Interoperability Insights: Demonstrating the Need and the Benefits of Connecting Health and Human Services

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Stewards of Change INSTITUTE

NIC NATIONAL INTEROPERABILITY COLLABORATIVE

STEWARDS OF CHANGE ISSUE BRIEF

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This Stewards of Change Institute (SOCI) Issue Brief examines the technical aspects of interoperability required to support integrated care and case management across multiple domains, including health, human services, education, housing, food, and justice. Such integration is necessary for more-effective understanding and utilization of the Social Determinants of Health and Well-Being (SDOH) for numerous programs, systems and domains; for this report, we chose one example to illustrate the challenges and benefits of integrating SDOH, with the hope/intent that readers will apply these lessons to their own work.

It is important to note that such integration is being required for many national, regional, state, and local initiatives, such as Integrated Care for Kids (InCK), the ONC's Leading Edge Acceleration Projects (LEAP), and a variety of multidisciplinary efforts by the Veterans Administration and Veterans Health Administration, the Visiting Nurses Association, United Way, and many others. So, another purpose of this SOCI Issue Brief is to support and inform these and other comparable undertakings at every level.

Most pointedly, such integration is especially critical today given the urgency of the coronavirus pandemic. This historic public health emergency clearly demonstrates the need to enable connections between social and health-related services to better assist a huge and growing number of people, most notably within racial and socioeconomic groups that were vulnerable even before the crisis arose.

The InCK Approach: Interoperability Insights from Child Welfare

The nation's healthcare system, particularly for children, faces significant challenges in identifying and addressing risk factors for complex physical, behavioral and mental health conditions. That is largely because the earliest signs of a problem — such as chronic absenteeism, behavioral issues in school or problematic family situations known to child welfare programs — may present outside of clinical care.

To tackle these challenges, the InCK program proposes the integration of care coordination and case management across physical, behavioral, and mental health, as well as other core services for children. Such coordination would enable more-holistic and -effective child- and family-centered care through enhanced information sharing, integration, and infrastructure across a spectrum of service silos, including (but not limited to) health, mental health, child welfare, education, and law enforcement.

InCK is an ambitious, unique, and forward-looking program that is requiring grantees to create data sharing and interoperability infrastructure to enable and/or improve coordinated care across health,

human services, education, and other programs. Accomplishing this challenge will require responsible and secure information-exchange that leverage national data exchange and transport standards and requirements, as well as state-of-the-art technology for managing security, privacy, and continuity of operations.

As a result, this approach should enhance care coordination and case management for children with physical, behavioral, and other health-related needs such as food insecurity and unstable housing. It should also improve child health, reduce inpatient stays, and avoid out-of-home placements through greater prevention, early identification, and treatment of behavioral and physical health issues.

A Scenario to Demonstrate Social Determinants Connections

A 10-year-old boy named Jameson has recently been placed back into foster care while his single mother, Sarah Thomson, is incarcerated for driving while under the influence of opioids and reckless endangerment. He was born with Neonatal Abstinence Syndrome (NAS) and has Asthma. He has no medical home and receives most of his care at the ER or urgent care facilities and has had minimal well-child care. He has watched far too frequently as Emergency Medical Services came to the house to resuscitate his mother. He has been in and out of Foster Care and has been receiving behavioral health therapy ever since Child Protective Services intervened as a result of his Adverse Childhood Experiences (ACEs) directly and indirectly due to his mother's addiction.

Jameson is behind on his education relative to his friends. Even though he had been held back to repeat first grade, he has never been screened for nor diagnosed with any developmental disabilities.

Jameson is traumatized by being separated from both of his parents, moved away from his friends, living in foster care with different unfamiliar families, and placed into new schools in which he knows no one. Over the past three years he has been repeatedly detached from his entire personal support system at the same time as he is being challenged with the new experiences of meetings with an overloaded case manager, appearances in family court, and the stress of his mother's addiction and his father's ongoing absence.

Jameson becomes withdrawn at school and testy with his foster parents. When he moved into his most recent foster care placement, he left his medications behind and he has neglected to continue his asthma controller inhaler treatments which contributes to poor physical and behavioral health. In addition, although he is in behavioral health therapy, Jameson uses drugs and alcohol as an escape from his misery and anxiety.

