



**COULD**

Child and Caregiver  
Outcomes Using Linked Data



# Linking Child Welfare and Medicaid Data: Lessons Learned from Two States



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## Child and Caregiver Outcomes Using Linked Data (CCOULD) OPRE & ASPE Report

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## Executive Summary

A large proportion of children who receive child welfare services are eligible for Medicaid. Linking Medicaid data to child welfare system data can identify opportunities to improve coordination between these two programs and improve the effectiveness and cost-effectiveness of their services, among other things. To demonstrate how this could be achieved, the Office of the Assistant Secretary for Planning and Evaluation, the Office of Planning and Research within the Administration for Children and Families, and RTI International (RTI) began the *Child and Caregiver Outcomes Using Linked Data* (CCOULD) project in October 2019.

The goal of the COULD project was to provide technical assistance to states in linking the Medicaid administrative claims of children and their caregivers with case-level data from the child welfare system and to combine the state-specific datasets into a multi-state, deidentified dataset for secondary data analysis by researchers. The linked dataset would contain information from both child welfare and Medicaid information systems on case demographics, medical diagnoses, services, outcomes, and other relevant information. The data would facilitate research on the relationships between receipt of child and caregiver Medicaid and child welfare services, health care outcomes, and child welfare outcomes. The passage of the 2018 Family First Prevention Services Act (FFPSA) created new incentives for states to better understand services provided by the child welfare system and/or Medicaid to families at risk of entering or re-entering the child welfare system. This project helped to facilitate these connections and research, by supporting data sharing between agencies and providing the technical expertise to support states in completing the work.

Following robust recruitment efforts by the project team, Kentucky and Florida signed onto the project. Florida created a linked dataset covering 2016 through 2021 that included 80% of children (N = 669,425) who had been in contact with Florida's child-welfare system. Florida linked 57,512 caregivers of those children to Medicaid records. Of the 669,425 Florida children who were linked to Medicaid, 8.5% also had at least one caregiver linked to Medicaid. Kentucky created a linked data set that covered the period 2016 through 2021 that included 81% of children (N = 216,738) who had been in contact with Kentucky's child-welfare system. Kentucky linked 46,809 caregivers of those children to Medicaid records. Of the 216,738 Kentucky children linked to Medicaid, 21.3% had a least one caregiver linked to Medicaid.

A de-identified dataset that combines both states' linked data will be available to researchers through the National Data Archive on Child Abuse and Neglect (NDACAN). This report describes the lessons learned from Kentucky's and Florida's experiences linking their child welfare system and Medicaid data.

Lessons learned pertained to (1) state recruitment and short-term and long-term sustainability of the linkage project; (2) data availability, consistency, and quality; (3) state and federal regulations related to data linkage and sharing; and (4) linkage methodologies. Regarding state recruitment and sustainability, it took the project team longer to recruit states than anticipated and more effort than expected to keep states engaged. Future linkage efforts could focus more attention on highlighting the specific operational value to states and their constituents of linking their data. A thorough understanding of states' data and operational readiness to undertake data linkage is also an important consideration for future efforts.

A lesson learned regarding data availability, consistency, and quality is that child welfare agencies may not have mature data dictionaries and user guides that can be shared. In CCOULD, the lack of documentation resulted in greater time demands on state or local agency personnel with institutional knowledge of the data who had to explain the data elements and infrastructure to the team charged with creating the linked dataset. A second lesson learned regarding data availability was that caregiver information, such as demographics and their relationship to the child, was often missing or incomplete. A third was that states could not readily provide detailed information on the title IV-E prevention services provided. This was due to service and cost data being stored in external service provider systems, child welfare services being paid for via lump sum contracts rather than fee-for-service, and the fact that child welfare services do not currently use standardized codes, as medical services typically do (e.g., current procedure terminology [CPT] codes).

Navigating the state and federal privacy laws and regulations pertaining to the sharing of identifiable child welfare data was challenging. States may benefit from clarifying their child welfare privacy regulations, improving cross-agency data sharing processes, and following federal guidance on navigating confidentiality laws and regulations.

To facilitate the data linkage, the CCOULD project created a common data model that employed the same variables and file structure between the two states, allowing for successful aggregation of linked data from multiple states. The CCOULD project was also able to successfully link most children and caregivers using social security numbers. Linkage of children to parents could be enhanced if Medicaid claims data had a family identifier. Because of a lack of family identifier in Medicaid claims, children and caregivers could only be linked if the caregiver's identifying information was included in the child welfare data.

The experience in linking data from two states through the CCOULD project provides a solid foundation for future linking efforts. As the value of integrating data across Medicaid and child welfare program becomes more apparent, more and more states may begin to build from this foundation.





## 1. Introduction

State or local child welfare systems and Medicaid programs have historically operated as largely separate systems. As child welfare programs focus more on preventing family removals, there is need to coordinate information and operations across child welfare and Medicaid programs. For example, the opioid epidemic had a cascading effect on children, leading to decreased family stability and increased family separations (Ghertner et al., 2018b). Connecting parents identified by the child welfare system as needing substance use treatment with Medicaid-funded treatment may help support parents in caring for their children and prevent separations.

The *Child and Caregiver Outcomes Using Linked Data* (CCOULD) project aimed to partner with two to four states to create a linked dataset of state Medicaid and child welfare system data that would facilitate research on the relationships between child and caregiver Medicaid coverage and services and child welfare services, health care outcomes, and child welfare outcomes. The project was funded by the Patient-Centered Outcomes Research Trust Fund in the U.S. Department of Health and Human Services (HHS) and guided by a Technical Expert Panel that included representatives from the Administration for Children and Families (ACF), the Office of the Assistant Secretary for Planning and Evaluation (ASPE) the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare & Medicaid Services (CMS), the National Institute on Drug Abuse (NIDA), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

The document is intended to provide information to state, tribal, and local child welfare, Medicaid, and behavioral health agencies that are interested in linking their Medicaid and child welfare data. The document may also be of interest to HHS agencies whose mission involves improving outcomes and services delivered to children served by child welfare agencies and the Medicaid program. Research organizations and technical assistance providers that collaborate with local agencies on similar projects or that study the relationship between Medicaid and child welfare may also benefit from the information provided. Finally, children and family advocacy organizations, which have been pressing for greater integration and coordination between child welfare and Medicaid, may value the lessons learned from this project.

The project team collaborated with Kentucky and Florida to link their child welfare and Medicaid data. This document describes the experiences of these two states in successfully linking Medicaid and child welfare data. For each state we describe the following:

- The roles and responsibilities of the agencies and external partners in the project
- The processes used to ensure that the project conformed to all Federal and state regulations pertaining to human subjects research, privacy protections, and data sharing

- The data elements available from Medicaid and child welfare and the quality of the data (e.g., degree of missingness)
- The development of a common data model to ensure that states' data could be combined into one dataset using common variable definitions and data structures
- The methods used to link Medicaid and child welfare data and the linkage success rates

We conclude the report with a summary of challenges, successes, and lessons learned across both states.

The lessons learned from Kentucky and Florida's experience linking Medicaid and child welfare data may not completely extend to other states. States differ in their organization, processes, legal and regulatory frameworks, and data structure, which may limit the generalizability of the lessons learned from Kentucky and Florida. Regardless, the success these states had should serve as motivation to other jurisdictions interested in linking data, and insights from the project can inform similar efforts in other places.

## **2. Background**

Public child welfare agencies typically receive and investigate reports of possible child abuse and neglect; provide services to families who may need assistance to safely care for their children; arrange for children to live with relatives or with foster families when they determine the children cannot remain at home; and arrange for reunification with their families of origin or other permanent families or connections for children and youth when they cannot return to their family of origin (Child Welfare Information Gateway, 2020). Medicaid is a joint federal-state insurance program that provides health insurance to lower-income children and families. Many children who receive child welfare services or are in foster care are also eligible for Medicaid. Many parents and caregivers of children placed in foster care may also be eligible for and receive Medicaid. By linking data among children and their caregivers who are served by both systems, agencies, researchers, and other interested groups can identify opportunities to improve service provision, care coordination, and potentially improve child and family outcomes.

A number of contextual factors indicate the need for linking data between child welfare and Medicaid systems. Little is known about how utilization of Medicaid services relates to child welfare-related outcomes, and increasing access to linked data can generate research on this topic. Research has demonstrated that children in foster care utilize more Medicaid services than comparable children not in foster care (Weigensberg et al., 2018). As child welfare stakeholders across the country are increasingly focused on capitalizing on opportunities to support and serve families to prevent involvement in child welfare systems

and subsequent placement in foster care, it is critical to understand how Medicaid-funded services can prevent such involvement.

Relatedly, the federal Family First Prevention Services Act (FFPSA; P.L. 115-123), which was enacted in February 2018, has several provisions to enhance public child welfare agency services for families to help children remain at home, to reduce the unnecessary use of congregate care, and to build the capacity of communities to support children and families (Children's Bureau, 2018). The law enables states and tribes operating a title IV-E program to use title IV-E funds for prevention services and programs identified by the Title IV-E Prevention Services Clearinghouse as meeting the evidence-based requirements in law, including mental health programs, substance abuse prevention and treatment, and in-home parent skill-based programs. Some aspects of these services may also be funded through Medicaid. In many cases, without linked data it is not possible to know when families are using services funded by these separate sources. Analysis of linked data can help determine how best to coordinate and optimize Medicaid and child welfare funding streams to reach program goals.

Linked data on services from child welfare and Medicaid can help us understand the effectiveness of interventions and improve coordination to address critical challenges faced by families at risk of child welfare system involvement. One such challenge is the ongoing overdose crisis. Parental substance use has long been associated with foster care placement (CDC, 2021; Clary et al., 2020; Ghertner et al., 2018a; Ghertner et al., 2018b; Gladden et al., 2019; Klaman et al., 2017; Quast et al., 2018; Radel et al., 2018a, 2018b; SAMHSA, 2016; Wilson et al., 2019) and increased complexity and severity of child maltreatment cases (Ghertner et al., 2018b). As the overdose crisis has worsened (CDC, 2021; Gladden et al., 2019), more young children have been reported to child welfare services and placed out of home (Quast et al., 2018). This problem is especially pronounced in the field of maternal/fetal medicine, where neonatal opioid withdrawal syndrome has been a significant reason for placing infants in foster care (Loch et al., 2021). Receipt of substance use disorder services, such as medications and counseling, allows parents to increase their functioning and care for their families (Clary et al., 2020; Klaman et al., 2017; Radel et al., 2018a; SAMHSA, 2016; Wilson et al., 2019). Recent studies have specifically identified favorable associations between providing medications for opioid use disorder and a family's child welfare outcomes (Ali & Ghertner, 2022; Hall, Wilfong, Huebner, Posze, & Willauer, 2016). By linking Medicaid and child welfare data, policymakers can improve access to and coordination of substance use disorder interventions among families involved in both systems.

In the next sections, we present case studies describing Florida's and Kentucky's experiences linking child welfare and Medicaid data, and a summary of the lessons learned across both states.

### 3. Activities Common to Both States

In this section, we discuss activities related to the CCOULD project that were common to both Kentucky and Florida, including the state recruitment, addressing privacy regulations, and developing a common data model.

#### 3.1 Recruiting States

While many tribal and local jurisdictions have access to child welfare and Medicaid data, the CCOULD project team determined that the project resources would be most effective in working with state agencies. Tribal and local jurisdictions were considered less likely to have access to the infrastructure and resources needed to conduct the linkage or the volume of data required for robust data analysis. To inform the state selection criteria for the project, ASPE and ACF gathered information from stakeholders with expertise in state data capacity and infrastructure as it related to child welfare and Medicaid data systems. Federal stakeholders consulted included staff from the Division of State Systems at the Children's Bureau, the Division of State Systems at CMS, and NIDA. Nonfederal experts consulted included the American Public Human Services Association, the National Center for State Courts, Casey Family Programs, and the Arnold Foundation.

In May 2019, ASPE/ACF convened the aforementioned Technical Expert Panel to review draft state selection criteria to inform the recruitment and selection of states to participate in the project. Final selection criteria included the following:

- Interest and support from state executive leadership
- Existing partnerships between Medicaid and child welfare agencies and between Medicaid/child welfare agencies and research partners
- Infrastructure and capacity within Medicaid and child welfare agencies to support data linkage of high-quality data
- Experience linking and sharing data

In August 2019, ASPE/ACF presented an overview of the project's goals, objectives, and timeline at the National Child Welfare Evaluation Summit and held an informational webinar for interested states and their research partners. The webinar described the project goals, roles and responsibilities of different stakeholders, timeline and level of commitment, and next steps. Before the webinar, ASPE/ACF engaged with Children's Bureau and CMS partners to inform state child welfare and Medicaid representatives about the webinar. After the webinar, ASPE/ACF and RTI convened conference calls with seven states that expressed interest in the project. Follow-up calls were held with interested candidate states who met the selection criteria.

