New York studied outcomes and cost of youth exiting foster care, justice system, and dually involved youth.
- Found that all three groups faced significant challenges and incurred substantial service costs.

New York focused resources on preventing vulnerable youth from becoming system involved, including expansion of alternatives to detention and court involvement, and reducing the number of children in foster care through a focus on prevention.

#### 2. PREDICTIVE ANALYTICS TO HELP TREATMENT OF JUVENILE JUSTICE INVOLVED YOUTH [49].

- Oregon used administrative data to help identify youth most at risk of recidivism and launch Youth Reformation System.
- ▶ Using predictive analytics (the process of extracting information from data and using it to predict outcomes, trends, and behavior patterns) the system helps staff make data-informed decisions about the most effective placement, treatment, and services to help youth reform their lives and reduce recidivism.
- As a result, the number of youth being sent to prison has declined and the system has helped the state more accurately predict the number of facility beds it will need over the next ten years, which means cost savings.

#### **HOMELESSNESS**

#### 1. BETTER IDENTIFICATION OF STUDENTS EXPERIENCING HOMELESSNESS [50].

- A data sharing agreement between school districts and education providers and the human services agencies in Alleghany County led to better identification of homeless students.
- Educational providers identified 500 additional students who were homeless. Expected the number identified could continue to increase.
- Impact of better identification means more kids get the services they need and it also affects service allocation and state funding, which is based upon children experiencing a housing crisis.

#### 2. MORE TARGETED USE OF FUNDS TO HELP HOMELESS ADULTS [51].

- ▶ Researchers found Los Angeles county agencies spent nearly a billion dollars on single adults experiencing homelessness in 2015.
- Study formed the basis for the county's 2016 Homelessness Initiative plan, in which the Board of Supervisors voted to provide an additional \$100 million in one-time funding-nearly double what they usually spend on homelessness reduction efforts.
- ► The \$100 million will be used to prevent homelessness as well as fund other evidence-based programs such as rapid rehousing and permanent supportive housing.

#### 3. HOUSING INSECURITY RISK FACTOR FOR CHILD MALTREATMENT [52].

- New Jersey noticed a high rate of children mistreated or re-entering the child welfare system after reunification with their families.
- After analyzing the data, agency staff identified unstable housing as a key risk factor for this type of outcome.

► This led agency to develop a program to address homelessness and housing instability that has helped at least 40 families in 6 counties and continues to expand.

#### **HEALTH CARE**

#### 1. IMPROVE PRIMARY AND PREVENTIVE CARE FOR IMMIGRANT COMMUNITIES [53].

- New York used its data to develop a direct access health initiative for immigrant communities that are excluded from federal and state support.
- ► The focus is on providing culturally and linguistically competent care to diverse immigrant communities.

#### 2. BETTER CARE COORDINATION FOR DUAL-ELIGIBLES [54].

- Washington uses a tool, Predictive Risk Intelligence System (PRISM), to identify a subset of high-risk clients most likely to benefit from intensive, coordinated care management.
- ► The tool helps the state improve service delivery and allocate resources more efficiently among a high-risk caseload eligible for both Medicare and Medicaid, known as dual-eligibles.
- Early results from demonstration program showed an estimated \$21 million in Medicare savings.

#### 3. EVALUATION ON PROVISION OF MENTAL HEALTH SERVICES [55].

- Researchers in Los Angeles County used administrative data to evaluate LA County's Mental Health Services Act (MHSA), which provides funding for services that (1) prevented the onset of mental illness and (2) increased residential stability and positive mental health outcomes for individuals with serious mental illnesses.
- ► The study showed the programs were reaching vulnerable populations and that those reached experienced improvements in mental health and life circumstances.

#### 4. INDIANA EVALUATED ROOT CAUSES OF INFANT MORTALITY [56].

- Indiana had a high rate of infant mortality.
- ► To better understand the cause, Indiana commissioned a data-driven analysis that linked data across five state agencies, including vital records, Medicaid claims, taxable income, and demographics.
- ▶ The researchers found that young mothers on Medicaid were not receiving the recommended number of prenatal visits, and this high-risk population comprised only 1.6 percent of all births in Indiana but nearly 50 percent of the infant deaths.
- ► This finding led the Department of Health to commence a statewide education campaign and targeted outreach to address this high-risk cohort.