One day Jameson's Fourth Grade teacher notices that Jameson has come to school in a very drowsy condition, falling asleep several times at breakfast and in early morning classes. She sends Jameson to see Florence Whitaker, the School Nurse and writes up an Incident Report in the School Management Information System (SMIS) on her laptop.

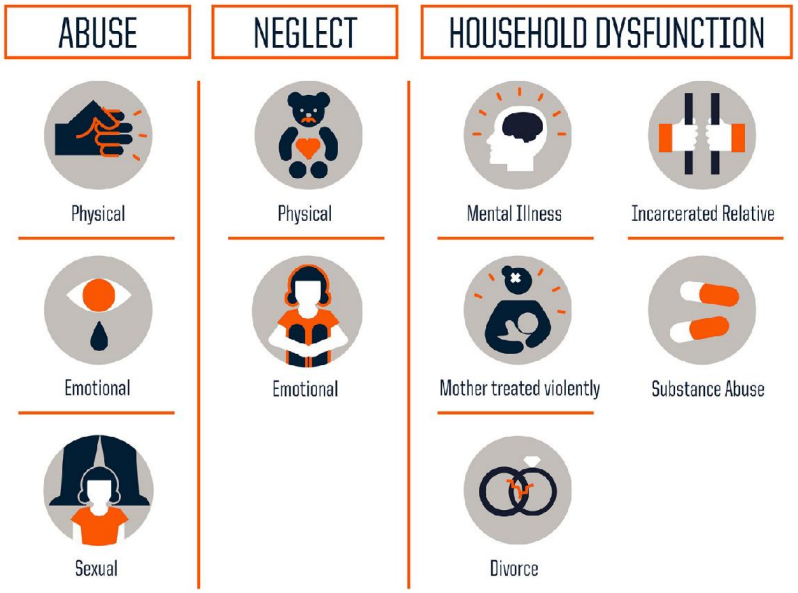
Florence begins to take Jameson's vital signs and record them in the School's EMR system. While she is talking to Jameson, she happens to notice what looks like an empty prescription bottle in his book bag – when she examines it, she finds it is from his mother's buprenorphine prescription. She immediately suspects that this is the cause for the drowsiness and now opens a triage instrument to ask Jameson some questions and record her observations of her behavioral concerns. The Triage tool guidance suggests an intervention of notifying the School Assistance Team, which includes Florence, the Principal,

and Gerald Brown LSW, a social worker in the Michigan Department of Health and Human Services (MDHHS) Monroe County office. The team determines that there is sufficient evidence to trigger the SMIS to generate a Mandatory Report to the MDHHS Child Protective services unit.

Jameson's Child Welfare case manager receives the Mandatory Report and now needs to work with Jameson's managed care assigned primary care physician, a psychologist, teachers, foster parents, and family court to get him additional behavioral health support and substance-abuse rehabilitation. Under the newly initiated Integrated Care for Kids program in his county, this report is going to be handled very differently than in the past….

Addressing Behavioral, Health, and Social Challenges

Unaddressed children's health needs can affect their ongoing functioning in schools, communities, and homes, and can have serious, long-term consequences. Early identification and treatment of children's multiple physical, behavioral, and other health-related needs and risk factors enables better management of chronic diseases, increases behavioral health access, responds to the opioid epidemic, and positively impacts the health of the next generation.



As noted in the InCK initiative, behavioral health conditions, including use of opiates and other substances, can lead to significant morbidity, healthcare utilization, and premature death especially for children and youth. Trauma and ACEs contribute to increased risk of behavioral health, mental illnesses, substance-abuse conditions, and early mortality. One in three children receiving benefits from Medicaid and the Children's Health Insurance Program have behavioral health needs, yet only one-third of them receive the care they need to heal. Opioids caused over half of the drug-related overdoses among youth in 2015, and adolescent deaths from drug overdoses are increasing.[1]

Integration Across Multiple Domains

The above scenario clearly illustrates the need to share information more effectively across human and health services to address mental and physical health challenges – as well as the potential benefits of doing so. At the same time, health and human services agencies have regulatory requirements and operational mandates to collect and maintain records associated with the children in state care.

