**Glossary of Key Data Exchange Standards Terms**

**Data:** The specific values assigned from observations or measurement to data components, e.g., the number of degrees [specific values] in temperature [data component]).

**Data Component:** The object that is being measured and can be quantified as parts of a whole.

**Data Harmonization:** The process of comparing two or more data component definitions and identifying commonalities among them that warrant their being combined, or harmonized, into a single data component.

**Data Exchange Standard:** A graphical and/or lexical representation of data, specifying their properties, structure, and interrelationships.

**Dataset:** An organized collection of data components such as in a table or other structure.

**Interoperability:** The capability for the automatic exchange of content (particularly data and images) between devices, networks or systems without human intervention.

**Information:** Generally, the aggregation of data to define a trend or statistic that informs decision-making.

**Information Sharing:** The delivery of information to a different user than the originator of the information to inform decision-making.

**National Information Exchange Model (NIEM):** An information exchange framework created to support automated information sharing across organizations.

**Information Exchange Package Documentation (IEPD):** Specification in sufficient detail for programmer to implement a specific information exchange.

**Metadata:** Describes a number of characteristics or attributes of data; that is, data that describes data. For any particular datum, the metadata may describe how the datum is represented, ranges of acceptable values, its label, and its relationship to other data. Metadata also may provide other relevant information, such as the responsible steward, associated laws and regulations, and the access management policy. The metadata for structured data objects describes the structure, data elements, interrelationships, and other characteristics of information, including its creation, disposition, access and handling controls, formats, content, and context, as well as related audit trails.
Introduction

The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program supports voluntary, evidence-based home visiting services for at-risk pregnant women and parents with young children up to kindergarten entry. The MIECHV Program builds upon decades of scientific research showing that home visits by a nurse, social worker, early childhood educator, or other trained professional during pregnancy and in the first years of a child’s life improve the well-being of children and families by preventing child abuse and neglect, supporting positive parenting, improving maternal and child health, and promoting child development and school readiness.

States, territories, and tribal entities receive funding through the MIECHV Program, and have the flexibility to select evidence-based or promising approach home visiting service delivery models that best meet state and local needs. The MIECHV Program is administered by the Health Resources and Services Administration (HRSA) in partnership with the Administration for Children and Families (ACF). In February 2018, the MIECHV Program was allocated $400 million per year through fiscal year (FY) 2022 through the Bipartisan Budget Act of 2018 (BBA).

The BBA also provided new authority to the MIECHV program to designate data exchange standards for information required to be electronically exchanged between the MIECHV state agency and other agencies within the state.

HRSA and ACF are engaging the home visiting field in a conversation about how data exchange standards can help achieve long-standing goals of state and local programs, such as better integration of data from home visiting programs with broader early childhood strategies and programs, improved interoperability among service delivery partners, and reduced data collection and reporting burden.

HRSA and ACF recognize that data exchange standards should be tools that assist state home visiting programs in exchanging relevant information with early childhood partners in systematic and standard ways in order to support more efficient and effective implementation of programs. As discussed in this brief, data exchange standards can provide a number of benefits, including:

- Improved, comprehensive service delivery through interoperability among partners;
- Better decision-making ability through reliable, consistent, and complete data;
- Increased and enhanced research, evaluation and continuous quality improvement capabilities;
- Renewed focus on service delivery through reduced data collection and reporting burdens; and,
- Increased capacity to improve the integration of early childhood systems of care.

Statutory Requirements for Data Exchange Standards for MIECHV

The following are the statutory requirements for data exchange standards between MIECHV awardees and other state agencies:

“The head of the department or agency responsible for administering a program funded under this section shall, in consultation with an interagency work group established by the Office of Management and Budget and considering State government perspectives, designate data exchange..."
It is important to note that the BBA included similar, although not identical, statutory requirements for other HHS programs, including Temporary Assistance for Needy Families (TANF), child welfare and foster care, and child support. Since these federal programs and MIECHV programs may work with some of the same families, efforts to address these statutory requirements are being coordinated and streamlined across federal programs to the extent practicable.