#### 5. REDUCING NEONATAL ABSTINENCE SYNDROME [57].

- ► In 2010, Tennessee's Medicaid agency noticed a significant uptick in the cost of neonatal intensive care.
- A review of the data showed an increase of infants born with neonatal abstinence syndrome (NAS), where infants experience withdrawal symptoms after birth as a result of in utero exposure to opioids.
- As a result Tennessee became the first state in the country to require NAS be reported for public health surveillance purposes.
- ▶ This has allowed the state to better target contraception and addiction treatment resources and as a result of its efforts, the state has seen the rate of NAS level off since 2013.

#### 6. REDUCING PRESCRIPTIONS OF ANTIPSYCHOTIC DRUGS FOR CHILDREN [58].

- A review of Arkansas Medicaid data showed a significant increase in new prescriptions of antipsychotic drugs for children, which carry the risk of significant side effects and should only be used as a last resort.
- ▶ When educational efforts failed to reduce the prescription rate, the Drug Utilization Board drafted new policies focused on reducing prescriptions in children less than 5 years of age, and therapeutic and high doses in all ages.
- As a result of the policies, including a manual review of certain prescriptions, from 2008-2015 the Drug Utilization Board saw a drop in prescriptions for all ages, including a 94 percent decrease in prescriptions for non-foster children under the age of six.

#### 7. REDUCING FRAUD AND ABUSE IN HEALTH CARE [59].

- ▶ Illinois uses Dynamic Network Analysis to link and analyze its administrative data and root out fraud and abuse in state healthcare program.
- ► This tool uses predictive analytics, auditing, data linkage, and data aggregation to detect fraud and in 2014 helped the state save, avoid paying, or recover \$94 million in improper fees.

#### 8. EVALUATE PERFORMANCE BASED CONTRACTING [60].

- ▶ Illinois incorporates specific performance goals into its contracts with service providers and uses data to evaluate providers on outcomes.
- ► Contracts include provisions to incentive performance, such as bonuses, and penalties if targets not met, such as contract termination.
- ► For residential mental health treatment, the state includes performance targets for the number of days patients spend in active treatment and percentage of patients who are discharged into a less restrictive treatment setting.
- ▶ As a result of performance-based contracting, from 2009-2011 Illinois saw a 50 percent increase of clients discharged to their home or a less restrictive setting.

#### 9. BETTER PROVISION OF HEALTH CARE TO HIGH-RISK INDIVIDUALS [61].

- Connecticut used predictive analytics to identify individuals with a high-risk of negative health outcomes.
- ► State then provided these individuals intensive case management, targeted medical and behavioral health services, and social services such as housing and food assistance.
- ▶ In 2016, Medicaid members receiving intensive case management saw a 19 percent reduction in emergency department visits and 43 percent reduction in inpatient admissions.

#### 10. USING ADMINISTRATIVE DATA TO ADDRESS THE OPIOID CRISIS [62].

- After a sharp increase in opioid-related deaths, the Massachusetts legislature directed multiple agencies to analyze administrative data relevant to opioid usage and prepare a report to help in addressing the epidemic.
- Findings included that more people died from illegal drugs than prescription opioids (even though prescription drugs fuel the epidemic) and people recently released from prison or jail were 56 times more likely to die from an overdose than members of the general public.
- ► The Department of Public Health is working with corrections on prison release procedures and incorporating alerts into the prescription monitoring system to flag high-risk patients for prescribers and pharmacists.
- ▶ The report also led to the passage of legislation to address the root causes of the opioid epidemic.

#### 11. SUBSTANCE ABUSE TREATMENT MAY CONTAIN MEDICAL AND LONG-TERM CARE COST GROWTH [63].

- ▶ Washington study showed that access to substance abuse treatment is key to contain medical and long-term care cost growth for persons enrolled in disability-related Medicaid coverage.
- ▶ Medical and nursing home costs grew much more slowly for group that received needed substance abuse treatment, when compared to group not needing substance abuse treatment.
- ▶ When funding for treatment was cut during the Great Recession, medical and nursing home costs actually grew much faster for group needing substance abuse treatment but not receiving it, suggesting that from a budgetary perspective cuts were counterproductive.

