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Progress Together

Response to the Request for Information on

Administration for Children and Families Development of Interoperability Standards for Human Service Programs

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Introduction

Mathematica is a nonpartisan research and data analytics organization with a mission to improve public well-being. Our staff have worked in close partnership with the Administration for Children and Families (ACF) for nearly 30 years. We currently support more than 20 active contracts for ACF that give us firsthand knowledge of ACF's mission, agencies, and programs, as well as the families its programs serve. Through these contracts, we are collaborating with and providing training and technical assistance (TA) to a diversity of health and human services agencies, including child welfare agencies, Temporary Assistance for Needy Families (TANF) agencies, primary care providers, federal grant recipients, and state, local, and Tribal governments. We understand their data systems and recognize future opportunities to improve data interoperability across the human services landscape.

We welcome the chance to help ACF consider the ways policy, research, training, and tailored TA might enhance opportunities to integrate disparate data sources and better serve participants in health and human services programs. In our response to this request for information, we also draw on our knowledge and experience in related domains that require data linkage and benefit from increased data interoperability, including Medicaid, education, labor, nutrition, and food security.

Item-by-item responses

1.1. Provide examples of the key enablers and/or inhibitors to using interoperable human services data standards (including data content and data exchange) in your program or agency.

From our experience collaborating with and providing training and TA to multiple state agencies, program offices, and federal grant recipients, we have seen the following factors encourage the expanded use of data and support for new initiatives such as interoperable data standards:

- **A clear vision rooted in real-world challenges and benefits.** Buy-in and support for any new initiative requires program and agency staff to understand the initiative's objectives and how it will address real-world challenges. As such, support for data interoperability standards will grow only to the extent that leaders and staff at programs and agencies see these standards addressing their priorities, such as (1) supporting care coordination to deliver services across programs more efficiently and (2) helping monitor and improve program integrity (for example, by monitoring contracted providers and reducing duplication of services and payments across programs and funding streams). ACF's inaugural Data Strategy plan, released in September 2024, marks an important step in this direction by articulating ACF's vision for enhancing and harmonizing data interoperability standards across its health and human services programs. The strategy explains that "whole-person service delivery depends on effective flow of information between service providers," and that this process can be accelerated by establishing "human services data interoperability standards." ACF should lead with this vision when seeking to gain buy-in and support for expanded use of interoperable data standards.
- **Mature data governance standards.** Clear and comprehensive data governance standards are key enablers for data interoperability. ACF's Data Governance Council, newly defined in the Data Strategy plan, will serve as the agency-level body to provide guidance, answer questions, and establish policies and processes that will apply across the agency. In conducting these activities, the council can make it easier for program and agency staff to adopt interoperable data standards by providing recommended administrative and technical controls for topics, including the following:
  - Data security (confidentiality, integrity, availability)
  - Data stewardship (for example, informed consent of minors, incarcerated people or those who may still be on parole and probation, and others)
  - Data privacy (for example, Health Insurance Portability and Accountability Act [HIPAA],
  - Family Educational Rights and Privacy Act [FERPA], special populations, and Internet of Things [IoT] data identifiers)
  - Determining how the industry will consider access, rectification, request for erasure or restricted processing, and portability
  - Multidirectional sharing with mutual benefit for all exchange partners
  - Data-quality performance metrics with policies that support improvement activities
  - Policies for applying CARE principles in Tribal data governance (where applicable)

- **Established requirements and sufficient resources.** Efforts to enhance data interoperability are typically burdensome and resource-intensive. In many cases, federal grant recipients and state, local, and Tribal governments face competing demands for their limited personnel and financial resources. More progress can be achieved when (1) data interoperability efforts are incorporated into program compliance requirements and (2) sufficient resources are provided to cover costs. Recent examples of resource provision include funding from the Centers for Medicare & Medicaid Services (CMS) to improve its Medicaid enterprise systems and Title IV-E funding to develop its Comprehensive Child Welfare Information System (CCWIS) .

Conversely, we have seen the following challenges limit and slow progress of data interoperability in human services programs:

- **Lack of common identifiers.** A major obstacle to data interoperability is linking disparate data sources that lack a common identifier. In many cases, data files, both within and across agencies, do not share a common unique identifier variable to link specific households or people across data sets. In these situations, linking records requires a complicated process of deterministic or probabilistic matching using a combination of available personally identifiable information (for example, first name, last name, date of birth, and address). Although researchers have developed functions to improve this process (for example, dtalink in Stata), it still requires highly technical staff and often yields incomplete or inaccurate results.
- **Outdated and siloed data systems.** Large volumes of human services data are collected, stored, and managed in siloed systems. These legacy data systems do not "talk" to one another, lack coordinated data standards, and are often incompatible with modern technology and privacy standards.
- **Lack of common data element definitions**. Human services programs and agencies often use different definitions for similar data elements. For example, depending on the characteristics of their service populations, they might have different definitions and categories for race and ethnicity, substance abuse, or veteran status. They might also lack clear documentation on data definitions and reporting requirements. For example, we have seen that programs that collect aggregate data do not always define clearly how the data should be aggregated. This challenge can lead reporting agencies to submit data that appear to be measuring the same construct but could differ in meaningful ways. Differences in data collection and reporting can also result from the natural tendency of program and agency staff to focus on what they need to best manage their individual programs, which can differ across states and programs.

