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

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. Achieving this goal will require responsible and secure information sharing that leverages 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 because his single mother, Sarah Thomson, is incarcerated for driving while under the influence of opioids and reckless endangerment. Jameson was born with Neonatal Abstinence Syndrome (NAS) and has asthma. He receives most of his care at the emergency room or urgent care facilities and has had minimal well-childcare. He has watched far too frequently as Emergency Medical Services came to his family’s home 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), which were directly and indirectly due to his mother’s addiction.

Jameson was held back to repeat first grade, but he has never been screened for nor diagnosed with any developmental disabilities. He has been traumatized, however, by his parent’s divorce, now being separated from both parents, being moved away from his friends, living in foster care with 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 support system even as he has been 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 is withdrawn at school and testy with his most-recent foster parents. When he moved in with them, he left his medications behind and has not continued his inhaler treatments for his asthma, which contributes to poor physical and mental health. In addition, although he receives behavioral health therapy, Jameson has begun using drugs and alcohol as an escape from his misery and anxiety.

One day, his fourth-grade teacher notices that Jameson is very drowsy when he comes to school, and even falls asleep sometimes at breakfast and in early morning classes. She sends Jameson to see Florence Whitaker, the school nurse and writes up a mandated 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 Electronic Medical Records system. While she is talking to Jameson, she notices 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 boy’s drowsiness and opens an app on her computer that provides questions to ask Jameson and records her observations. The app also suggests an intervention: Notifying the School Assistance Team, which includes the nurse, the principal, and Gerald Brown LSW, a social worker in the Michigan Department of Health and Human Services, Monroe County
office. The team subsequently determines that there is sufficient evidence to trigger the SMIS to generate a Mandatory Report to the county Child Protective Services unit.

Jameson’s foster care case manager receives the Mandatory Report and now needs to work with the boy’s primary care physician, a psychologist, teachers, foster parents, and the family court to get him additional behavioral health support and substance-abuse treatment. Under the newly initiated Integrated Care for Kids program in his county, this case will be handled very differently than it would have been 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 issues, 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, but only one-third of them receive the care they need. Opioids caused over half of drug-related overdoses among youth in 2015, and adolescent overdose deaths are increasing.¹

**Integration Across Multiple Domains**

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

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

● 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.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Specifications</th>
<th>Type of Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare</td>
<td>Medicaid Information Technology Architecture (MITA)</td>
<td>Architecture Framework</td>
</tr>
<tr>
<td></td>
<td>Health Level 7 version 2.5.1 (HL7v2.5.1)</td>
<td>Exchange Protocols</td>
</tr>
<tr>
<td></td>
<td>Health Level 7 C-CDA</td>
<td>Data Model</td>
</tr>
<tr>
<td></td>
<td>Fast Health Information Resources (FHIR)</td>
<td>Exchange Protocols</td>
</tr>
<tr>
<td></td>
<td>SMART-on-FHIR</td>
<td>Data Model</td>
</tr>
<tr>
<td></td>
<td>Proposed NIEM-on-SMART-on-FHIR</td>
<td>Exchange Protocols</td>
</tr>
<tr>
<td>Family Courts, Law Enforcement, Criminal Courts</td>
<td>Data Model</td>
<td>Best Practices</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------</td>
<td>----------------</td>
</tr>
<tr>
<td><strong>Homeless Management Information Systems (HMIS)</strong></td>
<td>API</td>
<td>Data Model</td>
</tr>
<tr>
<td>Family Courts, Law Enforcement, Criminal Courts</td>
<td>Architecture Framework</td>
<td>Exchange Protocols</td>
</tr>
<tr>
<td><strong>Justice Global Reference Architecture (GRA)</strong></td>
<td>Data Model</td>
<td>Best Practices</td>
</tr>
<tr>
<td>Education – K-12+</td>
<td>Data Model</td>
<td></td>
</tr>
<tr>
<td><strong>Ed-Fi Alliance</strong></td>
<td>Exchange Protocols</td>
<td>Data Model</td>
</tr>
<tr>
<td><strong>Postsecondary Electronic Standards Council (PESC)</strong></td>
<td>Data Model</td>
<td></td>
</tr>
<tr>
<td><strong>Common Education Data Standards (CEDS) – U.S. Department of Education</strong></td>
<td>Data Model</td>
<td></td>
</tr>
</tbody>
</table>

**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 theoretically makes healthcare information 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 the 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 which 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 organizational ability to automate the mandated (or simply desired) collection and sharing of information 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/re-entry 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 “silied” 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 the Medicaid Information Technology Architecture Technical Architecture Committee (MITA TAC). The project is based on cross-domain person matching; semantic data interoperability between HL7/FHIR and NIEM data models; and 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 justice and human services), multi-architecture and multi-protocol information exchange supporting interoperability among healthcare, human services, education and justice agencies.

Using an open source/open-API approach, Project Unify 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 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 Social Determinants 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, systems and domains 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 Center for 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.