

STATE HEALTH POLICY

STATE HEALTH POLICY BRIEFING PROVIDES AN OVERVIEW AND ANALYSIS
OF EMERGING ISSUES AND DEVELOPMENTS IN STATE HEALTH POLICY.

This issue brief is the first in a series of Assuring Better Child Health and Development (ABCD) III Innovation Briefs that will focus on promising methods states use to improve care coordination and service linkages to support healthy child development. It focuses on electronic information-sharing systems that Illinois is building or adapting to improve care coordination for children with or at risk of developmental delays. Illinois is poised to improve care coordination by implementing an electronic referral initiation and feedback system, a positive step toward the goal of ensuring children receive appropriate services and achieve the best possible outcomes. These system changes have implications for information sharing to support care coordination statewide and for other populations.

The ABCD program is funded by The Commonwealth Fund, administered by NASHP, and designed to assist states in improving delivery of early child development services for low-income children and their families by strengthening primary health care services and systems that support the healthy development of young children. Since 2000, ABCD has helped 27 states create models of service delivery and financing through a laboratory for program development and innovation. ABCD III began in October 2009. For more information about ABCD please visit: <http://nashp.org/abcd-history>.

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Briefing

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Building Electronic Information-Sharing Systems to Support Care Coordination in Illinois

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Through the current Assuring Better Child Health and Development learning collaborative (ABCD III), five states (Arkansas, Illinois, Minnesota, Oklahoma, and Oregon) are supporting healthy child development through care coordination and linkages among primary care providers and other providers of community services for young children and their families.¹ The ABCD III state initiatives have been underway for two years and a number of early lessons have already emerged.²

Outlined in the brief are lessons from Illinois' ABCD experience in building and adapting electronic information-sharing systems. These lessons may inform the efforts of state policymakers in others states as they attempt to improve care coordination. They include:

- Relationship building and communication among state agency staff are critical to data sharing success.
- Building systems for multiple uses capitalizes on the investment.
- Getting information to flow among various databases is complex, but pays off in automating processes that currently depend on phone- or email-based communications.
- Pilot testing and training providers on new systems is critical to success.

INTRODUCTION

Illinois designed its ABCD III project, Illinois Healthy Beginnings II: Coordinating Medical Homes and Community Services (IHB2)³, to build on a successful history of coordination and collaboration among Medicaid, Title V and Women, Infants, and Children (WIC) programs, the public health infrastructure, primary care providers, and many additional stakeholders.⁴ Illinois ABCDIII project staff is testing improvements to the referral, feedback, and care coordination process at pilot sites comprised of primary care providers (PCPs)/medical homes and community referral agencies, which include regional Early Intervention (EI) service centers, known in Illinois as Child and Family Connections (CFC). The Illinois Department of Healthcare and Family Services (HFS), the state's Medicaid agency, leads the project with pilot site activities coordinated by the Illinois Chapter of the American Academy of Pediatrics (ICAAP). The ABCD III initiative supports and systemizes these improvements through sustainable state-level changes that improve the flow of information to and from PCPs/medical homes to ensure appropriate and effective referral, follow up, and coordination of care for children with or at risk for developmental delay.

Illinois aims to ensure that children receive well-coordinated and comprehensive care in which collaboration among providers

and families ensures the best possible outcomes are achieved.⁵ In order to do so, Illinois is using standardized referral and referral feedback forms (which may be adapted by other states); expanding existing data sharing between two state agency databases containing information needed to track Early Intervention referrals and treatment, and creating a new electronic data capture system to submit referrals electronically (using the content of the standardized referral forms) from the child's PCP to Early Intervention.⁶

The goals are to:

- create a flow of referral and referral outcome information that facilitates collaboration between PCPs and Early Intervention regional offices;
- give PCPs the tools to access the information that they need; and
- reduce the burden on families who would normally have to independently initiate contact with the Early Intervention regional office for further assessment of their child.

Table 1 describes the various data systems. Although some of these systems may be unique to Illinois, other states may have comparable systems on which to build.