Mature data standards exist for health data (for example, Fast Healthcare Interoperability Resources (FHIR) and the Observational Medical Outcomes Partnership Common Data Model). However, these standards do not encompass the broad array of data elements relevant to human services programs and agencies. Currently, expanding these standards to support data fields specific to human services programs requires custom extensions or data-mapping exercises, which are time- and labor-intensive.

1.2. How is the ability to exchange human services data impacted by state or federal law, policies, or other governing frameworks (including CMS Interoperability rules)?

A complex network of laws, policies, and governing frameworks strongly influences the exchange of data within and between human services agencies. These regulations are designed to protect privacy and ensure the secure handling of sensitive information, but they may also introduce challenges that can hinder seamless data exchange. Navigating this complex environment requires a nuanced understanding of the various governing frameworks and a commitment to finding solutions that respect legal requirements and the practical needs of data exchange.

Federal and state frameworks. Federal frameworks, such as the CCWIS final rule, highlight the need and opportunity for interoperability between various data systems. Funding opportunities and TA resources, such as those attached to CCWIS, can incentivize agencies to develop interoperability solutions that prioritize data quality by emphasizing exchange standards while preserving flexibility to customize data systems to meet the functional needs of the agency. For example, CCWIS encourages bidirectional data exchange between child welfare agencies and Medicaid agency systems, while providing flexibility for Title IV-E and Medicaid agencies to align on a common data model that is mutually feasible between both parties.

However, state-specific laws and policies sometimes create barriers to data exchange. In a recent series of in-depth interviews we conducted with state child welfare directors, respondents flagged state laws and regulations that prohibit interchange based on data classification or a person's protected status as a key barrier to data exchange. For example, state child welfare directors pointed to well-intentioned regulations and policies intended to avoid identifying children in maltreatment cases as a barrier to sharing data with partner agencies such as Medicaid agencies. These situations underscore the need for alignment at various levels of government and the potential role of federal agencies in facilitating data interchange through clear guidance and support. For example, the Child Welfare Health Infrastructure for Linking and Data Analysis of Resources, Effectiveness, and Needs (CHILDREN) Initiative is a direct response from the Assistant Secretary for Planning and Evaluation to the challenge of building successful data linkages between child welfare agencies and Medicaid agencies.

Privacy regulations. The interpretation of federal privacy and data-sharing consent protocols may also restrict data sharing when misconceptions or confusion exist about the extent to which data sharing is permitted by law. This dynamic can restrict data interoperability even when it is legally permissible. Frameworks and clear guidance with use cases, such as ACF's Confidentiality Toolkit, are key to navigating these challenges. Adding another layer to this intricate system, Tribal sovereignty and the privacy laws governing Tribal communities can complicate the integration of federal standards with Tribal regulations. Tribal–state compacts outlining data-sharing terms are essential for ensuring data exchange respects Tribal governance while meeting federal requirements.

2.3. What are the benefits of moving to a common interoperable data standard like Fast Healthcare Interoperability Resources (FHIR)?

Interoperable data standards ease data sharing and use and increase efficiency by ensuring a predictable data structure. This structure allows scarce labor time to be spent creating analyses and applications with value to organizations and people, while limiting time spent learning and supporting multiple bespoke file formats and coding systems. In addition, a central authority can host and update documentation of the standards, which in turn can reduce total costs and improve the reliability and accuracy of the documentation.

FHIR is a prominent example of an interoperable data standard in the healthcare industry, and there is strong evidence that its adoption can lead to improved data sharing between providers, easier integration of technological systems, and reduced risk of errors. As one example, Intermountain Health used FHIR as the foundation for an application that supports clinical diagnosis and treatment plans. Without an interoperable data standard to build on, this development process would have required more time, funding, and testing before making an impact on operations and improving the experiences of patients.

Although FHIR is designed to promote consistency in data structures, the platform is still broad and flexible enough to work in different contexts and support new applications. For example, although not initially designed for this purpose, FHIR resources helped support a coordinated healthcare response to the COVID-19 pandemic. As another example, in response to mounting research on the importance of social determinants of health (SDOH) such as housing, food security, and employment, new resources were added to the FHIR core to help track that information.

3.2. Describe use cases that benefit from interoperable data standards for advancing service coordination activities among state and federal programs (e.g., clinical, administrative, operations). Tell us about systems currently used that are API-enabled.