A common use case within Family Services is the intake process of a child into foster care. When that occurs, for example, a caseworker must collect at least these records relating to the child:

[1] https://www.cms.gov/newsroom/fact-sheets/integrated-care-kids-inck-model

- current and past case plans
- current and past service plans
- educational transcripts
- individual education plans
- medical health summaries
- immunization history and forecast
- mental health summaries
- family court history and appointments
- family court petitions and reports
- child support history and judgments
- juvenile justice history
- juvenile justice findings and orders

These records come from multiple local, regional, state, and federal agencies that cross many diverse data domains and require different, specific data-exchange protocols. A caseworker seeking to stabilize a family or respond to a crisis may not even be aware that the individuals involved are receiving services from another system, let alone have access to all the relevant information from other systems, such as:

- physical health
- behavioral health
- early childhood care
- education
- housing
- food insecurity
- child welfare
- family courts
- juvenile justice
- criminal justice

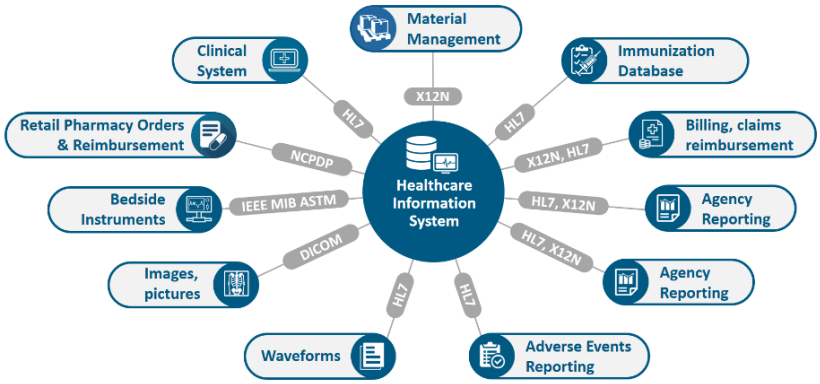
Each of these requires its own information-exchange architecture specifications.

Domain	Specifications	Type of Standard
Healthcare	Medicaid Information Technology Architecture (MITA)	Architecture Framework
	Health Level 7 version 2.5.1 (HL7v2.5.1)	Exchange Protocols Data Structure
	Health Level 7 C-CDA	Data Model
	Fast Health Information Resources (FHIR)	Exchange Protocols Data Model
	SMART-on-FHIR	Exchange Protocols Data Model Best Practices
Human Services, Child Welfare, Early Childcare, Housing, Food Security, Family Courts, Law Enforcement, Criminal Courts	National Information Exchange Model (NIEM)	Data Model
	Proposed NIEM-on-SMART-on-FHIR	Exchange Protocols Data Model

		Best Practices
	Homeless Management Information Systems (HMIS)	API Data Model
Family Courts, Law Enforcement, Criminal Courts	Justice Global Reference Architecture (GRA)	Architecture Framework Exchange Protocols Data Model Best Practices
Education – K-12+	Ed-Fi Alliance	Data Model
	Postsecondary Electronic Standards Council (PESC)	Exchange Protocols Data Model
	Common Education Data Standards (CEDS) – U.S. Department of Education	Data Model

Why is FHIR Important to Cross-Domain Integration?

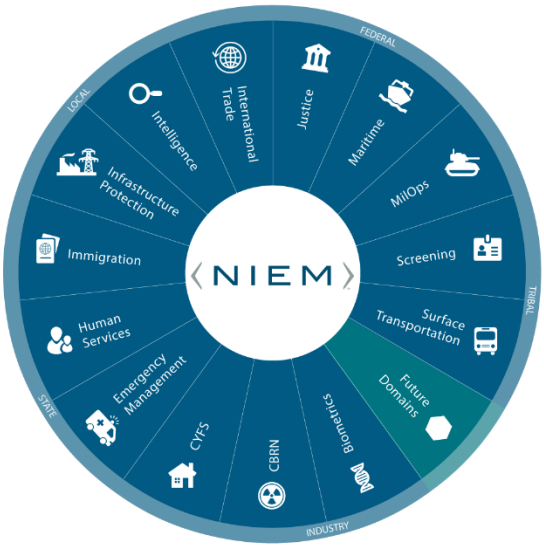
The magnitude, complexity and sophistication of healthcare has driven the rapid development and adoption of the HL7 Fast Healthcare Interoperability Resources (FHIR) standards. FHIR simplifies healthcare information exchange by focusing on the most widely used healthcare resources, satisfying 80 percent of the healthcare information exchange use cases. In doing so, FHIR dramatically reduces the cost of deploying standards-based healthcare information exchange for most users. This also makes healthcare information theoretically more available to non-clinical domains such as human services, child welfare, education, etc.