Kentucky signed onto the project in August 2020, and Florida signed on in January 2021. The project provided each state with an honorarium to offset some costs associated with participating in the project.

### **3.2 Addressing Privacy Rules and Concerns**

Access to data from Medicaid and child welfare systems is governed by a range of federal and state statutes, regulations, and other policies. Medicaid data contain protected health information (PHI), and both data systems contain personally identifying information (PII). Federal rules on PHI and medical record privacy are guided by the Federal Health Insurance Accountability and Portability Act (HIPAA) and its implementing rules (45 CFR Part 160 and Subparts A and E of Part 164). Information sharing on substance use treatment are covered by 42 CFR Part 2 (Code of Federal Regulations, n.d.). SAMHSA's recent guidance on 42-CFR-Part 2 Revised Rule clarifies that "disclosures for research under Part 2 are permitted by a HIPAA-covered entity or business associate to individuals and organizations who are neither HIPAA covered entities, nor subject to the Common Rule (re: Research on Human Subjects)" (SAMHSA, 2020).

Walton et al. (2020) reviewed state laws pertaining to the sharing of child protective services data (i.e., maltreatment investigations and services related information) for research or evaluation. This review revealed that state laws have primarily relied on the language in the Child Abuse Prevention and Treatment Act that established annual reporting of state data through NCANDS to outline the terms of child protective services data sharing for research and evaluation. They identified 29 states that expressly describe disclosure of their child protective services case data to those engaged in research, and 23 states (including Washington, DC, and Puerto Rico) have no such language.

RTI provided support to Florida and Kentucky in identifying federal guidance and legal expertise to interpret these relevant privacy rules, eventually determining that none of the rules impeded data linking as envisioned by CCOULD. More details on state-specific privacy rules are addressed below. In November 2020, RTI's Institutional Review Board (IRB) determined that the CCOULD project was human subjects research classified as "exempt", qualifying in the category of a demonstration project supported by a federal agency.

### **3.3 Common Data Model**

Common Data Models (CDMs) allow for the systematic analysis of disparate databases by transforming data contained within those databases into a common format (data model) as well as a common representation (terminologies, vocabularies, coding schemes). On the Medicaid side, the CCOULD CDM includes information on Medicaid enrollment, diagnoses, procedures, healthcare services, and Medicaid expenditures. Medicaid file structures and variables were based on the [Transformed Medicaid Statistical Information System \(T-MSIS\)](#)

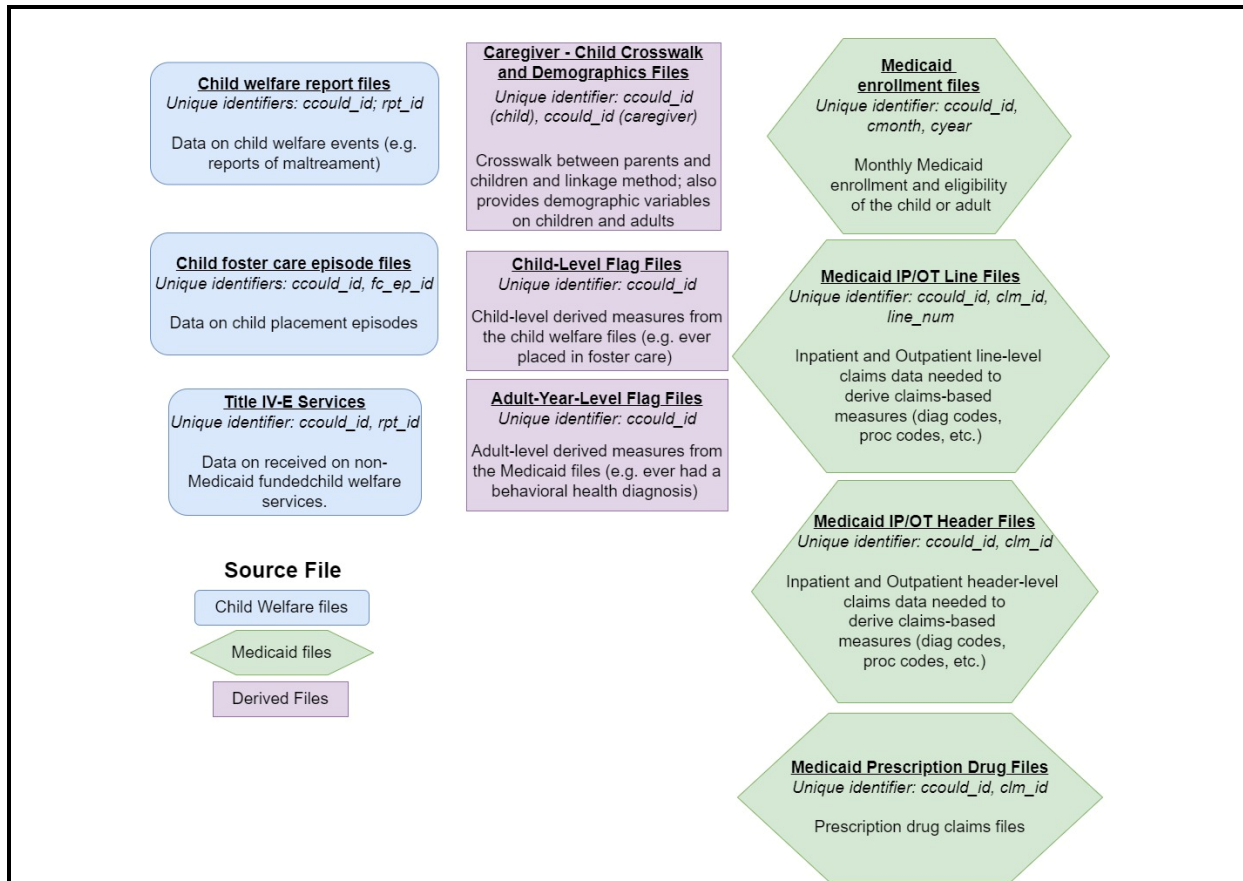
analytic file structure and data dictionaries. T-MSIS analytic files are a series of datasets created by CMS from state-submitted Medicaid program data that are optimized for analytics.

On the child welfare side, the CDM includes information on reports of maltreatment, investigations, report dispositions and maltreatment types, foster care entry and exit dates, circumstances associated with a child's removal, total numbers of removals from home, and placement types. The child welfare service variables were selected and coded, drawing from the variables submitted to the Federal government by state child welfare agencies in the [National Child Abuse and Neglect Data System](#) (NCANDS) and the [Adoption and Foster Care Analysis and Reporting System](#) (AFCARS). The CDM also contains a series of child- and adult-level flags designed to facilitate use of the dataset by researchers unfamiliar with either Medicaid or child welfare data.

Because Florida and Kentucky were both familiar with T-MSIS, NCANDS, and AFCARS, both states were able to adapt their data to the CDM. The Medicaid administrative claims for Florida and Kentucky matched the CDM structure straightforward. The child welfare data took additional effort because the data were stored in structures that required merging and cross-checking.

The CDM is described in two files: an Excel workbook and programming specifications (see **Appendix A**). The Excel workbook contains worksheets coinciding with each data file. The worksheets list the variables contained in the data files, the source of the variables, the variable's character type and length, and the variable label. An introduction sheet includes file structure information and research questions to be answered with the data. The programming specifications provide detailed guidance on variable definition and how to derive each of the Medicaid-specific files in the CDM. The files in the CDM adhere to the structure laid out in **Figure 1**.

**Figure 1. Common Data Model File Structure**



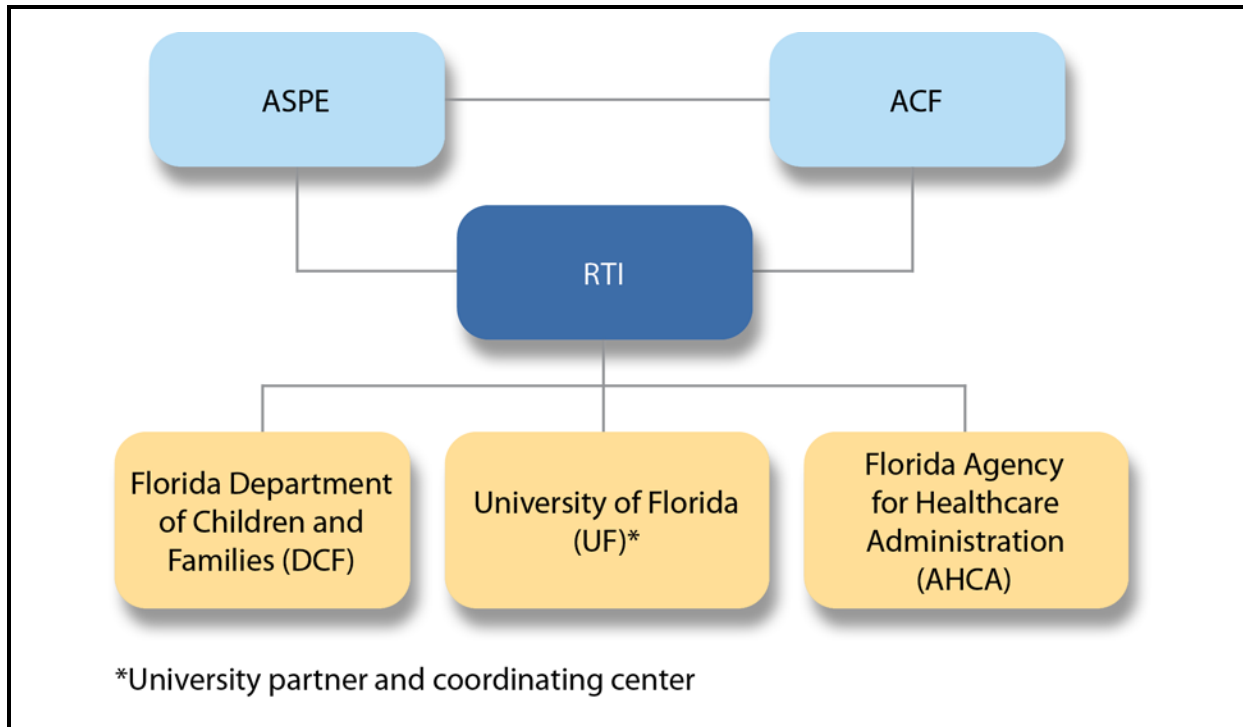
## 4. Case Study: Florida

### 4.1 Florida’s Participating State Agencies and External Partner

Two Florida state agencies—the Department of Children and Families (DCF; which is responsible for child welfare) and the Agency for Health Care Administration (AHCA; which is responsible for Medicaid)—participated in CCOULD. These agencies have a long-standing relationship of data sharing and analysis with researchers at the University of Florida (UF). Faculty and staff in UF’s Health Outcome and Biomedical Informatics department had extensive prior experience analyzing Florida Medicaid and DCF data for children in foster care. DCF and AHCA opted to continue their collaboration with UF for CCOULD. UF served as the CCOULD coordinating center for Florida, with responsibility for all data analysis and linkage. UF was the recipient of the CCOULD honorarium.

Figure 2 shows the organizational structure of the CCOULD project in Florida.

**Figure 2. Organization of the CCOULD project in Florida**



## 4.2 Privacy, Human Subjects Research, and Data Sharing Protections

RTI began the project by reviewing the state privacy laws pertaining to the project with the Florida project members. Florida statute 39.202 (see **Appendix B**) allows for the sharing of child welfare reports for bona fide research purposes, specifically:

- (i) *Any person authorized by the department who is engaged in the use of such records or information for bona fide research, statistical, or audit purposes. Such individual or entity shall enter into a privacy and security agreement with the department and shall comply with all laws and rules governing the use of such records and information for research and statistical purposes. Information identifying the subjects of such records or information shall be treated as confidential by the researcher and shall not be released in any form.*

This provision in the statute supported Florida's ability to share data for CCOULD.

The UF IRB determined that CCOULD was exempt human subjects research.

UF's partnership with the Florida state agencies created data-sharing efficiencies for CCOULD. AHCA's existing contract with UF was amended to add CCOULD as a deliverable. Additionally, because UF was already a designated recipient of data for children in foster care, DCF was able to quickly establish a new agreement with UF to also share data for



children with screened-in maltreatment reports. The data use agreement (DUA) between DCF and UF was signed in November 2021.

RTI's privacy officer negotiated and secured a DUA between RTI and UF that allowed RTI to receive the linked Florida data, conduct quality checks and statistical disclosure analyses on the linked data, and then provide a de-identified linked dataset to a public data archive for access by researchers. Florida use the [Federal Demonstration Partnership \("FDP"\) DUA templates](#)<sup>1</sup> (One-Way DTUA and the "DTUA Attachment 2 – Limited Data Set). The DUA was signed in July 2021. The DUA included a full list of variables that RTI would receive from UF. The DUA required that all personally identifying information (PII) for individuals in the AHCA and DCF data remained with UF and not be shared with RTI. The only protected health information (PHI) that RTI would receive from UF was Medicaid service dates. RTI would then statistically de-identify the linked dataset before making it available to external researchers.

