COULD

Caregiver and Child Outcomes Using Linked Data

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of the Assistant Secretary for Planning and Evaluation

OPRE

September 21, 2020

Valeria Butler, OPRE and Emily Madden, ASPE

BACKGROUND

January 21, 2016

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Project Origins

- Patient Centered Outcomes Research Trust Fund (PCORTF)
  - Competitive process
  - Funded project FY2020

- Partnership between ASPE and OPRE, in ACF

- 'Linking State Medicaid and Child Welfare Data for Outcomes Research on Opioid Use Disorders and other Behavioral Health Issues' - → Child and Caregiver Outcomes Using Linked Data (CCOULD)

Project Team

- **Federal Project Team**
  - Valeria Butler, OPRE/ACF
  - Emily Madden, ASPE
  - Robin Ghertner, ASPE

- **RTI Project Team**
  - Tami Mark, PI
  - Melissa Dolan, PM
  - Ben Allaire
  - Christina Bradley

Project Goals

- Support states in creating linked data from child welfare and Medicaid systems for research on parents who have substance use disorders and other behavioral health issues, and have children in the child welfare system

- Develop data infrastructure for ongoing data linking and analysis to inform policy decisions at local, state, and federal levels

- Develop a roadmap that provides for other states to link their own data

Key Objectives

- *Objective 1*-Develop linked datasets across State Medicaid and child welfare systems, in 2-4 states, linking parent records as well as child records.

- *Objective 2*-Prepare research-use datasets and develop a process for external researchers to access the data.

- *Objective 3*- Create a roadmap for other states to follow that documents the process and lessons learned.

- *Objective 4*- Design, conduct, encourage analyses on linked data

Key Strengths

- Paves the way for new measures of success related to treatment of Opioid Use Disorders (OUD)

- Leverages existing data sources and builds infrastructure to better support research for patient centered outcomes

- Has both research benefits as well as service benefits

- Scalable and sustainable

Site Selection Criteria

- Select states based on selection criteria, e.g.:
    - State interest and buy-in from leadership
    - Existing infrastructure and capacity
    - Policies around data sharing
    - Research partners

Example Analyses

- Identify trends in uptake and receipt of Medicaid-funded SUD treatment by parents involved in child welfare systems.

- Identify opportunities to connect parents involved in child welfare systems with treatment for SUD.

- Identifying treatment and service strategies that are most likely to be successful in treating SUDs among parents with children in child welfare systems

Example Analyses

- Examine how involvement in the child welfare system and services provided by child welfare are associated with treatment uptake, adherence, and subsequent behavioral health outcomes

- How receipt of/adherence to treatment by parents with children involved with child welfare relates to outcomes for their children; for example:

  – Length of time in foster care

  – Repeat maltreatment

  – Re-entry to foster care

End users of the data

Primary end users of the data will be:

- – Researchers within HHS
- – PCOR researchers interested in exploring the social determinants affecting treatment effectiveness
- – Researchers in public health, substance use, and child welfare fields
- – State Medicaid, child welfare, and SUD treatment agencies

End Users of the data

Secondary end users of the data will be:

- National and state health policy groups, governmental agencies, including HHS, as well as nongovernmental entities
- Child welfare advocacy groups, agencies and legislators

Family First Prevention Services Act

- The Family First Prevention Services Act was signed into law as part of the Bipartisan Budget Act on February 9, 2018.

- Reforms the federal child welfare financing streams to provide services to families who are at risk of entering the child welfare system.

- FFPSA aims to prevent children from entering foster care by allowing federal reimbursement for mental health services, substance use treatment, and in-home parenting skill training

- Funds can be used to provide services to *parents* of children who are "at risk" of entering foster care

Benefits to Linked Data

- Support program evaluation, research on program effectiveness, and build an evidence-base for new interventions

- Provides infrastructure to support approaches to blend multiple funding sources (i.e., Medicaid, foster care funds) to provide a continuum of treatment and recovery supports.

- Supports case management by state agencies and caseworkers to provide a more complete picture of all the services provided to a family, and identify gaps and opportunities for new services.

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14

PROJECT PLAN AND OBJECTIVES

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Immediate Objectives

✓ 1 - Longitudinal, person-level datasets **linking state Medicaid records with child welfare records** for **parents and children** involved in the child welfare system, available to the states for their use

✓ 2- **Archived Data files accessible** with appropriate privacy protections to **states, researchers, and evaluators for secondary analysis**.

✓ 3 - A **roadmap for other states to follow,** documenting challenges and successes in sharing and linking data.

Data Linkage

- Up to 5 years of individual-level, longitudinal data
- Linked dataset comprised of state data from sources such as:
  - child welfare events, including services
  - Medicaid or Children's Health Insurance Program (CHIP) beneficiary summary for children and their parents,
  - Medicaid or CHIP claims for children and their parents
  - Additional data as relevant/available

Common Data Model

- Develop a common data model that will define Medicaid and child welfare data elements consistently across participating states.
  - Identify variables that can be commonly defined across states to be included in a combined dataset.
  - For variables that are not commonly defined across states, compare definitions and specifications across the states using their definitions, value sets, and frequencies and reconcile them.