Today's health IT landscape is a sophisticated, heterogeneous environment composed of a wide assortment of healthcare settings, stakeholders, and information systems, specifically for healthcare delivery. The sheer number and diversity of healthcare entities (e.g., providers, payers, researchers, and beneficiaries) presents a considerable information-sharing challenge within the healthcare ecosystem. The healthcare data-exchange standards have evolved over the years to improve messaging and drive high data quality. These structure and syntax standards include:

- Digital Imaging and Communications in Medicine (DICOM): Imaging
- National Council for Prescription Drug Programs (NCPDP): Pharmaceutical Data
- HL7v2.x: Messaging
- HL7v3: Clinical Document Architecture (CDA), C-CDA, Continuity of Care Document (CCD) documents
- HL7 FHIR: RESTful API and Healthcare Resource standards

How the National Information Exchange Model (NIEM) and Other Standards Can Expedite Information Sharing with Non-clinical Data Sources



The systematic breakdown in communications and information-sharing between emergency and first responders during the catastrophic events of 9/11 served as an interagency driver to develop National Information Exchange Model (NIEM). It was then adopted by national and regional law enforcement and public safety information exchanges.

NIEM specifies the foundation and building blocks for interoperable information exchange by serving as a common XML vocabulary, integrated with established standards and processes, to support cross-domain information-sharing and efficient information exchange among interrelated public and private service domains (e.g., law enforcement, public safety, healthcare, etc.). As a result, NIEM:

- Breaks down interagency stovepipes
- Enables agencies to share information across system, agency, and jurisdictional borders
- Improves decision-making, agility, and efficiency to satisfy business needs
- Supports interoperability and reuse, thereby reducing costs

NIEM has expanded and experienced many changes since its formal launch in April 2005. As of April 2020, there were at least 16 NIEM domains and emerging communities of interest, including Agriculture, Biometrics, Chemical Biological Radiological and Nuclear Defense, Emergency Management, Human Services, Immigration, Infrastructure Protection, Intelligence, International Trade, Justice, Maritime, Military Operations, Screening, and Surface Transportation. All 50 states and at least 19 federal agencies are now using NIEM. The benefits of NIEM have also extended to Europe, Canada, Australia, and Asia.

As NIEM's adoption continues to expand, non-clinical NIEM domains that utilize health data elements for information exchange will require support to successfully navigate through the complexities of the health IT/health information exchange (HIE) environment. Furthermore, operational health IT/HIE safeguards must be in place to ensure the legal, secure, and private exchange of health information.

Let's Get Technical: Improving Information Exchange and Project Unify

These domain-specific architecture standards are intended to improve the collection and sharing of relevant records within and among domains. However, the lack of mapping between different standards inhibits data sharing which severely limits organization's ability to automate mandated (or simply desired) records collection and sharing across domains. This unfortunate reality results in higher-than-necessary collection and maintenance costs, ad-hoc data normalization/transformation, and increased potential for data-entry/reentry errors. More pointedly, it inhibits the ability of case workers and other service providers to get the information they need to address the unique needs of their clients. This means the children and families they're seeking to help will experience poorer outcomes.

Many domains need to collect critical health information to meet the requirements of non-clinical scenarios (e.g., foster care records, family courts, emergency management, etc.). Too often, however, they cannot efficiently or routinely do so because that information is scattered among "siloed" programs, systems, and even entire domains. These domains often define their health-related data using NIEM, independent of and not (yet) aligned with clinical health-information standards (HL7/FHIR).