### **4.3 Data Availability**

Linked data for CCOULD were intended to support evaluations of the effectiveness of FFPSA/title IV-E services provided by the child welfare system and/or Medicaid in preventing child welfare involvement or reinvolvement. However, at the time the DUAs were being negotiated for CCOULD, only high-level information on child welfare services provided to children and families (i.e., services variables included in the National Child Abuse and Neglect Data System [NCANDS]) was available in DCF's Florida Safe Families Network (FSFN), an electronic records and case management system used by DCF to document and track child welfare cases. Detailed information on specific FFPSA-funded child welfare services and interventions, dates of service, and costs was housed separately in 20 local community-based care (CBC) provider agencies in six regions of the state. DCF is currently procuring a vendor to build a new Comprehensive Child Welfare Information System (CCWIS) system, which would consolidate detailed services data from multiple CBC agency data systems into the FSFN. This process is expected to take several years. Additionally, regarding data availability, demographic and identifying data on the parent/caregiver of children reported to DCF were only available for children/families who received in-home or foster care services.

### **4.4 Data Linkage**

Florida's DCF and AHCA passed their respective datasets to UF to conduct the data linkage. RTI worked with all three organizations to ensure a transmission of data to UF for linking, then predominantly worked with UF to create the linked dataset.

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<sup>1</sup> See <http://thefdp.org/default/committees/research-compliance/data-stewardship/>

Many methods of matching were discussed throughout the project, with particular emphasis on deterministic and probabilistic methods of matching. In November 2021, RTI held a linkage discussion with Florida, Kentucky, ASPE/ACF and CCOULD advisors with expertise in data science and data linkage. The linkage discussion with Florida and Kentucky included how to select high-quality linking variables, methods and decision rules needed for deterministic linkage, merits of deterministic and probabilistic matching, and the methods of probabilistic matching. Because the efficacy of deterministic linkage is a function of the quality of the linkage variables, we emphasized the importance of the selection of variables that have high discriminatory power (e.g., social security number [SSN] has more than 900 million possible correct values, whereas birth month only has 12), low missingness, and low possibility of miscoding.

In prior projects, UF followed a deterministic linkage approach as discussed in Dusetzina (2014), which involved linking using SSN, date of birth, and name. Under the CCOULD Project, UF linked deterministically using only SSN. Experts in data linkage highlighted that using additional variables for deterministic linkage will increase specificity (correctly identifying individuals who **should not be** linked) at the cost of lowering the sensitivity (correctly identifying individuals across the datasets who **should be** linked). For example, because names are often spelled differently in different data sets (e.g., William versus Bill), requiring that individuals be linked by SSN, DOB, and name would have resulted in the rejection of more true linkages than linking on SSN alone. UF noted that this approach may have the potential to incorrectly link two individuals assigned the same SSN (e.g., a baby recorded with its mother's SSN). For this project, however, we followed the advice of the data linkage experts in only linking via SSN.

For children and caregivers without SSNs, UF linked using an ID recommended by RTI consultants, which was termed the LongID. The LongID was modeled after the SLK-581 identifier, which is straightforward to implement and has a low rate of incorrect links (Australian Government, n.d.). The LongID was specified for this use as the concatenation of the first three letters of child or caregiver's last name + the first two letters of the child or caregiver's first name + child or caregiver's date of birth (as DDMMYYYY) + sex (M/F).

**Table 1** presents the linkage statistics for Florida. From 2016 through 2021, 1,387,677 child welfare reports or investigations were recorded in the Florida child welfare system. These include reports that were substantiated as well as those that were not determined to be substantiated. These reports represented 837,568 unique children (a child could have more than one report/investigation). Out of 837,568 children, the system had demographic information for 835,758 children (1,385,387 reports/investigations). The dataset also contained demographic information on 84,559 caregivers.

UF linked 80% (669,425 / 835,758) of the children in the child welfare system to a Medicaid record. Of these 669,425 linked children, 70% (470,992 / 669,425) were linked via SSN,

and 30% (198,433 / 669,425) were then linked via LongID. The caregiver linkage rate was not as high as the link for the children; 68% (57,152 / 84,559) were linked to Medicaid. Most caregivers were linked using SSN. Almost all children had only one caregiver linked to Medicaid (57,002). Overall, 8.5% of the 699,425 children linked to Medicaid also had a caregiver linked to Medicaid.

**Table 1. Child Welfare and Medicaid Linkage Statistics from Florida, 2016–2021**

Population	Number of Observations	Percentage of Total Children/Caregivers	Percentage by Linked Method
Child Welfare Reports or Investigations occurring from 2016 to 2020	1,385,387		
Number of children represented in the child welfare reports or investigations from 2016 to 2020	835,758	100%	
Children linked to Medicaid	669,425	80%	
Children linked to Medicaid with SSN	470,992		70%
Children linked to Medicaid with LongID	198,433		30%
Unlinked children	166,333	20%	
Number of caregivers represented in the child welfare reports of investigations from 2016 to 2020	84,559		
Caregivers linked to Medicaid	57,152	68%	
Caregivers linked to Medicaid with SSN	55,040		96%
Caregivers linked to Medicaid with LongID	2,112		4%
Unlinked caregivers	27,407	32%	

Note: 50,545 caregivers were associated with children who received foster care and 36,921 caregivers were associated with children who received in-home services. Some of the children who received foster care services may have also received in-home services.

We assessed the quality of the LongID linkage approach by comparing the agreement between the linkages using the LongID to the linkages using the SSN, assuming that the SSN was the gold standard (i.e., yielded correct linkages). **Table 2** displays those statistics. The False Negative rates (i.e., the rate for links that should have been made but were not) were 8.9% for children and 7.9% for caregivers. The False Positive rates (i.e., the rate of

links that are made that should not be made) were lower; 5.0% for children and 2.9% for caregivers. Because testing indicated that the LongID will result in some incorrect linkages, a variable was added to the research file to indicate which children and caregivers were linked with the LongID and which were linked using SSNs. Researchers concerned about incorrect matches may want to use only those records linked by SSNs.

**Table 2. Linkage Testing Among Children and Caregivers with Both SSNs and LongID information**

Population with SSN and LongID Available	Reported Rate, %
Children linked with SSN but not LongID (false negatives)	8.9
Children linked with LongID but not SSN (false positives)	5.0
Caregivers linked with SSN but not LongID (false negatives)	7.9
Caregivers linked with LongID but not SSN (false positives)	2.9

## 5. Case Study: Kentucky

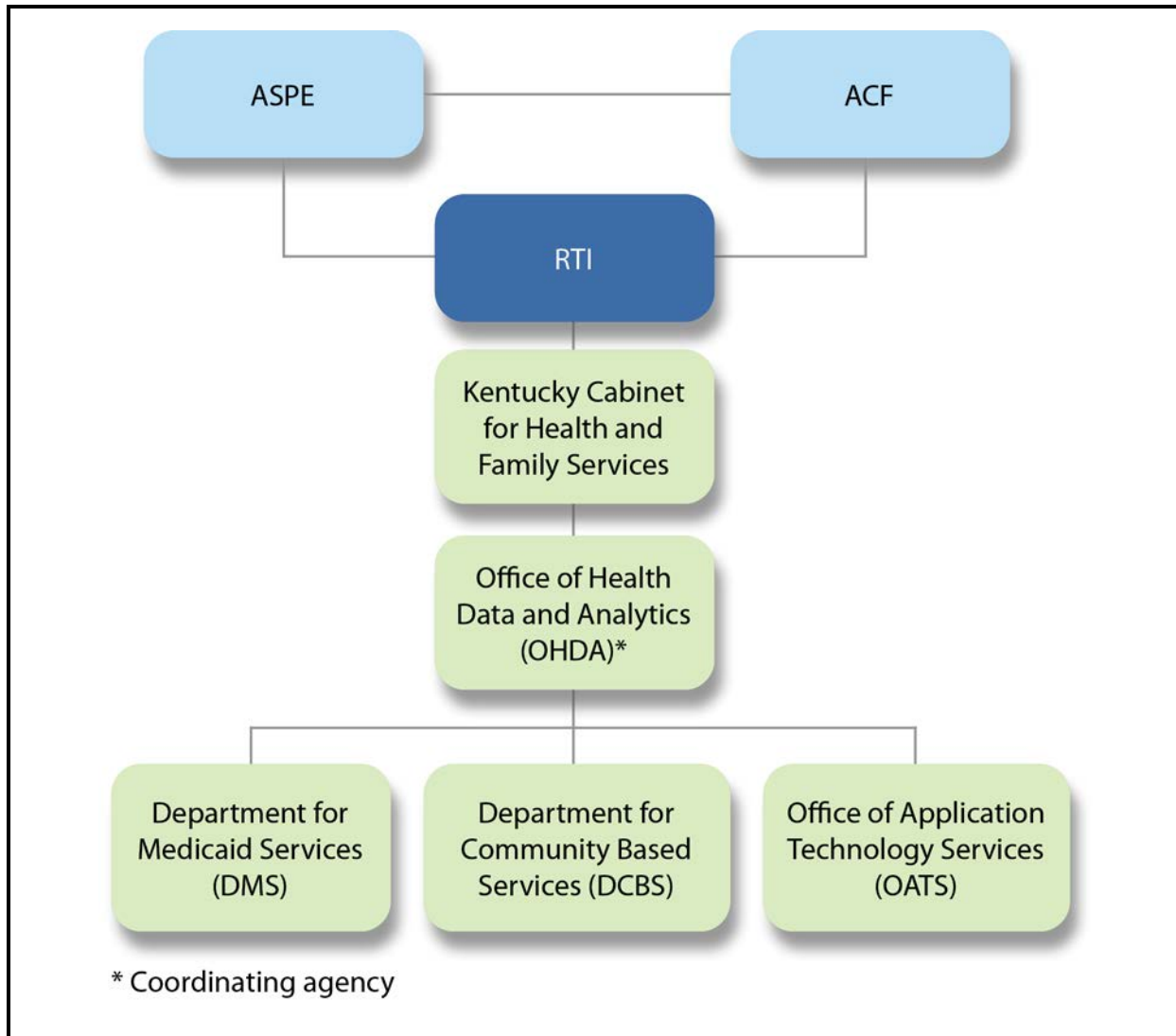
### 5.1 Kentucky’s Participating State Agencies

Several state agencies within the Kentucky Cabinet for Health and Family Services participated in CCOULD, including the Office of Health Data and Analytics (OHDA); Department for Community Based Services (DCBS), which has responsibility for child welfare services; Office of Application Technology Services (OATS); and Department for Medicaid Services (DMS). Researchers in OHDA served as the coordinating center for Kentucky, with responsibility for all data analysis and linkage. The Kentucky Cabinet was the recipient of the CCOULD honorarium. **Figure 3** shows the organizational structure of the CCOULD project with the state of Kentucky.

### 5.2 Privacy, Human Subjects Research, and Data Sharing Protections

Kentucky statute 620.050 governing the confidentiality of child welfare maltreatment reports does not include explicit language about data sharing for research or evaluation purposes (see **Appendix C** for the Statute). The lack of such language made it more difficult to determine the permissibility of sharing these data and necessitated clarifications between the Kentucky Cabinet and the Kentucky Supreme Court. The Kentucky statute allows DCBS to share confidential information about a case with agencies with a “legitimate interest” in receiving the information. It was ultimately determined that the ASPE/ACF federal agency goal of analyzing trends and evaluating programs to improve service offered to DCBS clients is a “legitimate interest” and allowed data to be shared for CCOULD.

**Figure 3. Organization of the CCOULD Project in Kentucky**



Another area of negotiation prior to the DUA process was the sharing of child and parent/caregiver SSNs internally between the Kentucky Cabinet agencies—specifically between DCBS and the OHDA team linking child welfare and Medicaid records. To ensure that clients are connected to Medicaid and other services they are eligible to receive, DCBS verifies SSNs through the federal Social Security Administration (SSA). Once an SSN is verified, the SSA restricts how it can be used. To allow SSNs to be shared between agencies, no verification indicators from the SSA were passed to OHDA.

In January 2021, the Kentucky Cabinet IRB also determined that CCOULD was exempt human subjects research.

Three DUAs were negotiated and secured before data were linked for CCOULD: (1) a DUA allowing DCBS to share child welfare data with OHDA was signed in November 2021, (2) a

DUA allowing DMS to share Medicaid data with OHDA was signed in December 2021, and (3) a DUA allowing OHDA to share linked child welfare and Medicaid data with RTI was signed in January 2022. All PII for individuals in the DMS and DCBS data remained with OHDA and was not shared with RTI. The only PHI that RTI received from OHDA were Medicaid service dates. In March 2022, Kentucky streamlined its DUA process via a Master Data Agreement (MDA) between constituent Cabinet for Health and Family Services agencies, resulting in much faster turnaround for approvals when the DUA needed to be amended to clarify the data elements requested.