#### CORRECTIONS

#### 1. PAY FOR PERFORMANCE: REDUCING RECIDIVISM [64].

- Pennsylvania Department of Corrections has pay for performance contracting with community correction centers, which act as halfway houses to help recently or soon-to-be paroled inmates transition back into society by providing therapy, substance abuse counseling, assistance looking for work, and educational or vocational training.
- ► The department sets recidivism targets for the centers and if they achieve a better-than-expected rate, they are eligible for incentive bonus and if they fail to meet the target they may have their contract terminated.

▶ Pay for performance contracts resulted in an 11.3 percent reduction in the recidivism rate for the 2014-2015 fiscal year.

#### **EMPLOYMENT**

- 1. IMPROVING ATTENDANCE FOR SUMMER YOUTH EMPLOYMENT PROGRAM [65].
  - ► The District of Columbia runs a summer youth employment program that connects city residents between the ages of 14-24 with summer jobs in both the public and private sector.
  - ▶ Staff noticed that attendance would decrease over the course of the summer program and used routinely collected administrative data to conduct a randomized control trial to determine the most effective strategies to improve attendance.

#### PROGRAM EVALUATION/PREDICTIVE RISK MODELING

- 1. RANDOMIZED CONTROL TRIAL ON NURSE-FAMILY PARTNERSHIP PAY FOR SUCCESS [66].
  - Nurse-family partnerships match vulnerable first-time parents with specially trained nurses who conduct home visits from early pregnancy until age two and support the mothers.
  - South Carolina is enrolling over 4,000 first-time, low-income mothers in the program and will conduct a randomized control trial to evaluate the program objectives, including a reduction in preterm births, child hospitalization and ER visits due to injury, and increasing healthy spacing between births.

### **END NOTES**

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- [5] Robert M. Goerge, Cheryl Smithgall, Roopa Seshadri, and Peter Ballard, Illinois Families and Their Use of Multiple Service Systems, Chapin Hall Issue Brief (February 2010), available at <a href="https://www.chapinhall.org/wp-content/uploads/Goerge Illinois-Families-Their-Use Brief 2010.pdf">https://www.chapinhall.org/wp-content/uploads/Goerge Illinois-Families-Their-Use Brief 2010.pdf</a>. This estimate is based on a study of Multi-System Families conducted by Chapin Hall, in which 6.9% of Illinois families accounted for 63% of problems addressed with services provided by the State's Department of Child and Family Services. Further, 23% of those families used 86% of the social service dollars in the state. See Appendix A for how New Mexico Appleseed arrived at this approximation from New Mexico using the Chapin Hall report.
- [6] See Appendix A. In our quest to fulfill the goal of Senate Memorial 50 (2017), New Mexico Appleseed and BBER repeatedly met and spoke with state agencies and the LFC. We learned that not only does this integrated data not exist, obtaining the data for SM 50 would be next to impossible and require the cooperation of multiple state agencies as well as executed MOUs, a process that could take years. As a result, we were not been able to develop a complete profile of these families based on actual New Mexico data, and have instead relied on an estimate.
- [7] This is not intended to be an exhaustive list and part of the work of the CFD Commission is to identify additional data that may inform its work.
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- [24] A copy of the legislation is available from New Mexico Appleseed.
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- [36] The Chapin Hall study concluded that the aggregated share of resources consumed by Multi-System Families in Illinois was 86 percent.
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- [38] This figure includes budget totals for the following categories as reported by the Legislative Finance Committee for fiscal years 2012-16: CYFD Protective Services, Medicaid Behavioral Health, Behavioral Health Services (non-Medicaid), CYFD Behavioral Health Services, Juvenile Justice Facilities, and Inmate Management and Control. These figures include administrative and facilities costs directly related to the execution of the programs.
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