Integrating Maternal and Child Health Data Systems

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Introduction

What happens when state health programs use separate data systems to serve the same population, such as mothers and children? State policymakers know that when those data systems do not "talk" to one another, states may waste resources on duplicative data entry and system maintenance; providers and state agencies may struggle to access information important to the health of mothers and children; and care may be uncoordinated or otherwise compromised.

Integrating maternal and child health data can help states keep important information from falling through the cracks. If a child in Illinois has an abnormal hearing screening, the state's data system can help identify the child's primary care provider for follow-up. When a clinic in Utah checks a child's immunization status in the state registry, it can also access the child's hearing screening results and electronic health record (EHR). In this way, data integration can help states expedite the referrals, services, and follow-up a child needs.

Some states are tackling the data integration challenge head-on. In the spring of 2015, NASHP worked with the Iowa Child and Family Policy Center (CFPC) to gather information for the State of Iowa Department of Public Health as they drafted a request for proposals to integrate maternal and child data sets. NASHP solicited input on states' experiences integrating maternal and child health data systems from our Assuring Better Child Health and Development (ABCD) alumni network--a nationwide network of child health experts and policymakers.[1] Many in the network expressed interest in the idea of integrating maternal and child health data systems, and a few shared experiences with data integration. NASHP interviewed state officials in Illinois, New Jersey, Rhode Island, and Utah; and a state contractor in Connecticut. This report contains recommendations for Iowa based on our research.

Comparative Analysis

As shown in Table 1, of all the maternal and child health data sources used by states, vital records data is the only one included in integrated data systems in all five states. Immunization and hearing screening data are incorporated in four states. Three states currently incorporate lead screening and newborn bloodspot testing, while only two of the interviewed states incorporate the Women, Infants and Children (WIC) program, early intervention data, oral/dental health data, and claims data for Medicaid or the Children's Health Insurance Program (CHIP). In addition to what is shown in the chart, Rhode Island's data system also includes home visiting, developmental screening, and some limited asthma data.

Of the states we spoke with, only Illinois incorporates Medicaid claims data into a multi-agency integrated state database. Connecticut Voices for Children uses Medicaid claims data, but its integrated data set is used primarily for research and advocacy, while Illinois uses the data for claims analysis and reporting. The most comprehensive integrated data systems we looked at are those maintained by Illinois and Rhode Island, which incorporate at least seven maternal and child health data sources.

Most of the states with whom we spoke are not able to access clinical data from electronic health records (EHR) through their integrated data systems. One New Jersey state official notes that EHRs have great potential to streamline access to data, despite some resistance to them on the part of providers and families. If Iowa's integrated data system were able to access EHRs, the state could obtain a wide range of maternal and child health data; however, legal and privacy issues would need to be addressed. Utah has designed its Child Health Advanced Records Management (CHARM) system to allow providers to access a child's EHR via CHARM's web-based application. Illinois has not designed its data system to access EHRs, but suggests that Iowa consider doing so. Rhode Island's KIDSNET system does not include access to EHRs, although KIDSNET does receive immunization data through EHRs, and will soon receive congenital heart disease screening data from hospital EHRs.

Recommendations

The five states with whom we spoke had a range of experience with integrating maternal and child health data. From our conversations and our review of supporting materials, we distilled six recommendations that we hope will be useful to Iowa as it develops its plan for an integrated data system.

1. **Separating the needs assessment from the development and implementation process may lead to a stronger product.**

Our state interviewees agreed on the importance of conducting a thorough needs assessment before requesting proposals for data integration. In Utah, the state project team worked with a contractor to perform a needs assessment as part of their two-year planning and assessment process, which was supported by a Health Resources and Services Administration (HRSA) grant. At the conclusion of the planning and assessment process, Utah entered into a non-competitive, sole-source contract with a different contractor to develop and implement the CHARM data system.

Rhode Island also issued an RFP solely for the planning and requirements documentation process. The vendor for the requirements documentation process was barred from submitting a proposal to construct the system, to prevent vendors from limiting the potential of the system by only proposing to build something within their own

Table 1.
Maternal and Child Health Data Included in Integrated Data Systems

	Hearing Screening	Lead Screening	Immunizations	Medicaid /CHIP claims	Vital Records	Newborn Blood-spot Testing	WIC	Oral/ Dental Health	Early Intervention
CT[2]				x	x			x	
IL	x	x	x	x	x	In process	x	x	
NJ	x	x	x		x	x			
RI	x	x	x		x	x	x		x
UT	x	x	x		x	x			x

capabilities. Such a needs assessment also can sharpen the focus on intended concrete uses for the integrated data set and what will be entailed in uses for this purpose – including uses at the practitioner-client service level, at the monitoring and coordination level, and at the research and knowledge-building level (see recommendation 2).

2. Iowa may benefit from building a system that can easily accommodate future use by multiple users, such as legislators, researchers, advocates, or other user groups.

Even though Iowa currently seeks to benefit state and local agencies, providers, and families, the integrated data system could be built to accommodate future uses. For example, while state agencies in Connecticut rely on Connecticut Voices for Children's integrated data for program evaluation and Title V reporting, reports based on analyses of the Medicaid/CHIP data are also used by legislators, policymakers, researchers, providers, and advocates in the state.[3] Iowa could maximize the utility of its new system by designing it with future evidence-based policy initiatives or research projects in mind.