### 5.3 Data Availability

Although Kentucky had made significant progress integrating title IV-E prevention services information into its data systems when DUAs were negotiated for CCOULD, these services data were not yet available for linkage.

Prior to the 2018 FFPSA, DCBS partnered with therapeutic foster care organizations and other health and human services agencies to provide services to children and families. As a result, services data were housed in the individual partner systems and not in their data system, Workers Information System (TWIST). Post the state's implementation of a title IV-E prevention plan, beginning in late 2019, DCBS began adding title IV-E prevention services data to TWIST per ACF requirements.<sup>2</sup> Variables included type of services received, dates of services, and successful completion of treatment. These data did not include service costs, however, and could not be linked with Medicaid given a 9-month lag in Medicaid data being available for receipt and import. Therefore, the Kentucky child welfare services data available for CCOULD is similar to that provided by Florida.

### 5.4 Data Linkage

**Figure 4** describes Kentucky's processes for investigating and acting upon child welfare calls to their agency. The information from these calls is entered into their TWIST data system. This information was extracted and linked to Medicaid claims data as part of this linkage project.

**Table 3** presents the linkage statistics for Kentucky. From 2016 through 2021, the Kentucky child welfare system recorded 278,282 child welfare reports or investigations. These reports represented 268,753 unique children (a child could have more than one report/investigation). The dataset also contained information on 55,033 caregivers.

Kentucky linked 81% (216,738 / 268,753) of the children in the child welfare system to a Medicaid record. Of these 216,738 linked children, 93% (201,095 / 216,738) were linked via SSN, and 7% (15,643 / 216,738) were linked via LongID. Among the caregivers, 85%

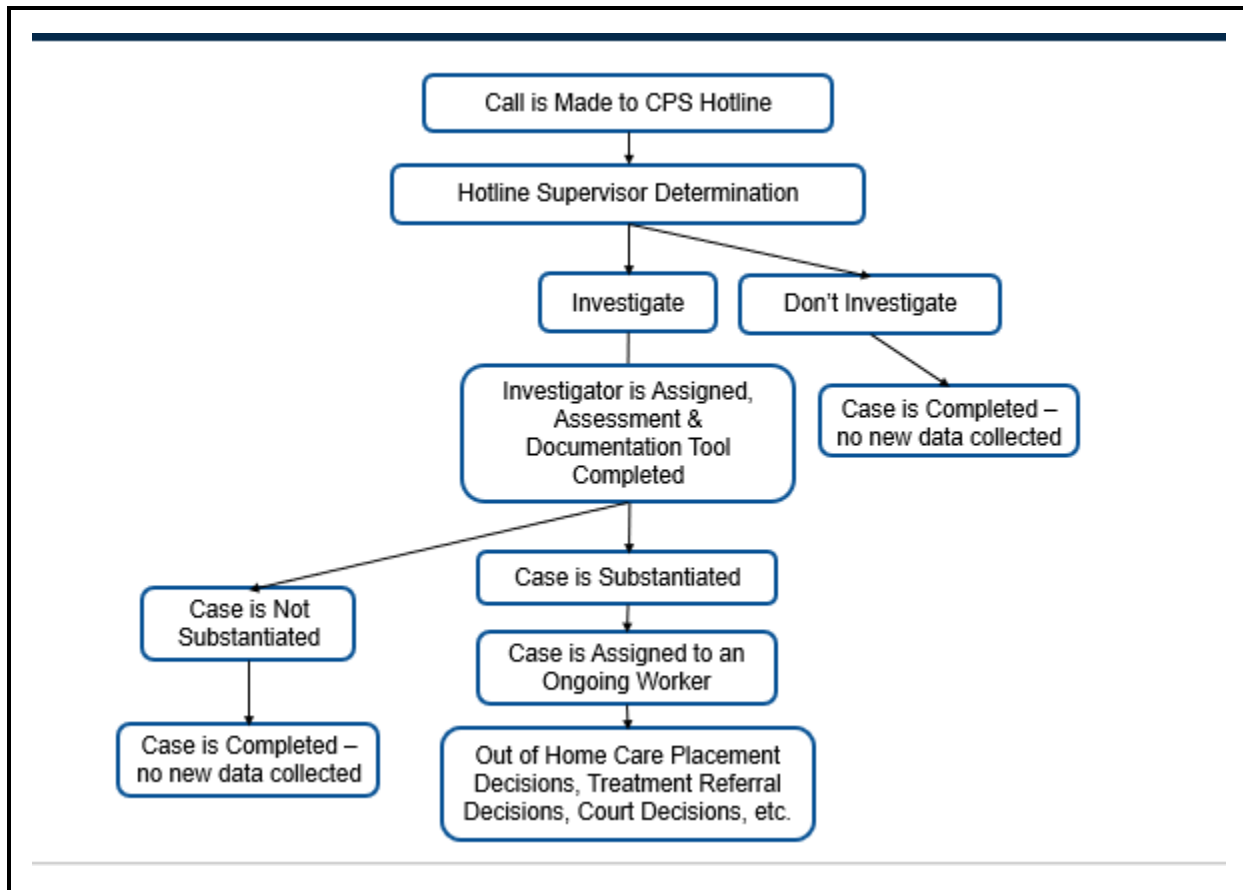
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<sup>2</sup> See <https://www.acf.hhs.gov/cb/training-technical-assistance/revise-technical-bulletin>; <https://www.acf.hhs.gov/cb/training-technical-assistance/technical-bulletin-prevention-program>

(45,672 / 46,809) were linked to Medicaid. 98% of caregivers were linked using the SSN. Of the 216,738 Kentucky children linked to Medicaid, 21.3% had a least one caregiver linked to Medicaid.

As in Florida, we assessed the quality of the LongID linkage approach by comparing the agreement between the linkages using the LongID with the linkages using the SSN, assuming that the SSN was the gold standard (i.e., yielded correct linkages). **Table 4** displays those statistics. The false negative rates (i.e., the rate for links that should have been made with the LongID but were not) were 9.2% for children and 14.6% for caregivers. The false positive rates (i.e., the rate of links that should not be made with the LongID but were) were 10.5% for children and 10.2% for caregivers. The false negative and positive rates were higher in Kentucky than in Florida.

**Figure 4. Kentucky’s Data Generating Process for Child Welfare Cases**



CPS = Child Protective Services

**Table 3. Child Welfare and Medicaid Linkage Statistics from Kentucky, 2016–2020**

Population	Number of Observations	Percentage of Total Children/Caregivers	Percentage by Linked Method
Child Welfare Reports or Investigations occurring from 2016 to 2020	278,282		
Number of children represented in the child welfare reports or investigations from 2016 to 2020	268,753	100%	
Children linked to Medicaid	216,738	81%	
Children linked to Medicaid with SSN	201,095		93%
Children linked to Medicaid with LongID	15,643		7%
Unlinked children	50,103	19%	
Number of caregivers represented in the child welfare reports or investigations from 2016 to 2020	55,033		
Caregivers linked to Medicaid	46,809	85%	
Caregivers linked to Medicaid with SSN	45,672		98%
Caregivers linked to Medicaid with LongID	1,137		2%
Unlinked caregivers	8,223	15%	

**Table 4. Linkage Testing Among Children and Caregivers with Both SSNs and LongID Information**

Population with SSN and LongID Available	Reported Rate, %
Children linked with SSN but not LongID (false negatives)	9.2
Children linked with LongID but not SSN (false positives)	10.5
Caregivers linked with SSN but not LongID (false negatives)	14.6
Caregivers linked with LongID but not SSN (false positives)	10.2

KY provided the same concerns as UF with regards to linking on SSN alone. However, we again followed the data linkage experts and also, to maintain consistency between the two datasets linked on SSN alone.

## 6. Summary of Challenges, Successes, and Lessons Learned

In this section, we summarize some of the key challenges, successes, and lessons learned from the CCOULD project.



## 6.1 State Participation

As described in **Section 1**, ASPE and ACF began recruiting states through a webinar in August 2019. The project team continued to recruit states from Fall 2019 through 2020. In August 2020, Kentucky signed a Memorandum of Understanding (MOU) agreeing to participate in the project. In January 2021, Florida signed an MOU confirming its participation in the project.

*Challenge: Timeliness of recruiting state participants.* It took longer than expected to identify and enroll states willing to partner in the project. There were several reasons candidate states did not participate in CCOULD. Because child welfare and Medicaid agencies are separate organizational entities within state agency systems, it was necessary to conduct outreach and recruitment efforts with each organization prior to scheduling meetings that included both parties. In some candidate states, only one agency—child welfare or Medicaid—was responsive or interested in the project. Some candidate states had already linked their data and therefore did not perceive the project as adding value. Additionally, in Winter 2020, states were focused on addressing the COVID-19 public health emergency, which added to the difficulty of securing state leadership buy-in.

*Successes.* Despite the delays, two states agreed to participate in the study and successfully completed the data linkage.

*Lessons Learned.* State capacity/readiness assessments supported the identification of a subset of candidate states and guided recruitment discussions with those states. As previously noted, the project team looked for states that met the following criteria: leadership buy-in, existing infrastructure and capacity for data linkage, and policies that supported data sharing.

States that met the criteria were contacted and invited to learn more about the project through virtual meetings. These meetings allowed the project team to present the goals of the project, learn more about linkage efforts states had engaged in to date, and discuss the logistics and expectations of CCOULD participation.

After states joined the project, it was important to build strong relationships with them and their partners and to provide the technical assistance needed to overcome obstacles around data sharing that emerged as MOUs and DUAs were being reviewed and negotiated.

Future efforts could generate greater state interest in data linkage by pointing to specific information that could be learned from the linked data that would be of clear value to state agencies that oversee child welfare or Medicaid programs. Kentucky noted that the ASPE Research Brief entitled *Substance Use, the Opioid Epidemic, and the Child Welfare System: Key Findings from a Mixed Methods Study* (Radel et al., 2018b) was important for convincing stakeholders to participate in CCOULD. However, neither Kentucky nor Florida had immediate plans to analyze the data. Federal agencies could canvass state agencies to

determine their informational needs for the linked data. Information generated from the CCOULD data set may also be useful as examples to motivate participation. For example, the CCOULD study revealed that at least 80% and 86% of children involved in the child welfare systems in Florida and Kentucky had Medicaid coverage. This datapoint highlights the critical need to coordinate Medicaid services with child welfare services. For example, even parents without Medicaid coverage can receive family therapy under Medicaid if it is determined to be beneficial to the child.

## 6.2 Maintaining Momentum and Sustainability

CCOULD goals were twofold: (1) to provide technical and financial assistance to states during the project period to support the preparation of a linked child welfare and Medicaid dataset and (2) to identify strategies for states to continue to link child welfare and Medicaid data beyond the project period. The project provided each state with a \$125,000 honorarium to cover some of the cost of participation. Honorariums were provided directly to Kentucky and to Florida's research partner (UF).

*Challenge 1: Burden on State staff resources.* UF indicated that the CCOULD project required 0.71 FTE in labor hours. Kentucky indicated that the CCOULD project took 452 hours or about 0.22 FTE. Securing state staff resources was a challenge for CCOULD. States indicated, at times, that their staff needed to focus on competing priorities, and there was no alternate staff member with the needed analytic and/or information technology expertise.

*Challenge 2: Delays in securing DUAs.* Securing final DUAs took months (see **Figure 5**). In both the Kentucky cabinet and Florida's DCF, changes in leadership necessitated an extension of the DUA negotiation timeline to allow for the new leadership team to become familiar with the CCOULD project. In March 2022 and after the CCOULD DUA was in place, the Kentucky Cabinet streamlined its DUA process and eliminated the involvement of its procurement office. This change will benefit future collaborations.

*Successes.* Despite delays and participating state staff juggling multiple priorities, the project achieved its objective of partnering with two states, linking child welfare and Medicaid data in each state, and developing a merged, linked dataset that could be accessed by researchers.

*Lessons Learned.* States completed CCOULD activities outside of their immediate operational needs and mandated activities. It remains to be seen whether states can devote the necessary time and resources state to continue linking their child welfare system and Medicaid data without a sustainable source of funding for such efforts, a regulatory requirement, and/or a pressing internal need. However, we anticipate that the effort required to continue/sustain linkage will be lower post-CCOULD participation, as state agencies have shared data internally and developed infrastructure. Although states that opt

to implement the Comprehensive Child Welfare Information System (CCWIS) are required to have a bi-directional data exchange with Medicaid Information Management Systems to support the sharing of data on demographic information, immunizations, prescriptions, and other health services (Children's Bureau, 2021), CCWIS requirements do not specify the need to link Medicaid and child welfare data for policy analysis, research, or evaluation purposes. As states realize the value of the linked data, and become facile with processes of linking the data, they may be more likely to link and conduct analyses of their data on an ongoing basis to support policy analysis.