Curating Data for Research Use

- Data quality analysis, missing data imputation
- State-level linked data *with identifiers* is available to the state agency and its research partner, if applicable
- Conduct statistical disclosure analysis and modify variables to reduce the likelihood of parent, child, or family identification while maintaining only the state abbreviation.

Archived Data

- Develop research use datasets that combine state-level data.
  - General release/Public Use File that would contain no PHI or PII.
  - Restricted release file that would include some PHI (e.g., dates of diagnosis and/or service receipt).
- Develop dataset documentation and codebooks
- Archive at the National Data Archive on Child Abuse and Neglect (NDACAN) www.ndacan.acf.hhs.gov

Roadmap

- Document lessons learned, including:
  - Barriers to participation
  - Motivating or contributing factors for participation

- Conduct interviews with key staff from the sites about the process and document lessons learned for a roadmap.

Sites

✓ Kentucky Cabinet for Health and Family Services

Other site(s) still in negotiation.

Goal is to have 2-3 states participating.

Looking Forward

Though nascent, this project lays the groundwork to build partnerships, strengthen data sharing efforts, and show how administrative data can be leveraged to gain insights into better service provision and prevention of child abuse and neglect for children and families.

- *Possibilities* for future
  - Analysis
  - Additional states
  - Additional datasets
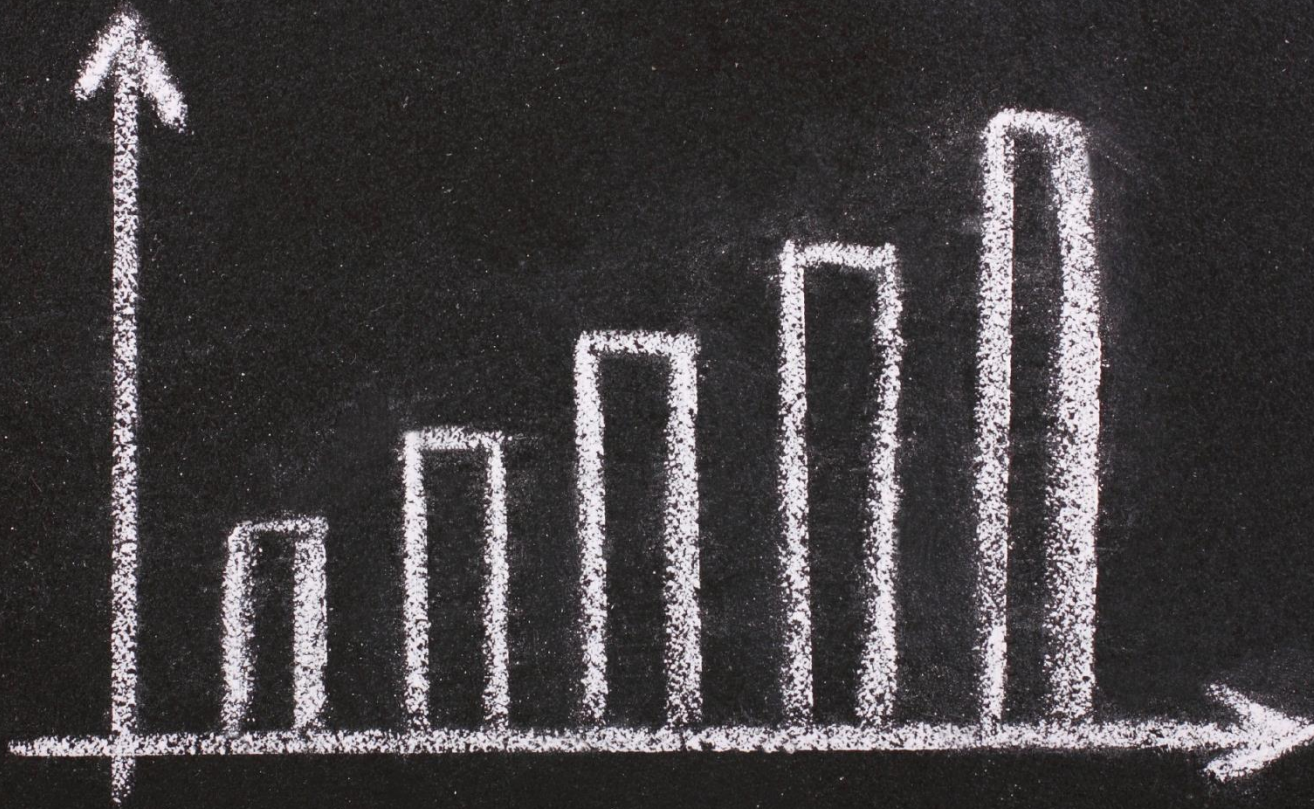
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Valeria Butler, OPRE valeria.butler@acf.hhs.gov
Emily Madden, ASPE Emily.madden@hhs.gov

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