Table 2 shows that state agencies and healthcare providers most commonly have direct access to the integrated data systems. All five states reported that departments of public health and human, social, and/or family services used the system, and three states reported providers using it. In Illinois, providers do not have direct access to the Enterprise Data Warehouse but can check eligibility, do claims inquiries, and submit claims through a different system. Less common was researcher access to the integrated data system, with only Connecticut reporting direct access by researchers. Rhode Island regularly provides data sets to researchers, but they do not typically have direct access to the data system. Iowa might consider whether its system should support use by researchers, families, or other user groups.

3. Iowa should carefully consider whether it is essential to replace existing data systems with the new integrated system, instead of allowing existing systems to remain in place.

Several states reported satisfaction with the integration of their maternal and child health data systems using a federated model that does not replace existing data systems. For example, the Illinois Departments of Public Health, Healthcare and Family Services, and Human Services all maintain their own systems but contribute data, pursuant to a multi-agency data sharing agreement, to a data warehouse maintained by the Medicaid agency. Utah's CHARM database similarly operates under a federated model in which each public health program maintains its own data system but contributes data to CHARM under a data-sharing agreement. The state agencies appreciate being allowed to keep their own data systems, which have long been used to generate required reports for federal agencies and other entities. Utah's federated system also reduced duplicative tests and expedited appropriate referrals, services, and follow-up. Rhode Island's integrated system, KIDSNET, is the sole database for many programs, although some programs still

Table 2.
Users Accessing Integrated Maternal and Child Health Data Systems

	Pediatricians /PCPs	Other providers	State Department of Human Services/ Social Services/Family services	State Department of Health/ Public Health	Researchers
CT			x	x	x
IL			x	x	
NJ	x	x	x	x	
RI	x	x	x	x	
UT	x	x	x	x	

maintain their own data systems and use KIDSNET as their data warehouse to provide web-based user access to providers and other community partners.

Table 3 shows that the states themselves are responsible for the maintenance of the integrated data system in all but one of the states we interviewed, with three of the states relying on contractors to assist state employees with maintenance. Connecticut Voices for Children maintains the integrated data system in that state.

4. The RFP's description of work should make clear whether eliminating existing data systems is a requirement of the data integration project.

Unless the importance of replacing existing systems is made clear, vendors may propose meeting the state's other requirements by constructing a data hub into which existing separate data systems will fit. If Iowa reviewers will only consider applications that eliminate existing data systems, or will award more points to applications that eliminate existing systems, then those conditions should be made explicit in the RFP.

5. Iowa's approach to vendor contracting needs an eye toward the long term.

The contractor who developed and implemented Utah's system remained involved in the data system over the long term, and Utah feels this longstanding relationship has been beneficial to the project. Similarly, Rhode Island reports that using the same vendor long-term helps ease staff transitions and

provides helpful historical knowledge. One state reports that changing vendors every few years can be disruptive, and that it would be ideal to find a vendor with whom the state can build a long-term relationship.

Some states emphasized the importance of anticipating changes to the agreement between the state and the vendor. Connecticut's agreement included a process by which either the state or the vendor could initiate a request to conduct optional activities related to the contract's scope of work.

6. Contracts need strong provisions to guard against problems with the vendor that go beyond late completion of deliverables.

According to news sources, one state's contract with a vendor to create an integrated data system for anti-poverty programs had no clause allowing the state to penalize the vendor in the event of a problem. The state terminated its contract with the company due to delays and other problems. Iowa might consider providing more detail about what constitutes satisfactory completion of deliverables.

Table 3.
Maintenance of Integrated Maternal and Child Health Data Systems

	State	Contractor
CT		x
IL	x	x
NJ	x	
RI	x	x
UT	x	x

Conclusion

States were very interested in Iowa's data integration efforts and acknowledge the importance of integrating data systems. State interviewees were very generous with their time and indicated that they would be willing to answer additional questions Iowa might have as the project unfolds.

Endnotes

1. The NASHP ABCD Resource Center is designed to provide state policymakers, primary care providers and other child and family service providers with easy access to research and resources that they can use to promote early childhood health and development. It can be accessed at http://www.nashp.org/abcd-map.

2. The entity that maintains the data integration in Connecticut is not a state agency. Connecticut Voices for Children is a private organization that contracts with the state to conduct independent performance monitoring with ongoing support from the state legislature and a two-year contract aligned with the biennial budget process.

3. A report produced by Connecticut Voices for Children demonstrates the analysis made possible by the data integration. Among other findings, the report found that mothers participating in the state's Medicaid and CHIP program were less likely to get early prenatal care than other Connecticut mothers (Connecticut Voices for Children, "Births to Mothers with HUSKY Program and Medicaid Coverage: 2010," February 2013).

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Acknowledgments:

The author wishes to thank the officials from the following states who generously gave their time to inform and review this report: Illinois, New Jersey, Rhode Island, and Utah. Thanks, also, to Connecticut Voices for Children for their input, to Taylor Kniffin and Jill Rosenthal from the National Academy for State Health Policy for their contributions and guidance, and to the Iowa Child and Family Policy Center for their generous support.