**Figure 5. Timeline of CCOULD Milestones**



### 6.3 Child Welfare Data Availability, Consistency, and Quality

The CDM developed for CCOULD was intended to guide the development of a research use dataset that combined linked child welfare and Medicaid data from two or more states. A set of data quality checks were developed for states to assess and adjust their data as needed before submitting them to RTI for statistical disclosure analysis and harmonization.

*Challenge 1: Lack of data documentation.* In both states, RTI began the project by asking for data dictionaries and code books; however, Kentucky could not provide complete documentation for its child welfare system data. Florida provided more documentation, but it took several iterations between UF, RTI, and DCF to clarify what each variable in the child welfare file meant and to translate that information into a list of variables that would be contained in the CDM and defined in the RTI-UF DUA.

*Successes.* Florida's DCF's willingness to answer questions about the data as the project progressed ensured that there was a common understanding of the child welfare data structure and variables.

*Lessons Learned.* To support analysis and evaluation of state child welfare data, states should maintain high-quality data dictionaries. States may be able to leverage the materials that ACF has created such as technical bulletins on data exchange standards to develop data dictionaries (Children's Bureau, 2022).

*Challenge 2: Caregiver information may be missing or incomplete.* Information on caregivers was less uniform and robust than information on children. Kentucky and Florida seemed to differ in what information they collected from caregivers (e.g., SSNs), how they described the relationship of the caregiver to the child (e.g., primary/secondary caregiver versus biological parent, foster parent, grandparent), and the extent to which caregiver information was collected or maintained in screened-in maltreatment reports.

*Lessons Learned.* State child welfare agencies could place greater emphasis on collecting and maintaining detailed information about caregivers, including SSNs. However, this may be contingent on the operational necessity of collecting such information, as federal rules do not require caregivers to provide social security numbers for child welfare services. For example, Kentucky attempts to enroll eligible caregivers in other state programs when they come in contact with the child welfare system (e.g., the Supplemental Nutrition Assistance Program). Therefore, caregivers have an incentive to provide SSNs, and Kentucky staff have an operational reason to collect it. If states are focused on only the data elements required for reporting to NCANDS and AFCARS, PII may not be collected for all caregivers involved in the child welfare system. The availability of caregiver SSNs and demographic information increase the probability of linking caregivers to children, allowing for a more robust examination of child and family outcomes.

*Challenge 3: Title IV-E Prevention Services information not available.* During CCOULD, both Florida and Kentucky were in the process of incorporating title IV-E prevention services information from external providers into their state data systems. As a result, neither state could provide detailed information on prevention services provided to children and families, or the cost of those services.

*Lessons Learned.* As these and other states begin to implement the title IV-E prevention program, information about the types of evidence-based prevention services provided, service dates, and service costs will be more readily available. Future data linkage efforts may be in a position to examine the quality and utility of these data.

*Challenge 4: Lack of standard codes or definitions in child welfare data systems.* Medicaid claims data use standard nomenclature, known as the [Healthcare Common Procedure Coding System](#), for identifying services that are also used by providers to bill for services.

This system was developed and is maintained by the American Medical Association and by CMS. In contrast, ACF does not prescribe standard codes or definitions for the specific child welfare services reported to NCANDS or provided as title IV-E prevention services, though states must report the service category (i.e., mental health, substance use, or parenting support) of each title IV-E prevention service in reporting child-specific data. States may differ in their definitions of child welfare-related interventions, such as substance abuse or mental health services, and information on the duration or intensity of service receipt is often lacking. This may be a natural consequence of Medicaid being both a federal- and state-funded system and of Medicaid data being derived from a fee-for-service payment system. Child welfare providers are paid largely through state contracts or grants that may be reimbursed by federal funds but are not necessarily per-unit of service. As previously noted, the inclusion of title IV-E prevention funded services in state data systems may, over time, increase the standardization and specificity of prevention-related child welfare services.

*Lessons Learned.* Title IV-E prevention requirements for evidence-based services may advance the quality and completeness of certain services data collected and reported by child welfare agencies. However, title IV-E prevention requirements will not capture all of the services provided by child welfare.

*Successes.* Using the TMSIS, AFCARS, and NCANDS as a foundation and then refining with the states as needed to reflect their unique data variables and structures, RTI was able to create a common data model that allowed the data from two state Medicaid and child welfare systems to be merged into one dataset. Future projects should build off and enhance the common data model format developed from the CCOULD project.

## **6.4 State and Federal Regulations Related to Sharing Child Welfare Records**

*Challenge: Navigating complex privacy rules and regulations.* CCOULD data were subject to state and Federal privacy and human subject protection regulations. Decisions about data sharing, privacy, and human subjects for CCOULD necessitated the involvement of multiple stakeholders from ASPE, ACF, RTI, Kentucky, and Florida, including staff with technical expertise in child welfare and Medicaid data, legal counsel, HIPAA privacy officers, IRBs, and contracts administrators.

*Lessons Learned.* Linking efforts can take advantage of existing technical assistance resources. States may benefit from using the Office of Planning and Research's (OPRE's) [Confidentiality](#) toolkit (Gabay, 2021), which was released in October 2021. The toolkit focuses on information sharing for individual case planning and decision-making at a program level, rather than research, analysis, and evaluation. Nevertheless, it offers important regulatory context for states to consider when balancing the risks and benefits of data sharing across state Medicaid and child welfare agencies.

Another resource for states is the [Children's Bureau-CMS Toolkit for Data Sharing for Child Welfare Agencies and Medicaid](#). This technical guide aims to assist state child welfare and Medicaid agencies in supporting and developing automated, bi-directional data exchanges between their information systems. The guide also includes confidentiality considerations.

States may also benefit from revisiting their laws pertaining to the sharing of child welfare records of research and evaluation, given the evolution in the availability of electronic data, as well as the greater emphasis on preventing child removals.

Collaborating with Kentucky and Florida to navigate privacy and data sharing rules facilitated RTI's access to the Medicaid claims data which contains claims and diagnosis codes pertaining to substance use disorders.

## **6.5 Linking Child Welfare and Medicaid Data**

Once the UF and Kentucky OHDA teams had obtained person-level files for child welfare and Medicaid, the CCOULD project team focused on providing technical assistance and linkage solutions to both states to support the identification of child-caregiver pairs and the preparation of a linked dataset to be submitted to RTI.

*Challenge 1: Data quality issues in variables used for linking.* As previously noted, the success of deterministic linkage hinges on the quality of the linking variables. It was difficult for states to assess how much missingness existed in proposed linkage variables, as many data systems were not designed to answer questions around the missingness of our proposed linkage variables. Furthermore, maintaining consistent methods and timelines for linking across the two states was challenging. The two states possessed different strengths with regard to linking, and this made it difficult to provide uniform, one-size-fits-all recommendations for conducting the linkage.

*Lessons Learned.* The heterogenous nature of the two states' data and administrative systems, in particular the approval of the DUAs and accessing the data, meant that the project timelines needed significant buffer to achieve our goals. The time constraints of the project necessitated linkage solutions that were easily implemented by states, such as the use of the deterministic linkage methods.

*Challenge 2: Probabilistic matching can yield more linked data, but the states did not have the time or resources to pursue it.* Probabilistic matching may have yielded additional linkages not captured by direct matching using SSN or the long-identifier. However, the project timeline for CCOULD did not allow for an exploratory analysis of probabilistic matching methods.

*Lessons Learned.* Future efforts could incorporate probabilistic methods. States could benefit from webinars and technical assistance pertaining to probabilistic matching approaches and easier tools to implement probabilistic matching approaches.

*Successes.* SSNs were more-often available for children than we had anticipated reducing the need to use probabilistic matching. SSNs were available less frequently for caregivers, but they were still available for a significant subset of caregivers. As a result, the project successfully linked thousands and children and caregivers in child welfare to their records in Medicaid.

Based on this two-state case study, SSNs are well-populated and of high quality in child welfare records. We do not know whether this is the case in other states. Kentucky pointed out that its high rate of SSNs may be a result of their decision to structure one of its public assistance divisions with the Department for Community-Based Services, the same department that contains the state's child welfare division. Staff in the same division can help enroll people in benefits, where SSNs are critical, and investigate allegations of child abuse and neglect. These staff may have established practices that are more diligent about collecting SSNs.

*Challenge 3: Lack of family identifiers.* Because Medicaid datasets do not usually have a family identifier, children cannot be linked to parents or caregivers using the Medicaid claims files.

*Lessons Learned.* We linked caregivers in the child welfare file to caregivers in the Medicaid file by first linking caregivers to children in the child welfare data. If there was a family identifier on the Medicaid data, more caregivers could have been found to have Medicaid coverage.

Because they are a unique identifier, SSNs provide the highest-quality linkages between children and caregivers in Medicaid and child welfare systems. However, SSNs are subject to heightened privacy protections under HIPAA and state regulations and are not always available for children and families served by the child welfare system. The project was able to link using SSNs despite these privacy protections by having the states do the linkage, rather than trying to have the external research organization (i.e., RTI) obtain the SSNs and do the data linkage. Future projects may benefit by following this approach.

## **6.6 Data Harmonization**

Before submitting the combined dataset to NDACAN, the project team harmonized the data from the two states ensure that all variables were in a uniform format and conformed to the specifications in the Common Data Model. This involved generating and thoroughly reviewing frequency distributions and crosstabs of the variables to ensure that the elements of the dataset, including the variable names, variable labels, and response categories. The review identified only a few inconsistencies which were recoded or re-formatted to be consistent.

*Challenge 1:* Discrepant variable coding and formats. Harmonization efforts revealed several variables that were coded differently by each state. For example, missing was sometimes coded as “999” rather than “.”; this was not a significant challenge to correct. It required carefully reviewing the frequencies of each state’s submitted data.

*Challenge 2:* Race/ethnicity information is stored in both the child welfare and Medicaid data systems in Florida and Kentucky. When more than one race was provided for a single person, RTI adjudicated the race variable

*Successes:* The use of a common data model minimized the discrepancies in data submitted by the two states and resulted in the need for only minor adjustments during harmonization.

## 6.7 Data Archiving

The project team established the following criteria for selecting a data archive:

- Secure storage of large national-level datasets
- Cost to the project and researchers
- Timeline for making the data available to the research community
- Familiarity of the archive to researchers, particularly those who are likely to be interested in child welfare research

We began identifying data archives by searching the internet. After reviewing the search results in the context of our experience and expertise with different data archiving organizations, we narrowed the options to two data archives:

- The National Data Archive on Child Abuse and Neglect (NDACAN) at Cornell University (<https://www.ndacan.acf.hhs.gov>)
- The Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan (<https://www.icpsr.umich.edu/icpsrweb/content/datamanagement/index.html>)

These two archives are well-known in the research community and have established reputations for the secure storage of large national-level datasets. NDACAN receives its funding through a contract with the U.S. Children’s Bureau and houses about 50 datasets on the topic of child abuse and neglect. ICPSR is funded through grants from several federal agencies and foundations and by annual membership fees paid by universities and research institutions. Members are given free, unlimited access to all datasets. ICPSR houses about 15,000 datasets from all areas of social science research.

Both archives are well-established and are equally qualified to serve as the project’s archive. Ultimately, the project team selected NDACAN as the repository for CCOULD based on accessibility of the data to the research community and the timeline for making the data available. In addition to CCOULD, NDACAN houses three large child welfare datasets familiar to most child welfare researchers: the National Survey of Child and Adolescent Well-Being



(NSCAW), the National Child Abuse and Neglect Data System, and the Adoption and Foster Care Analysis and Reporting System.

This was the first time that NDACAN had archived insurance enrollment and encounter data. RTI provided NDACAN information on HIPAA Privacy Rule as well as HIPAA's guidance regarding methods for de-identification of protected health information. The guidance explains the two methods that can be used to satisfy the Privacy Rule's de-identification standard: Expert Determination and Safe Harbor. RTI used a combination of expert determination and safe harbor to ensure that the data provided to NDACAN was de-identified.

*Challenges:* Because NDACAN had not previously archived Medicaid claims data, RTI worked closely with NDACAN to address concerns about HIPAA privacy rules and disclosure risk.

*Successes:* RTI developed clear documentation to explain the approach to de-identifying the claims data and collaborated with NDACAN to determine that the risk of re-disclosure was minimal. Additionally, RTI and NDACAN added a statement to the CCOULD DUA for researchers to indicate that estimates with cells of less than 10 observations should not be released.

