Developing Data Sharing Agreements to Use Early Care and Education Administrative Data

Webinar
October 16, 2018
Overview of CCADAC
Kelly Maxwell, Child Trends

Developing Data Sharing Agreements
Van-Kim Lin & Sara Shaw, Child Trends

Expert Presentations
Pam Joshi, Brandeis University
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Facilitated Discussion
CCADAC is supported through the Office of Planning, Research and Evaluation (OPRE) in the Administration for Children and Families (ACF), with funds set aside for research in the Child Care and Development Block Grant Act and managed through the Child Care and Early Education Policy Analysis (CCEPRA) contract with Child Trends.

- Ivelisse Martinez-Beck, CCEPRA Project Officer, OPRE

The primary purpose of the CCADAC is to support the use of administrative data to address policy-relevant early care and education research questions for state child care administrators and their research partners.

- Kathleen Dwyer, and Jenessa Malin, OPRE leads
Where to find resources on using administrative data?

http://www.researchconnections.org/content/childcare/understand/administrative-data.html

Organizes resources by topic:
• Managing administrative data
• Analyzing administrative data
• Linking administrative data
• Data confidentiality and security
Developing Collaborative Partnerships with State Agencies

Determining the Feasibility of Using Administrative Data

Considerations in Preparing to Analyze Administrative Data

Early Childhood Data Definitions: A Guide for Researchers Using Administrative Data

Opportunities through State Agency Research Partnerships for Using Administrative Data to Support Early Care and Education

Guidelines for Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research

Van-Kim Lin & Sara Shaw, Child Trends
Purpose: To provide guidance to researchers about how to prepare data sharing agreements related to the use of ECE administrative data from state agencies

A **data sharing agreement** is a formal document of agreement between two entities that specifies the conditions under which data are to be shared.
Steps to Developing a Data Sharing Agreement

Step 1: Identify the data needed to answer the research question

• Develop a list of all necessary data elements
  • Work in conjunction with state agency staff
• Data may be in multiple locations
  • Use unique identifiers to match individuals
  • Determine how and who to merge datasets

Step 2: Identify the organizations that own, oversee, or manage the data.
Steps to Developing a Data Sharing Agreement

Step 3: Identify the individuals who will be responsible for developing, reviewing, and approving the data sharing agreement.

• Anticipate legal concerns early
• Create a timeline

Step 4: Develop a draft agreement.

• Use an existing template if available
• Consider federal and state regulations
Steps to Developing a Data Sharing Agreement

Step 5: Share the draft agreement
• Allot time for reviews and revisions from both parties

Step 6: Finalize the agreement and obtain approval signatures from any relevant parties
Common Components of a Data Sharing Agreement

Contact information for all key personnel, including:
- Name of organization authorized to share the data
- Name of the organization that will use or is requesting the data
- Project contacts and approved researchers
Common Components of a Data Sharing Agreement

Purpose of research including the following elements:

- Research questions
- Benefits of the research for state agencies involved
Common Components of a Data Sharing Agreement

Information about the data being requested including:

- Data elements
- Period of data use
Common Components of a Data Sharing Agreement

Key personnel expectations and responsibilities including:
- Roles and responsibilities of participating parties
- Compensation
- Ownership of the analyzed data
- Review of publication prior to release
Information on managing the security of the data including:
- Security guidelines
- Protocol for reporting an issues or breaches
Expectations for managing the project including:
- Process for making modifications or changes to the agreements
- Methods for destroying the data at the end of the project
- Retention of de-identified data for restricted access use
A note on Institutional Review Board (IRB) requirements:

- Researchers may be required to obtain IRB approval
- In some cases a data sharing agreement may be required for IRB submission
- If an IRB is required, documentation may be included
State Administrative Data Sharing Agreements: Researcher Perspective

Pam Joshi
Child Care Administrative Data Analysis Webinar
October 16, 2018

MA Child Care Research Partnership
Funded by: HHS/ACF/OPRE Child Care Research Partnership Grant
Prepare: before talking to a state …

