

EXECUTIVE SUMMARY

**Cheaper, Faster, Better:
Are State Administrative Data the Answer?**

**The Mother and Infant Home Visiting Program
Evaluation-Strong Start
Second Annual Report**

OPRE Report 2015-09

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Executive Summary

Adverse birth outcomes, including low birth weight and preterm births, are strong determinants of compromised health and development in infancy and early childhood. These outcomes are also financially costly to both families and the Medicaid program, which provides health care for many low-income families. Home visiting, which provides individualized education, support, and referrals to community resources, has been found to improve prenatal and infant health when provided to expectant women and families with infants. Because home visiting programs often serve women who may be otherwise disconnected from health and social safety net services, these programs reach the most socially isolated families, who have high levels of unmet health and other social service needs.

The Mother and Infant Home Visiting Program Evaluation-Strong Start (MIHOPE-Strong Start) is the largest study to date to examine the effectiveness of home visiting services on improving birth outcomes and infant and maternal health care use. By including a national sample of pregnant women on Medicaid, the study also hopes to provide information on whether home visiting programs can reduce short-term Medicaid costs. The study is being sponsored by the Center for Medicare and Medicaid Innovation (CMMI) of the Centers for Medicare and Medicaid Services (CMS) and the Office of Planning, Research and Evaluation (OPRE) in the Administration for Children and Families (ACF) in partnership with the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA). The study is being conducted by MDRC in partnership with James Bell Associates, Johns Hopkins University, and Mathematica Policy Research.

MIHOPE-Strong Start is studying the effects of home visiting on Medicaid recipients for two national models with prior evidence of improving birth outcomes: Healthy Families America (HFA) and Nurse-Family Partnership (NFP).¹ Both HFA and NFP have been widely implemented across the country, although previous studies documenting impacts have been constrained to a few communities or are somewhat dated. In order to provide the most reliable estimates of the effects of home visiting, eligible women are being randomly assigned either to a program group, which can receive home visiting services from the program sites in the study,

¹To determine which national models are evidence-based, the U.S. Department of Health and Human Services (HHS) funded the Home Visiting Evidence of Effectiveness (HomVEE) review, conducted by Mathematica Policy Research (Avellar and Paulsell 2011), which assessed the quality of the research evidence and documented impacts of home visiting programs on a range of domains, including child health, child development and school readiness, maternal health, positive parenting behaviors, child maltreatment, crime and domestic violence, family economic self-sufficiency, and referrals and coordination. Sarah Avellar and Diane Paulsell, *Lessons Learned from the Home Visiting Evidence of Effectiveness Review* (Princeton, NJ: Mathematica Policy Research, Inc., 2011).

or to a control group, which receives referrals to other services in the community. In addition to estimating impacts, MIHOPE-Strong Start is studying how local programs operate and are implemented to improve birth and health care outcomes.

Information on birth outcomes, health care use, and associated costs will come from state vital (birth certificate) records and Medicaid systems. Administrative data are primarily designed to allow for the effective administration of programs and services, not necessarily for research purposes. However, policymakers, program administrators, and researchers have increasingly emphasized the potential value of using — and are thus encouraging the broader sharing of — administrative records already collected and housed by state agencies to evaluate a range of complex health and social programs more quickly, effectively, and cost-efficiently. A detailed delineation of the administrative data acquisition process in MIHOPE-Strong Start can inform this broader discussion.

The current report describes the process of acquiring administrative data, specifically Medicaid data and vital records, across 20 different states and over 40 agencies.² Among the key findings are the following:

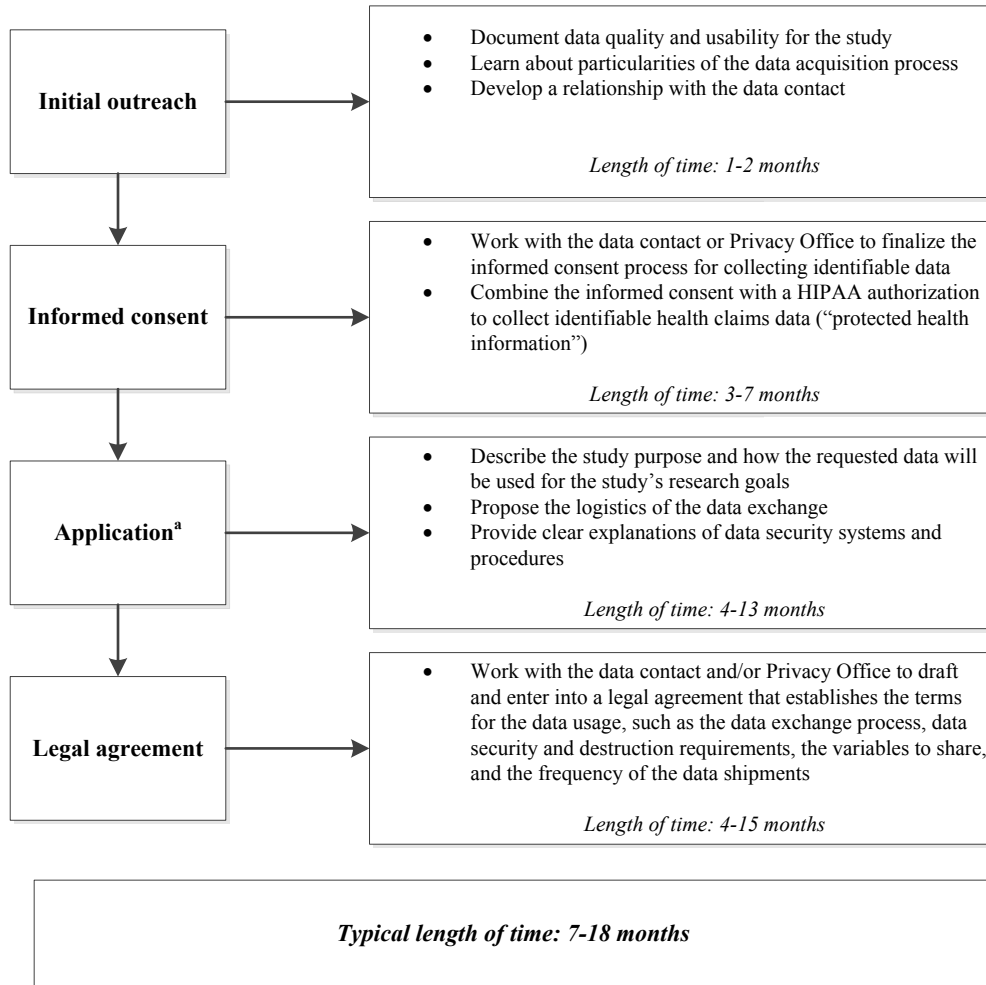
- **Gaining access to administrative records across numerous states and across different agencies within a state is a many-faceted process** (Figure ES.1). For MIHOPE-Strong Start, this process typically includes a series of conversations with a relevant contact at each agency, getting approval for the study's informed consent form, submitting an application to access data, and entering into a legal agreement. The procedural step of getting approval from a review committee for MIHOPE-Strong Start to obtain data is somewhat surprising in that most data agencies do not defer to MDRC's Institutional Review Board, which means that the study has to go through multiple reviews by different state departments and data agencies, at times resulting in changes to the study's informed consent form.
- **Entering into legal agreements often requires legal consultation and negotiations around data usage and destruction as well as around publications review and approval procedures.** Most agencies provide their own legal agreements for sharing data, but these agreements often are not conducive to MIHOPE-Strong Start's design or deliverables and require extensive negotiating to modify the terms.

²MIHOPE-Strong Start began in September 2012. Final results from the study, including implementation and impact results for the full MIHOPE-Strong Start sample, will be produced in 2017.

The Mother and Infant Home Visiting Program Evaluation-Strong Start

Figure ES.1

Data Acquisition Process: Typical Length of Time to Complete Each Step



SOURCE: MDRC calculations based on administrative data acquisition efforts with 42 data agencies for birth certificate and Medicaid data as of November 2014.

NOTES: Estimates of the typical length of time (in months) to complete each data acquisition stage are based on the middle 50 percent of targeted MIHOPE-Strong Start states. Data acquisition activities may be completed sequentially or concurrently depending on the data agency’s protocol. These estimates are still preliminary since administrative data acquisition has not been completed in all states. HIPAA = Health Insurance Portability and Accountability Act of 1996.

^aSome agencies may not have an application process and require only an approved consent form and a signed legal agreement. Therefore, the data acquisition process shown in this figure can be reduced to three out of the four stages when a data agency does not require an application to release identifiable data.