## 7. Discussion

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### Summary of CCOULD Lessons Learned

- Internal data sharing initiatives within state agencies are subject to many legal, procedural, and regulatory provisions, which can slow down intra-agency data sharing.
  - Honorarium or site payments may not fully offset participation burden.
  - MOUs and DUAs must be site-specific, and negotiations can be time-consuming.
  - Real and perceived regulatory and privacy concerns are equally important to address.
  - Documentation of state child welfare system variables could be more robust.
  - The lack of a family identifier in Medicaid claims and encounters data makes the identification of caregivers challenging.
  - State child welfare agencies are enhancing their ability to report on title IV-E prevention services.
  - Probabilistic matching may yield additional linkages not captured by deterministic matching.
- 

CCOULD is the first effort focused on producing a research use dataset containing longitudinal, linked child welfare, caregiver, and Medicaid data in two states. This proof-of-concept project has demonstrated the feasibility of supporting states to link child and caregiver records over multiple years and producing a harmonized dataset for researchers. The de-identified linked data from both states will be archived at NDACAN and available to researchers. Archived CCOULD data will allow for a more robust examination of the service receipt and trajectories of children and families involved in child welfare and Medicaid systems in two states. CCOULD

data may be particularly well suited for equity analyses, providing the research community

with an opportunity to examine equity in the context of factors such as service delivery/receipt and in child and family outcomes.

The sustainability of ongoing child welfare-Medicaid linkage in states participating in CCOULD is not yet known. However, both Florida and Kentucky reported that cross-agency DUAs could facilitate future data sharing and linkage activities. Barriers to sustainability may include state staffing/resource limitations or the absence of a requirement or internal need to analyze integrated data. Answering states' priority research questions with CCOULD data could support sustainability by illustrating the value of integrated data. Additionally, although the title IV-E prevention program provides funding through title IV-E for certain evidence-based prevention services to eligible children and their families, federal reimbursement requirements dictate the appropriate payer and that services/payments are not duplicative. These requirements may be met more easily if integrated data are available.

CCOULD data are not without their limitations. The research use dataset is limited to two states in the South and Southeast regions of the country and does not contain robust title IV-E prevention data. Toward the end of the CCOULD participation, state child welfare agencies were beginning to incorporate title IV-E prevention services, service dates, and service costs into their data systems. The framework and CDM developed on CCOULD sets the stage for future efforts to recruit additional states and prepare a combined research use dataset that includes title IV-E prevention services data.

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## **Appendix A. Common Data Model**

CCOULD Project

## Extraction code and syntax for states

**June 30, 2022**

The goal of this document is to provide detailed syntax on variable definitions and how to derive each of the child-welfare- and Medicaid-specific files in the Common Data Model (CDM) for the Child and Caregiver Outcomes Using Linked Data (CCOULD) project for the each of the two states in the COULD project. Additional guidance is provided for the child welfare and flags files.

### **Medicaid Data**

**Medicaid Enrollment File.** Additional detail on variable coding can be found on the Medicaid Enrollment tab in the COULD\_CDM\_DRAFT\_MO\_D\_YYYY.xlsx spreadsheet. Here we provide decision rules for how to roll up the requested data elements to a monthly level. The file will use enrollment/eligibility records from 2016 through 2020. Where possible we refer to specific fields as they are indicated in the CDM spreadsheet.

We do not provide decision rules for the following variables: COULD\_ID, CYEAR, MONTH, SUBMTG\_ST. Here are the decision rules for rolling up the remaining variables for the monthly enrollment file:

1. MCO (derived from DSS.T\_CA\_PROV\_KEY.ID\_MEDICAID): This variable should indicate if the member was enrolled in a Medicaid managed care organization (MCO) during the month. If they have at least one day of MCO enrollment set this variable to 1; otherwise, set this variable to 0. This variable should not indicate the specific MCO in which the member was enrolled.
2. Eligibility information:
  - a. CHIP (derived from DSS.T\_RE\_AID\_ELIG\_DN.CDE\_AID\_CATEGORY): If a member has any days during the month of CHIP enrollment, then set this variable to 1; otherwise, set this variable to 0.
  - b. FOSTER (derived from DSS.T\_RE\_AID\_ELIG\_DN.CDE\_AID\_CATEGORY): If a member has any days during the month with a foster care program code, then set this variable to 1; otherwise, set this variable to 0.
  - c. DUAL (derived from DSS.T\_RE\_BASE\_DN.IND\_MEDICARE\_A and DSS.T\_RE\_BASE\_DN.IND\_MEDICARE\_B): If a member has any days of dual eligibility for Medicare and Medicaid during the month, then set this variable to 1; otherwise, set this variable to 0.
  - d. DISABLED (derived from DSS T CDE\_AID3.CDE\_ABD): If a member was eligible for Medicaid due to disability during the month, then set this variable to 1; otherwise, set this variable to 0.
  - e. RESTRCT\_BNFT (derived from DSS T CDE\_AID3.CDE\_ABD): If a member was only eligible for some Medicaid benefits during the month (e.g., they were only eligible for medical benefits, and were not eligible for pharmacy benefits), then set this variable to 1; otherwise, set this variable to 0.

After rolling the data up to a monthly level, retain one record per member per month (if a member is not enrolled at all during a month, there should be no record for that month), and only retain the variables that are listed in the Common Data Model (see the Medicaid Enrollment tab).

**Inpatient (IP) and Other Therapy (OT) Header Files.** The first step is to split medical claims into two types. The first type will go into the IP Header File and will include all facility inpatient claims defined as facility claims with a type of bill code = 011x-012x (Inpatient hospital), 018x (Swing bed hospital), 021x-022x (Inpatient skilled nursing), or 028x (Swing bed skilled nursing). All other claims, which will include a mix of facility and professional,

will go in the OT Header File. Between the two files, this should encompass all medical claims from 2016 through 2020.

After splitting claims into these two buckets, the second step is to roll up a core set of variables to a “header” level. The purpose of this header file is to provide an easier-to-use file that contains a subset of claim information that researchers will frequently need on one record per unique claim ID. We will also retain the data at a line level to ensure that we do not lose details that may be needed by researchers on a more infrequent basis. Roll up rules are as follows:

1. Date variables (ADMT\_DT, DSCHRG\_DT, SRVC\_FROM\_DT, and SRVC\_THRU\_DT: derived from DTE\_ADMISSION, DTE\_DISCHARGE, DTE\_FIRST\_SVC, and DTE\_LAST\_SVC): If there are more than one start and end date (e.g., admission and discharge date) within the same CLAIM\_ID, then retain the earliest start date and the latest end date on the header.
  - a. The CDM refers to “Best Date”. By Best Date, we mean to prioritize dates as indicated above: the admission dates and discharge dates should be prioritized on the claim. In the absence of an admission and discharge date, use the service from date and service through date.
  - b. When handling date variables for the header record, it may make sense to also derive two new variables:
    - i. If DSS.T\_CA\_ICN.DTE\_DISCHARGE occurs before DSS.T\_CA\_ICN.DTE\_ADMISSION, set DSS.T\_CA\_ICN.DTE\_DISCHARGE equal to DSS.T\_CA\_ICN.DTE\_ADMISSION.
    - ii. Then create two new variables:
      1. START\_DT = DSS.T\_CA\_ICN.DTE\_ADMISSION if DSS.T\_CA\_ICN.DTE\_ADMISSION ne missing; otherwise, = DSS.T\_CA\_HDR\_DTL.DTE\_FIRST\_SVC.
      2. END\_DT = DSS.T\_CA\_ICN.DTE\_DISCHARGE if DSS.T\_CA\_ICN.DTE\_DISCHARGE ne missing; otherwise, = DSS.T\_CA\_HDR\_DTL.DTE\_LAST\_SVC.

The point of these latter two variables is to capture the best service date for the claim, which we assume to be an admission or discharge date where that date exists.

2. Diagnosis codes (DX\* derived from DSS.T\_CA\_ICN.CDE\_DIAG \*): For the IP Header File keep up to 12 diagnosis codes at the header level; for the OT Header File keep up to 5 diagnosis codes at the header level. Because there could be claims that have multiple distinct sets of diagnosis codes at the line level, we will keep all diagnosis codes at a line level. If the first (second, third, etc.) diagnosis code differs across lines, then retain the diagnosis code from the line with the earliest start date.
3. Procedure codes (PROC\* derived from DSS.T\_CA\_ICN.CDE\_PROC PRIM): For the IP Header File keep the first 6 procedure codes at the header level, after sorting data on START\_DT within CLAIM\_ID. We will store all procedure codes at a line level for OT claims.
4. Place of Service (POS derived from DSS.T\_CA\_CLAIM\_KEY.CDE\_POS): If there is more than one POS code across lines within the same CLAIM\_ID, then assign the POS associated with the line that has the largest AMT\_BILLED.
5. Billing provider data (BILL\_PRVDR\_NPI, BILL\_PRVDR\_TXNMY, BILL\_PRVDR\_TYP [the latter derived from BILL\_PROV\_TYPE]): If there is more than one billing provider across lines within the same CLAIM\_ID, then assign the billing provider associated with the earliest START\_DT.



6. Billed and paid amounts (BILL\_AMT derived from AMT\_BILLED and MDCD\_PMT derived from AMT\_PAID): Sum the amounts from each individual line to provide a header total for the entire claim.
  - a. For any of the following: prepaid amount, copayment amount, coinsurance amount, deductible amount, and generic. Please leave blank if not available.
7. Taxonomy: Please map your provider specialty codes to CMS national provider taxonomy codes.
8. Type of Service: Please ensure that your Type of Service variable is consistent with the Medicare Claims Processing Manual ([see here for more detail.](#)) If type of service is not available, please ignore this variable.

We would like to keep both acute and non-acute inpatient stays in the inpatient file. We are adding to the CDM an additional flag for acute stays based on the bill type. Set the acute stay flag equal to 1 if the bill type is 011x or 012x, otherwise set to 0.

**Inpatient (IP) and Other Therapy (OT) Line Files.** Follow the same process to separate claims into IP and OT buckets as with the corresponding header files.

Then rename variables according to the CDM documentation on the Medicaid IP OT Line tab. These files will keep the same structure as the data presented in the Limited Dataset Dictionary.

**Pharmacy Claims.** Separate out pharmacy claims from other claims.

Then rename variables according to the CDM documentation on the Medicaid Pharmacy Claims tab. This file will keep the same structure as the data presented in the Limited Dataset Dictionary.

### ***Child welfare files***

**Living arrangements.** To attach the living arrangements table to a specific report, please select the report that is prior to and closest in time to livarr1\_st\_dt.

### ***Xwalk files***

**FamID.** If a family ID is not present in the child welfare report data, please assign a family ID to every unique caregiver and child pair.

The following strategies are used to assign a rpt\_id for child-caregiver pairs

For child-caregiver pairs identified from foster care episodes:

- Select the report matching on the removal date shown in the NCANDS file (ch\_srvc\_foster\_cr\_dt)
- Select the report with the investigation start date (inv\_start\_dt) and the investigation completion date in NCANDS (rpt\_disposition\_dt) covering the removal date. If more than one reports are found, prioritize the one with the investigation start date (inv\_start\_dt) closet in time to the removal date.
- Select the report with the investigation start date (inv\_start\_dt) that is prior to and closet in time to the removal date.
- Select the report with the investigation start date (inv\_start\_dt) that is after and closet in time to the removal date.

For child-caregiver pairs identified from in-home services but not foster care episodes:

- Select the report with the earliest investigation start date (inv\_start\_dt) for the child.

### ***Flags files***

**Child-Level Flags File.** The child-level flags file is meant to provide a set of ready-to-use measures at the child level that can be used as a starting point for a variety of research studies. This file does not contain every measure that a research study may need but focuses on the most likely needed measures. Additional measures can be derived, and tailored to specific research objectives, from the other files included in the Common Data Model (CDM).