Drawing on lessons from ACF's Human Services Interoperability Innovations demonstration program in combination with our own experience collaborating with human services agencies, practitioners, and participants, we put forward two use cases as promising areas for current and future service coordination activities:

1. **Connecting child welfare and Medicaid data.** Linking data between child welfare and Medicaid data systems offers numerous benefits, such as improving care coordination across systems, identifying the unmet needs of children and families, tracking program integrity, monitoring spending, and supporting research and evaluation. The CHILDREN initiative is currently partnering with a few jurisdictions to integrate child welfare and Medicaid data, aiming to establish sustainable linked data infrastructures. Early insights from these partnerships emphasize the importance of including collaborators from various departments and roles in developing a data linking strategy, as well as the benefits of creating practical and relevant use cases that engage partners by demonstrating the mutual benefits of data linkage.

2. **Linking local service provider and TANF administrative data.** Improved integration between TANF administrative data sources and service provider directories holds promise to better connect TANF recipients and other people with low incomes to occupational supports best suited to their needs. Recent case studies of innovative state and local programs supporting these populations highlight numerous examples of the importance of data linkage and interoperability for enhancing service provision. Local and state-level data integrations paired with existing nationwide efforts to connect TANF recipients and people with low incomes to promising occupations can help reduce barriers to employment and support robust service provision.

These efforts can be paired with TA and transformative media such as podcasts, roundtables, research briefs, and other resources to disseminate best practices and areas for further research.

8.2. What top actions should the federal government take to provide technical assistance to encourage human services interoperability?

Creating lasting, meaningful change to existing data systems, processes, and elements will require a significant, sustained federal investment in training and TA. Three important areas where the federal government can focus its investments are as follows:

1. **Peer-to-peer learning.** From our experience providing training and TA to human services agencies and programs, we have found that sometimes the best way for an agency to work through a challenge is to connect with another agency that already worked through that challenge successfully. For example, within the child welfare domain, we have seen that states are eager to learn from one another and hear about the use cases of other states. In addition, states want to learn how other states navigated data sharing across agencies. Federal investments in training and TA should enable peer engagement and learning alongside other types of supports, such as written materials or one-on-one training and TA.
2. **Incorporating subject matter expertise.** Although the challenges related to human services interoperability are often technical, effective solutions require a deep understanding of human services programs and policies and the families these programs serve. Therefore, it is critical that federal investments in training and TA incorporate substantive program and policy expertise in addition to expertise in data and information technology (IT) systems.
3. **Ongoing support and resources.** Data interoperability is an ongoing journey. As such, there will be an ongoing need for technical support as standards, polices, and processes expand and evolve. A top action should be funding a resource dedicated to providing TA. TA could focus broadly on sharing and reinforcing best practices in data interoperability or focus narrowly on project- or program-specific use cases for fostering interoperable data exchanges between human services agencies. Moreover, Tribal communities, which often face unique challenges related to legacy systems and data sovereignty, could benefit from grants for TA to enhance Tribal IT capacity, a Tribal TA hub, and low-cost access to technical tools.

9.3. What data elements are a high priority to enable comprehensive case management, including whole-person care, referrals, and research?

Given the scale and complexity of developing interoperability standards for human services programs, we recommend pursuing an approach based on targeted investments; steady, incremental progress; and identifying key data elements that will have the biggest return on investment in terms of case management, quality and equity of care, health outcomes, and research.

First, a comprehensive set of demographic data elements would likely improve case management, allow for person-centered care, and enhance future research. A rich set of demographic data elements would include age, race and ethnicity, sex, sexual orientation, gender identity, household income and composition, education level, and limited English proficiency status. In addition, to better understand and serve Tribal communities, it is important include culturally sensitive indicators such as kinship care and migrant status.

Second, data elements that fall within SDOH reflect another high priority. The U.S. Department of Health and Human Services defines SDOH as the environmental conditions in which people are born, live, play, work, and age. Research shows these conditions have a large impact on people's overall health outcomes and quality of life, often greater than genetic factors or access to healthcare services. Healthy People 2030 group these environmental conditions into five main domains: (1) economic stability, (2) education access and quality, (3) healthcare access and quality, (4) neighborhood and built environment, and (5) social and community context. Table 1 lists a few examples of SDOH within each domain. Investing in data elements from each domain would aid future research across ACF programs and allow for better quality and equity of care.

Table 1. SDOH domains and examples

SDOH domains	Examples of data elements
Economic stability	• Enough money for food • Enough money for housing • Access to affordable child care • A sense of job security
Education access and quality	• Access to high-quality K–12 education • Finishing high school in four years • Enough money for college • Positive relationship with peers at school
Healthcare access and quality	• Access to health insurance • Having a primary care provider • Access to your own medical records • Access to transportation for medical visits
Neighborhood and built environment	• Access to grocery store • A sense of safety at home • Access to bike lanes and sidewalks in neighborhood • Access to the internet
Social and community context	• Having a support system to help in times of need • Belonging to social groups • Feeling welcome at your workplace • Feeling connected to people

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