TABLE 1 DATA SYSTEMS BEING ADAPTED IN ILLINOIS TO PROMOTE INFORMATION SHARING

Data System	Description
Cornerstone	The Illinois Department of Human Services (DHS) developed Cornerstone, a statewide data management information system that facilitates integration of community maternal and child health services provided by the Illinois Department of Human Services that are available to the state's residents. The system provides a single point of enrollment for state-funded programs and is the primary point of entry into state Early Intervention services. ⁷
Medical Electronic Data Exchange (MEDI)	The Illinois Department of Healthcare and Family Services (HFS), which houses Medicaid, developed the MEDI data exchange system. The MEDI data exchange system is an online web portal for registered users to verify patients' Medicaid eligibility status, submit claims, and access patients' paid claims history. All providers who serve as a certified medical home must be registered users.
Statewide Provider Database (SPD)	The Illinois Department of Children and Family Services (DCFS), which houses Child Welfare, developed the SPD. It provides comprehensive information on service agencies and programs in the state and provides geo-mapped information about those services. Caseworkers and community partners use the SPD across Illinois. Though early childhood is a focus, the database also contains information for many other programs, including mental health and substance abuse. ⁸

Much of the data needed to track Early Intervention referrals and outcomes is collected in the Department of Human Services (DHS) Cornerstone system. Early Intervention regional offices use Cornerstone as a point of entry. The system is used to coordinate Early Intervention assessments and track the referral process until completion. Cornerstone currently exchanges data with the Medical Electronic Data Interchange

System (MEDI), an online resource for PCPs/medical homes to verify patients' Medicaid eligibility status, submit claims, and view patients' paid claims history. However, this exchange does not extend to data regarding Early Intervention. The MEDI data exchange system does not have a referral initiation or feedback system of any sort.

The Illinois ABCD III project team reviewed an existing interagency data sharing agreement among the state agencies and found it covered the data they sought to exchange as part of this ABCD III project. Through conversations with various data sharing and collection entities, the team discovered there were opportunities to add new variables by modifying file layouts. These new variables correspond to the information collected on the Early Intervention referral and referral outcome forms.

Beyond the existing data sharing agreement, however, the state also found that a new mechanism would be required to be able to allow PCPs to initiate an electronic referral to Early Intervention. This system innovation, along with integrating service data from Early Intervention into the electronic MEDI data exchange system and building upon an existing database for human services, has the potential to expand to other projects as a means of enhancing care coordination.

DATA EXCHANGE TO COMPLETE THE COMMUNICATION LOOP

Care coordination helps link children and their families to services, avoid duplication of effort, and improve communication between families and providers. What makes care coordination difficult to achieve is that it generally requires linking various participants, including the medical, community, and other providers to each other and to the child and family.⁹ Coordinated care requires all of these entities to share appropriate and relevant information and communicate effectively.

As indicated above, providers in Illinois have access to a number of tools that can help them coordinate care for children. Illinois ABCD III project staff expects to work out some limitations of the independent systems through a series of steps including: building a new Early Intervention referral system, cross-walking data between Early Intervention and medical home systems, and increasing access to referral resources in the Statewide Provider Database. These changes, Illinois believes, will complete the communication loop and improve coordination of care.

AUTOMATING AND STANDARDIZING COMMUNICATION FROM EARLY INTERVENTION TO THE PCPs ABOUT THE RESULT OF A REFERRAL

An IHB2 survey of providers found that most providers gave the Early Intervention referral to the family to complete (as

opposed to making the referral directly to Early Intervention for the family), and they were not actively engaged in ensuring the family acted upon the referral. The survey also found that often PCPs do not receive referral outcome information and many PCPs reported feedback was often only received by asking the parent/guardian at the child's next visit. Through ABCD III, Illinois is piloting a new system that will allow completed standardized referral forms to be generated by the PCP/medical home and sent to the appropriate Early Intervention regional office, thus reducing the burden on families to initiate contact with the Early Intervention. PCPs/medical homes and community service providers in the pilot communities are testing a new [Standardized Illinois Early Intervention Referral Form](#). The paper-based document will be transferred into a web-based form that will be available on each PCP's customized MEDI data exchange home page.

Through innovations of the IHB2 project, HFS' MEDI data exchange system will be modified to build in new functionality to collect information necessary for PCPs to initiate an electronic referral to Early Intervention. The content of the standardized referral form defines a discrete set of key variables that are the foundation of a new MEDI system. The MEDI data exchange system will be modified to include an on-line data entry process whereby Early Intervention referral information is gathered from PCPs. These data will then be transferred to DHS' Cornerstone system to notify Early Intervention regional offices of a pending referral.

NOTIFYING THE PRIMARY CARE PROVIDER OF THE REFERRAL OUTCOME

The referral communication loop is closed by identifying the existing data in DHS' Cornerstone system that match variables within the Early Intervention referral outcome form. These referral outcome data will be transferred to HFS' MEDI data exchange system. Upon receipt of these data, the MEDI data exchange system will produce an e-mail notification to the PCP showing an update is available on one of their patients. Further, for Medicaid enrolled children, referrals to Early Intervention that were not initiated by the child's PCP will still be made available to the child's assigned PCP. This is possible since the Early Intervention intake and assessment information is routinely captured in DHS' Cornerstone system. Through the built-in consent process in the standardized referral form, parents/guardians can permit release of Early Intervention outcome information to the child's assigned PCP. The enhanced data exchanged between the

MEDI data exchange system and Cornerstone should assist PCPs in following up on Early Intervention referrals.