Here are the specifications for the derived variables in the child-level flags file:

1. RPT\_DT\_EARLIEST\_ANY: use the child welfare report file and find the earliest RPT\_DT's
2. RPT\_DT\_EARLIEST: use the child welfare report file and find the earliest RPT\_DT where RPT\_DISPOSITION=1 (Substantiated).
3. RPT\_DT\_MOST\_RECENT = use the child welfare report file and find the latest RPT\_DT where RPT\_DISPOSITION=1 (Substantiated).
4. MAL\_ALLCNT: use the child welfare report file and count the number of unique reports (RPT\_ID) where RPT\_DISPOSITION=1 (substantiated).
5. MAL\_PHYCNT: use the child welfare report file and count the number of unique reports (RPT\_ID) where CH\_MAL\_\* = 1 (Physical Abuse) and CH\_MAL\_\*\_DISPOSITION = 1 (Substantiated).  
*Notes: "\*" is a wildcard indicating that any of the CH\_MAL\_1 through CH\_MAL\_4 could be used as a criterion for the inclusion of a report in this count.*  
 If CH\_MAL\_\* = 1 (Physical Abuse), but the associated CH\_MAL\_\*\_DISPOSITION ne 1, then do not include the report in this count. For example, if CH\_MAL\_1 = 1 and CH\_MAL\_1\_DISPOSITION ne 1 but CH\_MAL\_2\_DISPOSITION = 1, then do not include.
6. MAL\_NEGCNT: same as above, but CH\_MAL\_\* = 2 (Neglect or Deprivation of Necessities).
7. MAL\_MEDNEGCNT: same as above, but CH\_MAL\_\* = 3 (Medical Neglect).
8. MAL\_SEXCNT: same as above, but CH\_MAL\_\* = 4 (Sexual Abuse).
9. MAL\_PSYCNT: same as above, but CH\_MAL\_\* = 5 (Psychological or Emotional Maltreatment).
10. MAL\_SUBEXPINF: set to 1 if the following criteria are met:
  - a. The child is an infant: CH\_AGE\_AT\_RPT\_DT = 0.
  - b. Referred to CPS by a health care provider: RPT\_SRC = 2 (medical personnel).
  - c. Born with and identified as being affected by substance abuse or withdrawal symptoms: CH\_ALC = 1 OR CH\_DRG = 1 OR [CH\_SRVC\_SUD=1 AND (CH\_ALC = 1 OR CH\_DRG = 1)]
11. FC\_PLCMT\_EVER: use the child foster care (FC) episode file and set to one if the child (CCOULD\_ID) has any records in the child FC episode file.
12. FC\_PLCMT\_CNT: count the number of episodes for the child observed in the child FC episode file. This will be based on the federal guidelines – number of placements.
13. RPT\_SUBABUSE: use the child welfare file and set this variable to 1 if the child (CCOULD\_ID) has any report where CH\_ALC = 1 or CH\_DRG = 1.
14. RPT\_INTDISAB: use the child welfare file and set this variable to 1 if the child (CCOULD\_ID) has any report where CH\_INTDIS = 1.
15. CLM\_PHYCONCNT: use the Medicaid IP and OT line files and set this variable equal to 1 if there are any claims for the child (CCOULD\_ID) where any of the diagnosis codes DX\* = T7412XA.
16. CLM\_PHYSUSCNT: same as above, but DX\* = T7612XA.
17. CLM\_NEGCONCNT: same as above, but DX\* = T7402XA.
18. CLM\_NEGSUSCNT: same as above, but DX\* = T7602XA.
19. CLM\_SHKBABY: same as above, but DX\* = T744XXA.
20. CLM\_NOSCHLDABCONCNT: same as above, but DX\* = T7492XA.
21. CLM\_NOSCHLDABSUSCNT: same as above, but DX\* = T7692XA.
22. ANY\_BHDX: use the Medicaid IP and OT Header files and set this variable to 1 if the child (CCOULD\_ID) has any claim with a primary diagnosis code (DX1) = F01-F99.
23. CLM\_MHPHYSIO: same as above but set to 1 if (DX1) = F01-F09.
24. CLM\_MHANSUD: same as above but set to 1 if DX1 = F10-F19.
25. CLM\_MHALC: same as above but set to 1 if DX1 = F10.
26. CLM\_MHOPIOID: same as above but set to 1 if DX1 = F11.
27. CLM\_MHCANNAB: same as above but set to 1 if DX1 = F12.
28. CLM\_MHSED: same as above but set to 1 if DX1 = F13.
29. CLM\_MHCOCAINE: same as above but set to 1 if DX1 = F14.
30. CLM\_MHOTHSTIM: same as above but set to 1 if DX1 = F15.
31. CLM\_MHHALLU: same as above but set to 1 if DX1 = F16.
32. CLM\_MHNICOT: same as above but set to 1 if DX1 = F17.
33. CLM\_MHINH: same as above but set to 1 if DX1 = F18.
34. CLM\_MHOTHPSYSUB: same as above but set to 1 if DX1 = F19.
35. CLM\_MHNONMOODPSYDIS: same as above but set to 1 if DX1 = F20-F29.
36. CLM\_MHMOODDIS: same as above but set to 1 if DX1 = F30-F39.

37. CLM\_MHNONPSYMETDIS: same as above but set to 1 if DX1 = F40-F49.
38. CLM\_MHBEHAVSYN: same as above but set to 1 if DX1 = F50-F59.
39. CLM\_MHPERDIS: same as above but set to 1 if DX1 = F60-F69.
40. CLM\_MHINTELDISAB: same as above but set to 1 if DX1 = F70-F79.
41. CLM\_MHDEVDIS: same as above but set to 1 if DX1 = F80-F89.
42. CLM\_MHBEHDISCHILD: same as above but set to 1 if DX1 = F90-F98.
43. CLM\_MHUNSPEC: same as above but set to 1 if DX1 = F99.
44. BH\_RX\_PSYCHOTROPIC: use the Medicaid Pharmacy claims and set this variable to 1 if the child (CCOULD\_ID) ever has a pharmacy claim with an NDC code = any of the codes in the “Psychotropic NDCs” value set in the CCOULD\_VSD.xlsx spreadsheet.
45. BH\_RX\_MOUD: use the Medicaid Pharmacy Claims and set this variable to 1 if the child (CCOULD\_ID) ever has a pharmacy claim with an NDC code = any of the codes in the “MOUD NDCs” value set in the CCOULD\_VSD.xlsx spreadsheet.
46. BH\_RX\_MAUD: use the Medicaid Pharmacy Claims and set this variable to 1 if the child (CCOULD\_ID) ever has a pharmacy claim with an NDC code = any of the codes in the “MAUD NDCs” value set in the CCOULD\_VSD.xlsx spreadsheet.
47. BH\_PSYCHOTHERAPY: use the Medicaid OT Line and set this variable to 1 if the child (CCOULD\_ID) ever has a PROC = any of the codes in the “Psychotherapy Procedures” value set in the CCOULD\_VSD.xlsx spreadsheet.

**Adult-level flags.** These flags are to be created in the same way as for the children.

## Appendix B. Florida Statute (39.202) Pertaining to Child Welfare Records

### 39.202 Confidentiality of reports and records in cases of child abuse or neglect.

(1) In order to protect the rights of the child and the child's parents or other persons responsible for the child's welfare, all records held by the department concerning reports of child abandonment, abuse, or neglect, including reports made to the central abuse hotline and all records generated as a result of such reports, shall be confidential and exempt from the provisions of s. [119.07](#)(1) and shall not be disclosed except as specifically authorized by this chapter. Such exemption from s. [119.07](#)(1) applies to information in the possession of those entities granted access as set forth in this section.

(2) Except as provided in subsection (4), access to such records, excluding the name of the reporter which shall be released only as provided in subsection (5), shall be granted only to the following persons, officials, and agencies:

(a) Employees, authorized agents, or contract providers of the department, the Department of Health, the Agency for Persons with Disabilities, or county agencies responsible for carrying out:

1. Child or adult protective investigations;
2. Ongoing child or adult protective services;
3. Early intervention and prevention services;
4. Healthy Start services;
5. Licensure or approval of adoptive homes, foster homes, child care facilities, facilities licensed under chapter 393, or family day care homes or informal child care providers who receive school readiness funding, or other homes used to provide for the care and welfare of children; or
6. Services for victims of domestic violence when provided by certified domestic violence centers working at the department's request as case consultants or with shared clients. Also, employees or agents of the Department of Juvenile Justice responsible for the provision of services to children, pursuant to chapters 984 and 985.

(b) Criminal justice agencies of appropriate jurisdiction.

(c) The state attorney of the judicial circuit in which the child resides or in which the alleged abuse or neglect occurred.

(d) The parent or legal custodian of any child who is alleged to have been abused, abandoned, or neglected, and the child, and their attorneys, including any attorney representing a child in civil or criminal proceedings. This access shall be made available no later than 30 days after the department receives the initial report of abuse, neglect, or abandonment. However, any information otherwise made confidential or exempt by law shall not be released pursuant to this paragraph.

(e) Any person alleged in the report as having caused the abuse, abandonment, or neglect of a child. This access shall be made available no later than 30 days after the department receives the initial report of abuse, abandonment, or neglect and, when the alleged perpetrator is not a parent, shall be limited to information involving the protective investigation only and shall not include any information relating to subsequent dependency proceedings. However, any information otherwise made confidential or exempt by law shall not be released pursuant to this paragraph.

(f) A court upon its finding that access to such records may be necessary for the determination of an issue before the court; however, such access shall be limited to inspection in camera, unless the court determines that public disclosure of the information contained therein is necessary for the resolution of an issue then pending before it.

(g) A grand jury, by subpoena, upon its determination that access to such records is necessary in the conduct of its official business.

(h) Any appropriate official of the department or the Agency for Persons with Disabilities who is responsible for:

1. Administration or supervision of the department's program for the prevention, investigation, or treatment of child abuse, abandonment, or neglect, or abuse, neglect, or exploitation of a vulnerable adult, when carrying out his or her official function;
2. Taking appropriate administrative action concerning an employee of the department or the agency who is alleged to have perpetrated child abuse, abandonment, or neglect, or abuse, neglect, or exploitation of a vulnerable adult; or
3. Employing and continuing employment of personnel of the department or the agency.

(i) Any person authorized by the department who is engaged in the use of such records or information for bona fide research, statistical, or audit purposes. Such individual or entity shall enter into a privacy and security agreement with the department and shall comply with all laws and rules governing the use of such records and information for research and statistical purposes. Information identifying the subjects of such records or information shall be treated as confidential by the researcher and shall not be released in any form.

(j) The Division of Administrative Hearings for purposes of any administrative challenge.

(k) Any appropriate official of a Florida advocacy council investigating a report of known or suspected child abuse, abandonment, or neglect; the Auditor General or the Office of Program Policy Analysis and Government Accountability for the purpose of conducting audits or examinations pursuant to law; or the guardian ad litem for the child.

(l) Employees or agents of an agency of another state that has comparable jurisdiction to the jurisdiction described in paragraph (a).

(m) The Public Employees Relations Commission for the sole purpose of obtaining evidence for appeals filed pursuant to s. [447.207](#). Records may be released only after deletion of all information which specifically identifies persons other than the employee.

(n) Employees or agents of the Department of Revenue responsible for child support enforcement activities.

(o) Any person in the event of the death of a child determined to be a result of abuse, abandonment, or neglect. Information identifying the person reporting abuse, abandonment, or neglect shall not be released. Any information otherwise made confidential or exempt by law shall not be released pursuant to this paragraph.

(p) An employee of the local school district who is designated as a liaison between the school district and the department pursuant to an interagency agreement required under s. [39.0016](#) and the principal of a public school, private school, or charter school where the child is a student. Information contained in the records which the liaison or the principal determines are necessary for a school employee to effectively provide a student with educational services may be released to that employee.

<sup>1</sup>(q) Staff of a children's advocacy center that is established and operated under s. [39.3035](#).

(r) A physician licensed under chapter 458 or chapter 459, a psychologist licensed under chapter 490, or a mental health professional licensed under chapter 491 engaged in the care or treatment of the child.

(s) Persons with whom the department is seeking to place the child or to whom placement has been granted, including foster parents for whom an approved home study has been conducted, the designee of a licensed residential group home described in s. [39.523](#), an approved relative or nonrelative with whom a child is placed pursuant to s. [39.402](#), preadoptive parents for whom a favorable preliminary adoptive home study has been conducted, adoptive parents, or an adoption entity acting on behalf of preadoptive or adoptive parents.

(3) The department may release to professional persons such information as is necessary for the diagnosis and treatment of the child or the person perpetrating the abuse or neglect.

(4) Notwithstanding any other provision of law, when a child under investigation or supervision of the department or its contracted service providers is determined to be missing, the following shall apply:

(a) The department may release the following information to the public when it believes the release of the information is likely to assist efforts in locating the child or to promote the safety or well-being of the child:

1. The name of the child and the child's date of birth;
2. A physical description of the child, including at a minimum the height, weight, hair color, eye color, gender, and any identifying physical characteristics of the child; and
3. A photograph of the child.

(b) With the concurrence of the law enforcement agency primarily responsible for investigating the incident, the department may release any additional information it believes likely to assist efforts in locating the child or to promote the safety or well-being of the child.

(c) The law enforcement agency primarily responsible for investigating the incident may release any information received from the department regarding the investigation, if it believes the release of the information is likely to assist efforts in locating the child or to promote the safety or well-being of the child.

The good faith publication or release of this information by the department, a law enforcement agency, or any recipient of the information as specifically authorized by this subsection shall not subject the person, agency or entity releasing the information to any civil or criminal penalty. This subsection does not authorize the release of the name of the reporter, which may be released only as provided in subsection (5).

(5) The name of any person reporting child abuse, abandonment, or neglect may not be released to any person other than employees of the department responsible for child protective services, the central abuse hotline, law enforcement, the child protection team, or the appropriate state attorney, without the written consent of the person reporting. This does not prohibit the subpoenaing of a person reporting child abuse, abandonment, or neglect when deemed necessary by the court, the state attorney, or the department, provided the fact that such person made the report is not disclosed. Any person who reports a case of child abuse or neglect may, at the time he or she makes the report, request that the department notify him or her that a child protective investigation occurred as a result of the report. Any person specifically listed in s. [39.201\(1\)](#) who makes a report in his or her official capacity may also request a written summary of the outcome of the investigation. The department shall mail such a notice to the reporter within 10 days after completing the child protective investigation.