Understanding Data Exchange Standards

Starting in the early 2000s, government agencies increasingly recognized the need for a seamless, interoperable way to facilitate information exchange across program areas. Recognizing that government agencies serve a common set of families and individuals, they set out to improve their ability to share data across programs in order to improve service delivery and, ultimately, the outcomes for these families and individuals.

There are many existing standards frameworks that could be adopted and modified to support MIECHV program data sharing. One example that was specifically mentioned in the statute as a model intergovernmental partnership for developing and maintaining interoperable standards is NIEM—the National Information Exchange Model. NIEM is a community-driven, standards-based approach to exchanging information. NIEM provides a framework and methodology to support individual communities of interest in developing their own and shared data standards. For more than ten years, NIEM has connected agencies and programs that share a common need to exchange information in order to advance their mission. Today, NIEM has been adopted by federal, state, and local agencies across multiple domains, including defense, justice, and human services, to name a few.

The federal government continues to play a pivotal role in establishing data exchange standards. For example, the ACF Interoperability Initiative provides leadership and technical support to federal, state, and local agencies to increase the capacity and efficiency of social service data systems to share data in a consistent, reliable manner. These efforts include creating common vocabularies so that data can be gathered in a more consistent way (making it easier to exchange), providing best practices for the implementation of interoperable data systems, and promoting the privacy and confidentiality of information sharing to mitigate any possible risks associated with such sharing.

Data Exchange Standards for Home Visiting

According to a 2017 national survey of local home visiting program managers conducted by the Home Visiting Applied Research Collaborative (HARC), many programs share child or family-level data with outside entities, most frequently linking their data with state data systems for the purpose of program performance reporting (51%) or data sharing with their national home visiting model (40%). A relatively small percentage (15%) report sharing data with state programs outside of home visiting; and only 6% share with other local programs.

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1 Section 50606 of the Bipartisan Budget Act of 2018 (Pub. L. 115-123)
2 https://www.acf.hhs.gov/opre/resource/acf-interoperability-initiative-overview
3 For example, the NIEM human services domain: https://www.niem.gov/communities/human-services
service providers. This research suggests that there are untapped opportunities for sharing data both to reduce reporting burdens in the near term, as well as to improve outcomes by making more robust data available for service providers to improve decision-making related to the children and families served by home visiting programs.

Interoperability Challenges and Opportunities for Home Visiting Programs

Establishing data exchange standards for home visiting programs is not an easy task due to the complexity of the home visiting field. However, it is the broad range of challenges to sharing data that gives rise to a substantial list of opportunities that can be realized through this work:

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<th>Challenge</th>
<th>Opportunity</th>
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<td><strong>Multiple stakeholders:</strong> There are many actors involved in the provision of home visiting services, including home visiting models, federal agencies, state administering agencies, regional collaboratives, local implementing agencies, researchers/evaluators, and foundations/philanthropy.</td>
<td>Establishing data standards can align stakeholders around consistent, reusable, and repeatable data terms, definitions, and processes, providing a cohesive center to the home visiting field.</td>
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<td><strong>Varied Goals and Objectives:</strong> In 2017, there were 18 home visiting models that met HHS’ criteria for evidence of effectiveness and were eligible for implementation under MIECHV. Each has varied goals and objectives. Additionally, there are many public and private home visiting funders seeking a range of information about a variety of program outcomes.</td>
<td>Data standards will enable different systems to exchange information by ensuring that information carries the same consistent meaning across various communities. By stitching knowledge together, the MIECHV Program, home visiting models, and local implementing agencies will be able to have a more complete picture of the impact of their services on outcomes for families and individuals.</td>
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<td><strong>Multiple systems:</strong> There is no standardized data system used across home visiting programs. Home visiting models utilize different data systems, some of which are not only considered to be proprietary but also have various legal and contractual issues regarding intellectual property and variations in the protection of privacy and civil liberties.</td>
<td>Data exchange standards can enable different systems to share data with each other even if they use different programming languages or operating systems. Stakeholders only need to agree on the definition and structure for the data being shared between systems (i.e., ‘on the wire’), retaining significant flexibility for how the data is defined and managed by individual programs.</td>
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<td><strong>Conflicting reporting requirements:</strong> Each stakeholder group mandates different reporting requirements, which can change frequently. Changes can be costly and time-intensive to implement. Reporting timelines may not be aligned.</td>
<td>Through the process of establishing agreed-upon terms, definitions, relationships, and data formats, reporting requirements can be more easily interpreted and reports more easily produced.</td>
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Challenge | Opportunity
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**Data quality issues:** Due to the multiple data systems used across home visiting programs, as well as the varied levels of skill among providers with data entry and systems use, there are known data quality issues, making program evaluation and quality improvement challenging for researchers and evaluators, home visiting models, state administrators, local implementing agencies, and the MIECHV Program. | Data standards improve data quality and enable better decision making. The use of data standards enables reusability of data elements and their metadata. Data standards ensure consistency of meaning and use across datasets.