Since Early Intervention does not mandate communication back to the PCP, this feedback is critical because the PCP is often not notified, creating a disincentive for PCPs to refer. In addition, if the PCP is not notified of the Early Intervention outcome, it may be more difficult to support the family in coordinating care. Current data indicates that approximately 10 percent of formal documented Early Intervention referrals come from medical homes/PCPs.¹⁰ Illinois hopes that once the new system is in place, that number will climb.

The referral and referral outcome data will also populate HFS' Enterprise Data Warehouse. The Enterprise Data Warehouse aggregates multiple data sources among the three state agencies identified in the interagency data sharing agreement. These data are consolidated in an effort to provide as complete a data set as possible that is matched at the person level. These consolidated data are a valuable resource for quality measurement and analysis purposes. In the future, HFS proposes the use of these Early Intervention referral data for quality measurement of the care coordination process.

MAKING IT EASIER FOR PCPS TO FIND SERVICES FOR CHILDREN WHO DO NOT QUALIFY FOR EARLY INTERVENTION

If a PCP is informed a child is ineligible for Early Intervention services, the goal is then to connect the child to other resources so that he or she receives needed interventions. However, one commonly cited barrier to increasing referrals to services by PCPs is lack of knowledge of available services.¹¹

Illinois intends to buttress the transformed referral process by ensuring that PCPs have information readily available to refer to a variety of services by increasing the number of PCPs who have access to the Statewide Provider Database. Currently the Statewide Provider Database is made available to PCPs at ABCD III's pilot sites with expansion planned. This expansion will equip more providers with an additional tool for supporting those children who are at risk, but not eligible for Early Intervention services. For ease of use, a hyperlink to the Statewide Provider Database will be included on the PCP's MEDI data exchange system homepage. In Illinois, children must be at or more than 30 percent delayed to be eligible for services. This leaves a significant number of children who are still at risk and in need of services but who do not qualify for Early Intervention services. Since the Statewide Provider Database

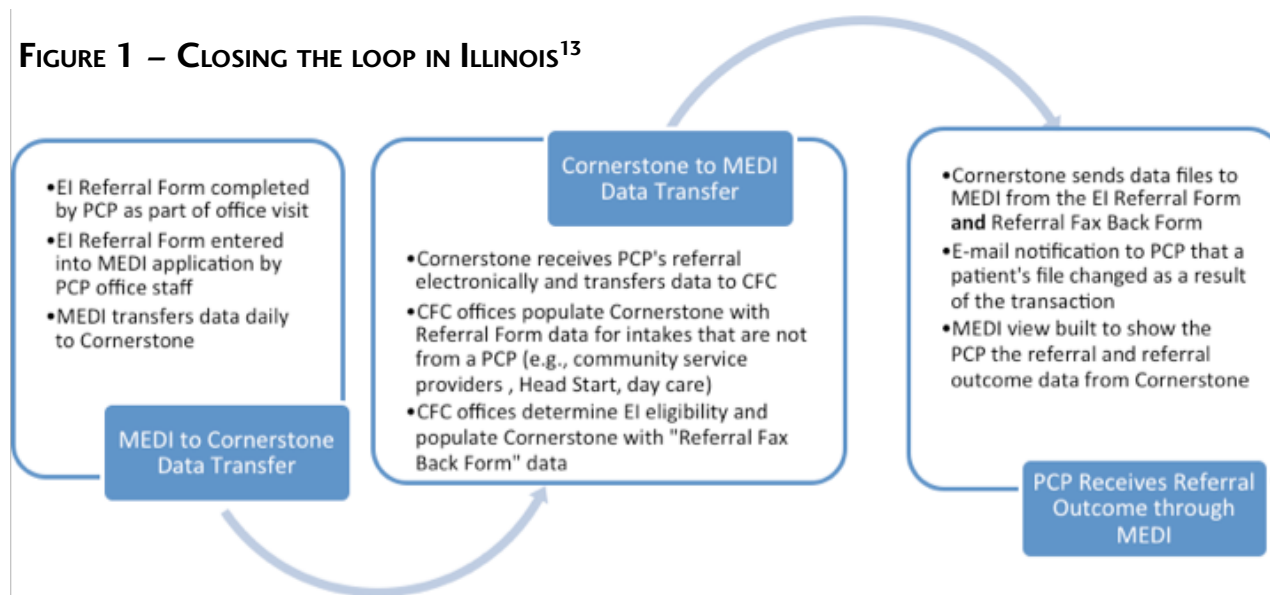
provides geo-mapped information about community-based services that meet the non-medical needs of children/families, the Illinois ABCD III team anticipates that increased access to the Statewide Provider Database will help PCPs find services for those children.¹²