(6) All records and reports of the child protection team of the Department of Health are confidential and exempt from the provisions of ss. [119.07\(1\)](#) and [456.057](#), and shall not be disclosed, except, upon request, to the state attorney, law enforcement, the department, and necessary professionals, in furtherance of the treatment or additional evaluative needs of the child, by order of the court, or to health plan payors, limited to that information used for insurance reimbursement purposes.

(7) The department shall make and keep reports and records of all cases under this chapter and shall preserve the records pertaining to a child and family until the child who is the subject of the record is 30 years of age, and may then destroy the records.

(a) Within 90 days after the child leaves the department's custody, the department shall give a notice to the person having legal custody of the child, or to the young adult who was in the department's custody, which specifies how the records may be obtained.

(b) The department may adopt rules regarding the format, storage, retrieval, and release of such records.

(8) A person who knowingly or willfully makes public or discloses to any unauthorized person any confidential information contained in the central abuse hotline is subject to the

penalty provisions of s. 39.205. This notice shall be prominently displayed on the first sheet of any documents released pursuant to this section.

**History.**—ss. 1, 2, 3, 4, 5, 6, ch. 63-24; s. 941, ch. 71-136; ss. 1, 1A, ch. 71-97; s. 32, ch. 73-334; s. 65, ch. 74-383; s. 1, ch. 75-101; s. 1, ch. 75-185; s. 4, ch. 76-237; s. 1, ch. 77-77; s. 3, ch. 77-429; ss. 1, 2, ch. 78-322; s. 3, ch. 78-326; s. 22, ch. 78-361; s. 1, ch. 78-379; s. 181, ch. 79-164; s. 1, ch. 79-203; s. 488, ch. 81-259; s. 11, ch. 84-226; s. 39, ch. 85-54; s. 14, ch. 85-224; s. 36, ch. 87-238; s. 2, ch. 88-80; s. 8, ch. 88-219; s. 26, ch. 88-337; s. 5, ch. 89-170; s. 5, ch. 89-278; s. 36, ch. 89-294; s. 2, ch. 89-535; s. 8, ch. 90-50; s. 7, ch. 90-208; s. 54, ch. 90-306; s. 9, ch. 91-57; s. 20, ch. 91-71; ss. 43, 48, ch. 92-58; s. 32, ch. 93-39; s. 16, ch. 93-214; s. 58, ch. 94-218; ss. 25, 46, ch. 95-228; s. 28, ch. 95-267; s. 15, ch. 96-402; s. 275, ch. 96-406; s. 1044, ch. 97-103; s. 15, ch. 97-276; s. 3, ch. 97-299; s. 15, ch. 98-137; s. 32, ch. 98-166; s. 3, ch. 98-255; s. 45, ch. 98-280; s. 32, ch. 98-403; s. 5, ch. 99-168; s. 11, ch. 99-193; s. 1, ch. 99-369; s. 18, ch. 2000-139; s. 2, ch. 2000-217; s. 6, ch. 2000-263; s. 51, ch. 2000-349; s. 12, ch. 2001-60; s. 27, ch. 2001-266; s. 2, ch. 2003-146; s. 1, ch. 2005-173; s. 1, ch. 2005-213; s. 6, ch. 2006-194; s. 3, ch. 2006-227; s. 2, ch. 2009-34; s. 2, ch. 2009-35; s. 4, ch. 2009-43; s. 2, ch. 2010-210.

<sup>1</sup>**Note.**—As enacted by s. 1, ch. 2005-173. For a description of multiple acts in the same session affecting a statutory provision, see preface to the *Florida Statutes*, “Statutory Construction.” Paragraph (q) was also enacted by s. 1, ch. 2005-213, and that version reads:

(q) The executive director or equivalent, and his or her designee, of a children’s advocacy center that is established and operated under s. 39.3035.

**Note.**—Former ss. 828.041, 827.07(15); s. 415.51.

## Appendix C. Kentucky Statute (620.050) Pertaining to Child Welfare Records

**620.050 Immunity for good-faith actions or reports** Immunity for good-faith actions or reports -- Investigations -- Confidentiality of reports -- Exceptions -- Parent's access to records -- Sharing of information by children's advocacy centers -- Confidentiality of interview with child -- Exceptions -- Confidentiality of identifying information regarding reporting individual -- Internal review and report -- Waiver -- Medical diagnostic procedures -- Sharing information with relatives -- Interaction among siblings who are not jointly placed.

(1) Anyone acting upon reasonable cause in the making of a report or acting under KRS 620.030 to 620.050 in good faith shall have immunity from any liability, civil or criminal, that might otherwise be incurred or imposed. Any such participant shall have the same immunity with respect to participation in any judicial proceeding resulting from such report or action. However, any person who knowingly makes a false report and does so with malice shall be guilty of a Class A misdemeanor.

(2) Any employee or designated agent of a children's advocacy center shall be immune from any civil liability arising from performance within the scope of the person's duties as provided in KRS 620.030 to 620.050. Any such person shall have the same immunity with respect to participation in any judicial proceeding. Nothing in this subsection shall limit liability for negligence. Upon the request of an employee or designated agent of a children's advocacy center, the Attorney General shall provide for the defense of any civil action brought against the employee or designated agent as provided under KRS 12.211 to 12.215.

(3) Neither the husband-wife nor any professional-client/patient privilege, except the attorney-client and clergy-penitent privilege, shall be a ground for refusing to report under this section or for excluding evidence regarding a dependent, neglected, or abused child or the cause thereof, in any judicial proceedings resulting from a report pursuant to this section. This subsection shall also apply in any criminal proceeding in District or Circuit Court regarding a dependent, neglected, or abused child.

(4) Upon receipt of a report of an abused, neglected, or dependent child pursuant to this chapter, the cabinet as the designated agency or its delegated representative shall initiate a prompt investigation or assessment of family needs, take necessary action, and shall offer protective services toward safeguarding the welfare of the child. The cabinet shall work toward preventing further dependency, neglect, or abuse of the child or any other child under the same care, and preserve and strengthen family life, where possible, by enhancing parental capacity for adequate child care.

(5) The report of suspected child abuse, neglect, or dependency and all information obtained by the cabinet or its delegated representative, as a result of an investigation or assessment made pursuant to this chapter, except for those records provided for in subsection (6) of this section, shall not be divulged to anyone except: (a) Persons suspected of causing dependency, neglect, or abuse; (b) The custodial parent or legal guardian of the child alleged to be dependent, neglected, or abused; (c) Persons within the cabinet with a legitimate interest or responsibility related to the case; (d) A licensed child-caring facility or child-placing agency evaluating placement for or serving a child who is believed to be the



victim of an abuse, neglect, or dependency report; (e) Other medical, psychological, educational, or social service agencies, child care administrators, corrections personnel, or law enforcement agencies, including the county attorney's office, the coroner, and the local child fatality response team, that have a legitimate interest in the case; (f) A noncustodial parent when the dependency, neglect, or abuse is substantiated; (g) Members of multidisciplinary teams as defined by KRS 620.020 and which operate pursuant to KRS 431.600; (h) Employees or designated agents of a children's advocacy center; (i) Those persons so authorized by court order; or (j) The external child fatality and near fatality review panel established by KRS 620.055.

(6)(a) Files, reports, notes, photographs, records, electronic and other communications, and working papers used or developed by a children's advocacy center in providing services under this chapter are confidential and shall not be disclosed except to the following persons: 1. Staff employed by the cabinet, law enforcement officers, and Commonwealth's and county attorneys who are directly involved in the investigation or prosecution of the case, including a cabinet investigation or assessment of child abuse, neglect, and dependency in accordance with this chapter; 2. Medical and mental health professionals listed by name in a release of information signed by the guardian of the child, provided that the information shared is limited to that necessary to promote the physical or psychological health of the child or to treat the child for abuse-related symptoms; 3. The court and those persons so authorized by a court order; 4. The external child fatality and near fatality review panel established by KRS 620.055; and 5. The parties to an administrative hearing conducted by the cabinet or its designee in accordance with KRS Chapter 13B in an appeal of a cabinet substantiated finding of abuse or neglect. The children's advocacy center may, in its sole discretion, provide testimony in lieu of files, reports, notes, photographs, records, electronic and other communications, and working papers used or developed by the center if the center determines that the release poses a threat to the safety or well-being of the child, or would be in the best interests of the child. Following the administrative hearing and any judicial review, the parties to the administrative hearing shall return all files, reports, notes, photographs, records, electronic and other communications, and working papers used or developed by the children's advocacy center to the center. (b) The provisions of this subsection shall not be construed as to contravene the Rules of Criminal Procedure relating to discovery.

(7) Nothing in this section shall prohibit a parent or guardian from accessing records for his or her child providing that the parent or guardian is not currently under investigation by a law enforcement agency or the cabinet relating to the abuse or neglect of a child.

(8) Nothing in this section shall prohibit employees or designated agents of a children's advocacy center from disclosing information during a multidisciplinary team review of a child sexual abuse case as set forth under KRS 620.040. Persons receiving this information shall sign a confidentiality statement consistent with statutory prohibitions on disclosure of this information.

(9) Employees or designated agents of a children's advocacy center may confirm to another children's advocacy center that a child has been seen for services. If an information release has been signed by the guardian of the child, a children's advocacy center may disclose relevant information to another children's advocacy center.

(10) (a) An interview of a child recorded at a children's advocacy center shall not be duplicated, except that the Commonwealth's or county attorney prosecuting the case may:

1. Make and retain one (1) copy of the interview; and 2. Make one (1) copy for the defendant's or respondent's counsel that the defendant's or respondent's counsel shall not duplicate. (b) The defendant's or respondent's counsel shall file the copy with the court clerk at the close of the case. (c) Unless objected to by the victim or victims, the court, on its own motion, or on motion of the attorney for the Commonwealth shall order all recorded interviews that are introduced into evidence or are in the possession of the children's advocacy center, law enforcement, the prosecution, or the court to be sealed. (d) The provisions of this subsection shall not be construed as to contravene the Rules of Criminal Procedure relating to discovery.

(11) Identifying information concerning the individual initiating the report under KRS 620.030 shall not be disclosed except: (a) To law enforcement officials that have a legitimate interest in the case; (b) To the agency designated by the cabinet to investigate or assess the report; (c) To members of multidisciplinary teams as defined by KRS 620.020 that operated under KRS 431.600 (d) Under a court order, after the court has conducted an in camera review of the record of the state related to the report and has found reasonable cause to believe that the reporter knowingly made a false report; or (e) The external child fatality and near fatality review panel established by KRS 620.055.

(12) (a) Information may be publicly disclosed by the cabinet in a case where child abuse or neglect has resulted in a child fatality or near fatality. (b) The cabinet shall conduct an internal review of any case where child abuse or neglect has resulted in a child fatality or near fatality and the cabinet had prior involvement with the child or family. The cabinet shall prepare a summary that includes an account of: 1. The cabinet's actions and any policy or personnel changes taken or to be taken, including the results of appeals, as a result of the findings from the internal review; and 2. Any cooperation, assistance, or information from any agency of the state or any other agency, institution, or facility providing services to the child or family that were requested and received by the cabinet during the investigation of a child fatality or near fatality. (c) The cabinet shall submit a report by September 1 of each year containing an analysis of all summaries of internal reviews occurring during the previous year and an analysis of historical trends to the Governor, the General Assembly, and the state child fatality review team created under KRS 211.684.

(13) When an adult who is the subject of information made confidential by subsection (5) of this section publicly reveals or causes to be revealed any significant part of the confidential matter or information, the confidentiality afforded by subsection (5) of this section is presumed voluntarily waived, and confidential information and records about the person making or causing the public disclosure, not already disclosed but related to the information made public, may be disclosed if disclosure is in the best interest of the child or is necessary for the administration of the cabinet's duties under this chapter.

(14) As a result of any report of suspected child abuse or neglect, photographs and Xrays or other appropriate medical diagnostic procedures may be taken or caused to be taken, without the consent of the parent or other person exercising custodial control or supervision of the child, as a part of the medical evaluation or investigation of these reports. These photographs and X-rays or results of other medical diagnostic procedures may be introduced into evidence in any subsequent judicial proceedings or an administrative hearing conducted by the cabinet or its designee in accordance with KRS Chapter 13B in an appeal of a cabinet substantiated finding of child abuse or neglect. The person performing

the diagnostic procedures or taking photographs or X-rays shall be immune from criminal or civil liability for having performed the act. Nothing herein shall limit liability for negligence.

(15) In accordance with 42 U.S.C. sec. 671, the cabinet shall share information about a child in the custody of the cabinet with a relative or a parent of the child's sibling for the purposes of: (a) Evaluating or arranging a placement for the child; (b) Arranging appropriate treatment services for the child; or (c) Establishing visitation between the child and a relative, including a sibling of the child.

(16) In accordance with 42 U.S.C. sec. 671, the cabinet shall, in the case of siblings removed from their home who are not jointly placed, provide for frequent visitation or other ongoing interaction between the siblings, unless the cabinet determines that frequent visitation or other ongoing interaction would be contrary to the safety or well-being of any of the siblings.

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