Project Description

To support implementation of this new authority, HRSA and ACF are engaging with a variety of home visiting and data sharing stakeholders, including MIECHV state and territory awardees, local implementing agencies, data exchange standards experts, home visiting field thought leaders, and federal staff, to learn more about the unique opportunities and potential challenges associated with establishing data exchange standards in the context of the MIECHV program. The focus of this effort is both on data exchange standards as well as how these standards can help promote the interoperability of home visiting data across sectors.

First, an expert roundtable took place in March 2019 to facilitate sharing stakeholders’ perspectives and to help inform the establishment of a vision for interoperability in relation to the MIECHV Program. The roundtable began the process of identifying data wants and needs and opportunities for cross-agency data sharing, as well as the rationale for data exchange standards and the identification of high-level use cases. These activities will form the basis for subsequent discussions to further define the needs and potential strategies to address those needs.

Following the roundtable, HRSA and ACF are engaging additional home visiting stakeholders, including state program administrators, local implementing agencies, model developers, and others in order to validate and refine the use cases and discuss data challenges and opportunities in more concrete terms based on work happening in the field. Each MIECHV awardee will be invited to be engaged in this process, as well as select state partners and local implementing agencies.

The objective of this process is to analyze the needs and opportunities to exchange data, to understand the value that could be derived from such information exchanges, and to identify the data components needed for a successful data exchanges. Moreover, the broader goal is to better understand how HRSA and ACF can support MIECHV awardees in identifying and improving interoperability strategies, including leveraging existing work.

Conclusion

HRSA and ACF are committed to a fully-inclusive process that increases understanding of the willingness and desire of the broader home visiting field to adopt such standards. Understanding that there are significant benefits to adopting standards, this project will explore the feasibility of such an undertaking, with the ultimate goal of improving service delivery and programmatic outcomes for children and families. Achieving maximum impact across benchmark areas in MIECHV will require strong and aligned systems and data exchange is a core ingredient of this comprehensive system.
Useful References Regarding Information Sharing

Administration for Children and Families, Interoperability framework and resources: https://www.acf.hhs.gov/about/interoperability

The Playbook for creating an information sharing and safeguarding environment can be found at: http://healthrecovery.org/safecare/

Guidelines for the development of an Information Sharing and Safeguarding (IS&S) Core Interoperability Framework (ICIF) that serves to enable wide-scale interoperability and trust within the Information Sharing Environment (ISE): http://standardscoordination.org/ICIF/introduction


Introduction to trustmarks: https://trustmark.gtri.gatech.edu/concept/

Fundamentals of NIEM: https://www.niem.gov/about-niem

Online training in the use of NIEM: http://niem.github.io/training/

Simple tutorial on how to construct an information exchange package documentation (IEPD) under NIEM: http://niem.github.io/training/iepd-developer/simple-iepd-tutorial/

NIEM Technical assistance and support: https://www.niem.gov/techhub

NIEM Human Services Domain including sample IEPDs: https://www.niem.gov/communities/human-services

The National Information Sharing Standards (NISS) Information Exchange Package Documentation (IEPD) and Justice Standards Clearinghouse: https://it.ojp.gov/niss

Information sharing standards resource page at IJIS: https://www.ijis.org/page/Info_Share_Standards