Even though there are effective standards for clinician-to-clinician health data exchange, there is an urgent need to be able to exchange healthcare information with a variety of non-clinical domains.

It is important for non-clinical health-related information to be compatible – or to become compatible – with existing health information standards (e.g. HL7, C-CDA, FHIR). Examples of the need to accomplish this interoperability include processing child welfare referrals, querying hospitals for available beds, dealing with disaster response, placing recovering drug users in halfway houses, etc.

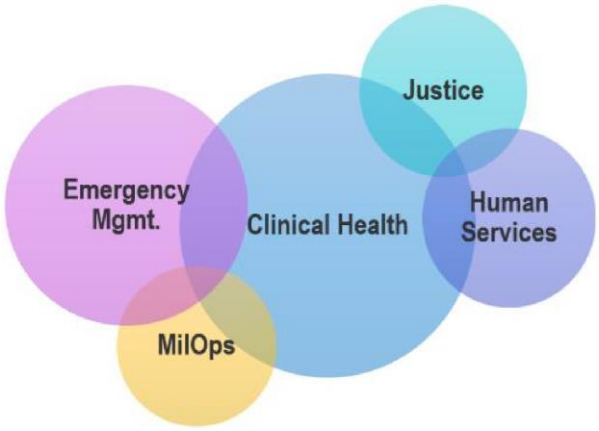
Project Unify is a Proof of Concept initiative led by the SOCI, its National Interoperability Collaborative (NIC) and MITA TAC. The project is based on cross-domain person matching, semantic data interoperability between HL7/FHIR and NIEM data models, syntactic data interoperability between HL7/FHIR Resources and NIEM data elements through the implementation of NIEM-on-SMART-on-FHIR protocol interoperability. We expect that this will result in a multi-domain (i.e. medical, educational, criminal, and human services), multi-architecture, and multi-protocol information exchange supporting interoperability among healthcare, human services, education, and justice agencies.

Project Unify using an open source/open-API approach will demonstrate the use of these information exchange services to collect cross-domain, use-case-driven records from multiple agencies and organizations, based on agency- and domain-specific data and protocol standards. That will enable access to the many different types of records needed to meet current requirements for integrated care and case management. Importantly, it will also enable and accelerate the collection of individual and population based SDOH data to improve outcomes for individuals, families, and communities.

NIC's key goal is to ensure that Project Unify's methodologies, tools and models are replicable, so they can be widely used by other organizations to accelerate their own cross-domain information-sharing and interoperability initiatives.

The Need for Data Mapping

For the reasons articulated above, there is an urgent need to identify and map key healthcare-related data elements to their non-clinical partner domains so they can be utilized for whole-person, integrated, and coordinated care. Without appropriate mapping, information silos will persist, and bidirectional, automated information exchange will be inhibited. Implementing a mapping process requires a technical explanation, starting with the understanding that interoperable information exchange among multiple domains is based on disparate data and protocol standards requiring:



- Semantic data interoperability, which defines what the data is across systems; i.e., comparing apples to apples, (or asserting that Patient Name in a healthcare system is the semantic equivalent of Client Name within a human services system).
- Syntactic data interoperability, which defines how the data is represented; i.e., so that systems know whether the apples are whole, sliced, or turned into sauce (or that Client Name is defined as a structure of Prefix, FirstName, MiddleName, LastName, and Suffix, not just a simple Full Name string).
- Protocol data interoperability, which defines how the data is exchanged; i.e. that the apple sauce is served in a small bowl, not a plate or a cup (or that resources utilizing other, non-NIEM standards such as FHIR are exchanged using RESTful API over HTTPS).

Syntactic and semantic data interoperability can be defined through common, cross-domain information models derived by mapping from health data standards to standards utilized by other domains, while maintaining fidelity with the original HL7/FHIR standards.

Conclusion

This SOCI Issue Brief uses the Integrated Care for Kids (InCK), an initiative funded by the Centers of Medicare and Medicaid Innovation (CMMI), to illustrate the far-broader need for interoperability and information-sharing across programs, systems, and domains. Our intent, with this paper and with Project Unify, is to provide practical guidance, tools, and models that can be leveraged, replicated, and improved over time to address the enormous and growing need for coordinated care across the nation.