- **Because of these multiple steps, the process for reaching an agreement with state agencies has been quite long.** Underscoring how variable the process is, it can take between 4 and 24 months to reach a legal agreement, with half the agencies taking between 7 and 18 months to reach a legal agreement. As of this report’s writing, 19 legal agreements have been executed — about half the legal agreements required to access Medicaid and vital records data. Among these first 19 agreements, it has taken 11 months, on average, to complete all the steps necessary to execute them.
- **Not all state agencies are willing to provide Medicaid and birth certificate data.** MIHOPE-Strong Start seeks identified administrative data — records that include personal information on individuals (such as name, date of birth, and residential location) — so that all data received can be linked together for analysis purposes. While most vital records agencies have been able to provide identified records, one state agency will not do so due to state statutes that permit the release of only deidentified data for researchers who are external to the department. Additionally, three Medicaid agencies thus far have indicated that they cannot provide any data to the study. Two of the three agencies noted that they have limited resources to provide data to external researchers. State Medicaid data agencies generally are more accustomed to providing data to a researcher or organization that is conducting services on behalf of the department or state, and thus are more willing to provide data for a research project where the agency can identify a direct programmatic benefit, is sponsoring the research, or is provided with findings from the study about its own state. With Medicaid being a state-administered program, each Medicaid data agency is different.
- **Some administrative data does not lend itself to rapid evaluation, due to the long lag in availability to researchers.** On average, the study team has found that Medicaid data are available more quickly than birth certificate data. However, as noted above, not all Medicaid and vital records agencies were willing to release the data for use in MIHOPE-Strong Start.
- **Many of the MIHOPE-Strong Start study participants are likely to be enrolled in Medicaid managed care organizations, which may make it more difficult to obtain accurate information on health care use.** Data quality may be lower from managed care organizations because they are not reimbursed per service and often use capitated payment plans, so there is less motivation to accurately record the specific services provided than there might be under other arrangements. It may also take longer for such data to

be available since they are not being promptly reported to the state for reimbursement purposes. This may make it difficult to extract information about exactly which services were rendered and their associated costs, particularly in states that have high penetrations of managed care organizations.

- **For most of the data agencies targeted in MIHOPE-Strong Start, birth certificate data will be available for the study to use within two years after the beginning of the calendar year in which the birth occurred.** Birth certificate data typically are processed by data agencies on a calendar-year basis, and are thus not usable in a real-time manner. For example, a birth record from January 2014 may not be available for a data agency to extract and provide to external researchers until late 2015.

Implications

Both lags in data availability and potentially lengthy waiting periods at each data acquisition step are important considerations for research studies such as MIHOPE-Strong Start, especially if the timely analysis of administrative records is of key interest or necessity. Researchers need to learn about each agency's expected lag in data availability when considering how long it will take to complete the proposed research, and program administrators and agencies interested in studies with a quick turnaround should remain cognizant of this potential barrier.

Although the data acquisition efforts in MIHOPE-Strong Start have proven labor intensive and the length of the procedural steps has varied across agencies in ways that could not always be predicted, the process is likely to be smoother if the study involves working with administrative data at only one or a few state agencies, or if the research study is funded or supported by the state that collects the data needed. This underscores a key challenge of MIHOPE-Strong Start, which is that the study is funded by a federal agency and relies on data from up to 20 states. Although many state data agencies are willing to provide data out of goodwill or for the perceived value of the research study, this has not been universal.

Researchers should further anticipate that most state agencies have their own Institutional Review Board (or other review committee), which will need to approve the research study. This process may involve multiple iterations and levels of approval. Research studies involving contact with human subjects and receiving informed consent must adjust the timing of program and participant recruitment according to the time it may take to gain approval from data agencies for these processes. Without confirmed programs for participation, some data agencies contacted by the MIHOPE-Strong Start research team would not review application materials. At the same time, recruitment of individuals in these programs could not occur until the intake procedures for informed consent had been approved by the data agencies and access to data was ensured.

Finally, the navigation of varying state systems that is required for acquiring data from numerous state agencies is likely to require significant staffing capabilities and the expertise to negotiate legal agreements for sharing data, including the guidance of an attorney with extensive knowledge about the research study, state statutes, and privacy protection laws. State agencies are increasingly requiring detailed data security plans, the written assurance and legal agreement that the organization will abide by the agency's own security requirements, copies of signed informed consent forms, and lengthy reviews of the research study and the organization's right to access the agency's identifiable data. These procedural requirements, while increasing a research project's time frame, staff efforts, and study costs, also signify the value placed on safeguarding the personal information of individuals.

Some circumstances may afford easier access to data. Medicaid data agencies are more accustomed to providing data to a researcher or organization that is conducting services on behalf of the department or state. In some cases, national administrative databases may offer an alternative to the difficulties associated with using administrative data from various state agencies. These national databases could not be used for MIHOPE-Strong Start because they typically do not identify individuals (and thus could not be matched to other data used in MIHOPE-Strong Start) or are not available for use by researchers for several years.

In short, while state administrative data can provide reliable information for a large number of families, the process for acquiring those data can be time consuming and labor intensive, reducing their utility for conducting fast studies with fewer resources.