• **Research agenda - initial set of questions**
  – Literature gaps, fed/state policy context, community concerns
  – Response to RFP may specify direction

• **Data needed to answer questions**
  – Levels: provider, children, family, voucher/contract
  – Type: program, child/parent outcomes, community
  – Location: one or multiple data systems or agencies

• **Data request process**
  – Already established?
Our process (for the partnership grant)

• **Initial questions: in response to a RFP**
  – RFP specified general set of questions and a deadline
  – Team expertise informed our direction
  – Identified topics that we could and could not answer

• **Identify a state contact**
  – Web search – understand agency organization
  – Talked to networks
  – Approached former state colleagues
  – Find the IT/admin data expert
Our process (for the partnership grant)

• **Multiple discussions with the state**
  – Agree on questions of mutual interest
  – Verify questions can be answered with existing data
  – Understand data infrastructure / capacity
  – Establish whether/how data can be linked across systems
    • Unique identifier essential
  – Identify requirements for secure transfers/data storage

• **Decide on communication process**
  – Level of partnership / staff involvement
  – Data requests
Multiple data sharing agreements

• MOU (submitted with grant)
  – Used the state’s MOU template
  – General parameters for requested data elements specified based on proposed study

• Additional agreements (after grant award)
  – Confidentiality agreement
  – NACCRAware (provider self-reported data)
  – No cost extension (extended date)

• Additional agreements (not pursued)
  – Employment data housed in different agency
Data sharing agreement: core research components

• **Purpose**
  – Research study abstract

• **Description of data**
  – Time period
  – General description of data elements
  – Data requests – timing of initial and quarterly

• **Data transfer process**
  – Protecting confidentiality
  – MOU applies to partners (No additional MOU for BU)
Lessons learned

• **Understand existing data agreements within and between agencies**
  – Are they established and if so is your data request covered
  – If they are not, has this been done, is another approval process required and what is the cost

• **Establish plan to link across data systems**
  – If there is not a unique id, consider which data elements need to be in the MOU
  – Anticipate time and labor costs to match data across systems
Lessons learned

• **Add one year to the agreement**
  – Anticipate a no cost extension to finish data analysis
  – E.g., agreement for a 4 year study covers 5 years
  – Avoids having to extend the agreement
Tips

• **Formalize process: input from state IT staff**
  – Tap into staff knowledge: data quality and how policy and practice is captured in the data
  – Before data requests, ask for ‘sample’ data to better understand what data to include in request
  – Schedule time to ask questions (i.e. save them up)
  – Ask for data documentation but don’t expect a codebook

• **Attend trainings**
  – Webinars on IT systems (for new staff or implementing IT system changes)
Naneida Lazarte Alcalá,  
OK Dept. of Education
Child Care Administrative Data Analysis Center (CCADAC) data sharing agreement
State agency perspective

Naneida Lazarte Alcala
Researcher and Data Scientist

Tuesday, October 16, 2018
Setting up data sharing agreements with state agencies

Overall approach: Researchers and agency staff

• Understand the broad meaning of the tool
• Keep in mind all the resources partners bring to the collaboration
• Build positive informal relationships
• Think long-term
Setting up data sharing agreements with state agencies

Overall approach: Researchers

- Learn about the organization structure and key players
- Learn about key federal and state laws and regulations about privacy and confidentiality
- Approach agency staff with effective and relevant information
Setting up data sharing agreements with state agencies

Agreement development: Researchers and agency staff

- Facilitate the process as much as possible for all partners
- Involve key individuals in all communications
- Discuss agency’s vetting process and timeliness
Setting up data sharing agreements with state agencies

Agreement development: Researchers and agency staff

• Make sure the agreement is clear and specific about its purpose, conditions, and prohibitions
• Ensure target data elements are jointly reviewed by all partners
• Review the steps of the project a head vis-à-vis the agreement clauses
QUESTIONS & COMMENTS
The views expressed in this presentation do not necessarily represent the views or policies of the Office of Planning, Research and Evaluation, the Administration for Children and Families or the U.S. Department of Health and Human Services.