CLOSING THE COMMUNICATIONS AND SERVICE DELIVERY LOOPS IN ILLINOIS – SYNERGY AMONG SYSTEMS

With the systems aligned, the communication process will become more automated and thus much simpler. After these steps are complete, the care coordination process in Illinois should flow as follows: the PCP or community service provider refers a child to Early Intervention via the standardized referral form (PCPs can also submit referrals through the newly designed system to Cornerstone.) Then, the Early Intervention regional office determines eligibility and enters it into Cornerstone. The child's PCP/medical home then receives an email alert via the MEDI data exchange system indicating that there is an update on the child's status; this update is provided even if the PCP was not the referring source (i.e. if a community service provider initiates the referral to Early Intervention, Early Intervention will identify the child's medical home so that the information flows to the PCP/medical home). This update will inform the PCP whether or not the child is eligible for Early Intervention services, or if the child is delayed but not eligible for services. If the latter scenario applies, then the provider can access the Statewide Provider Database through a link on the provider's MEDI data exchange system home page and search for the appropriate community-based services. This will have the effect of streamlining the referral process and closing the loop between the PCP and Early Intervention/other services offered by community service providers. Figure 1 (next page) illustrates the process.

STATEWIDE IMPLICATIONS FOR CARE COORDINATION

ABCD III in Illinois offers an early example of how data can be captured and shared electronically for purposes of care coordination and quality measurement. The data-sharing improvements are applicable for other issues and populations in which care coordination is critical. For example, Illinois is proposing the creation of a data exchange for women with high-risk pregnancies as part of a separate project under development, and Illinois will promote the use of the MEDI data exchange system among birth facilities to refer to Early Intervention, since

FIGURE 1 – CLOSING THE LOOP IN ILLINOIS¹³

low birthweight is one of the qualifying conditions for Early Intervention eligibility. The state is also discussing building expanded data exchanges to provide PCPs access to other program data that are collected under the interagency data sharing agreement, for example when genetic problems are present.

Several other state projects are seeking ways to build on ABCD III's innovations, including Illinois' Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) Quality Demonstration Grant, which supports state efforts to enhance medical home initiatives and health information exchange or technology. CHIPRA also provides the opportunity to evaluate models of care coordination to improve child health quality. The ability to demonstrate effective care coordination is critical to improving child health quality and implementing medical homes, health information exchange, and meaningful use initiatives.

Illinois is planning additional improvements to care coordination that may build on the care coordination infrastructure developed under the ABCD initiative. In 2011 Illinois enacted Public Act (P.A.) 96-1501. Section 23 of the act mandated that by 2015 at least 50 percent of children in the Medicaid population receive coordinated care.¹⁴ This mandate requires the state to have in place a data sharing system to support measurement of coordinated care. The cross-agency data exchange agreement and collaboration between HFS and DHS, and data capture and exchange systems that result from the ABCD initiative will inform the state's response to this new care coordination mandate.¹⁵

LESSONS LEARNED

Illinois' ABCD III project team has learned a number of lessons while building and adapting information-sharing systems.

- Relationship building and communication among state agency staff are critical to data sharing success.** Meetings among state staff in various departments (i.e. Department of Healthcare and Family Services Bureau of Maternal and Child Health Promotion, Bureau of Rate Development and Analysis, Bureau of Technical Support, Bureau of Information Services, Department of Human Services) have contributed to project success. There is significant investment in staff time, but through conversations with various data sharing and collection entities the state found there were opportunities to add new variables by modifying file layouts, making the data sharing process less difficult than expected.¹⁶
- Building systems for multiple uses capitalizes on the investment.** Developing an electronic data capture within HFS' MEDI data exchange system and a data receptor in DHS' Cornerstone system is a complicated process, both from the perspective of staff investment as well as IT infrastructure. Nevertheless, one strength of the project is that it is being built within the MEDI data exchange system, which is used by the majority of providers who participate in the Medicaid program. The significant initial investment of personnel is counterbalanced by the eventual payoff of automating systems for a variety of care coordination functions.

- **Getting information to flow among various databases is complex, but pays off in the ability to automate processes that currently depend on phone- or email-based communications.** The Cornerstone system vendor re-procurement led to delays at DHS, and other high priority projects within HFS also contributed to delays. This has led to a delay in the cross-agency data exchange agreement and caused it to proceed slower than expected. However, compatible systems will be better able to support data sharing and collaboration so that children receive well-coordinated and comprehensive care. It also provides a model for capturing and sharing data electronically that may support care coordination and quality measurement for other issues and populations.
- **Pilot testing and training providers on new systems is critical to success.** Before converting to electronic formats, the Illinois ABCD III team pilot tested a paper-based referral process to make sure it functioned as intended. As the Illinois ABCD III team works on data systems it continues to explore ways to ensure that PCPs will use the data appropriately and effectively. This will include training so that PCPs get accustomed both to the new

processes in the communication loop as well as the new systems that they can access. The ABCD III pilot process is critical to exploring ways to conduct effective training and support.

CONCLUSION

Illinois' ABCD III project activities provide lessons to other projects in several important areas about data sharing as it relates to care coordination. Illinois is poised to improve care coordination by implementing an electronic referral initiation and feedback system, a positive step toward the goal of ensuring children receive appropriate services and achieve the best possible outcomes. The fact that ABCD III efforts around data sharing and referral tracking align with goals of the CHIPRA Quality Demonstration Grant and with care coordination, which is now mandated by the state, has established ABCD III as a foundation for learning and expanding the developments of the project. As a result, these other state projects are poised to reap the benefits of ABCD III's lead and build upon the project's policy improvements. This will assist with both the sustainability of ABCD III and spread of improvements in care coordination in Illinois.

ENDNOTES

1 For more information about ABCD III please visit the National Academy for State Health Policy's (NASHP), "About ABCD III" page: <http://nashp.org/abcd-history>.

2 C. Hanlon and J. Rosenthal, *Improving Care Coordination and Service Linkages to Support Healthy Child Development: Early Lessons from a Five-State Consortium*. (Portland, ME: The National Academy for State Health Policy, June 2011). Available: <http://nashp.org/publication/improving-care-coordination-and-service-linkages>.

3 For more information about IHB2 please visit the Illinois Chapter American Academy of Pediatrics website: <http://illinoisAAP.org/> or contact Juanona Brewster, Director Early Childhood Development Initiatives at ICAAP (jbrewster@illinoisAAP.com)

4 Hanlon and Rosenthal, *Improving Care Coordination and Service Linkages*, pg. 33.

5 BMCHP Draft date 5/11/2011, Revised 7/1/2011.

6 To view the *Illinois Early Intervention Referral Form* and the *Illinois Early Intervention Program, Child and Family Connections Referral Follow-Up Form* please visit: <http://www.nashp.org/abcd-state/illinois>.

7 Illinois Department of Human Services, "Cornerstone." State of Illinois. Accessed July 29, 2011. Available: <http://www.dhs.state.il.us/page.aspx?item=32215>.

8 Illinois Department of Children and Family Services, "Statewide Provider Database: Connecting Caseworkers and Community Partners to Service Providers," *Statewide Provider Database Brochure*, State of Illinois, November 2009. Available: <http://www.state.il.us/dcf/library/index.shtml>.

9 K. Johnson, J. Rosenthal, *Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States*. (Portland, ME: The National Academy for State Health Policy, April 2009) pg. 11. Available: <http://nashp.org/publication/improving-care-coordination-case-management-and-linkages-service-young-children>.

10 J. Doetsch, "Illinois Healthy Beginnings II: Building Information-Sharing Systems." Presentation, *From Medical Homes to Neighborhoods: Using Community Health Teams and Networks to Improve Patient Care; A Joint NASHP ABCD III Learning Collaborative/Homes to Neighborhood Learning Community Meeting*, from Burlington, VT, July 19, 2011.

11 K. Johnson, J. Rosenthal, *Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States*. (Portland, ME: The National Academy for State Health Policy, April 2009) pg. 9. Available: <http://nashp.org/publication/improving-care-coordination-case-management-and-linkages-service-young-children>.

12 Bureau of Maternal and Child Health Promotion, "ABCD III, Illinois Healthy Beginnings II Pilot Project: Improving Medical Home and Early Intervention Referral and Feedback Communication Loop." Illinois Department of Healthcare and Family Services, State of Illinois: July 1, 2011: pg. 3.

13 Figure comes from the Bureau of Maternal and Child Health Promotion, "ABCD III, Illinois Healthy Beginnings II Pilot Project: Improving Medical Home and Early Intervention Referral and Feedback Communication Loop." pg. 3.

14 State of Illinois, *Public Act 096-1501*, January 2011. Available: http://hfs.illinois.gov/assets/096_1501cc.pdf.

15 *Ibid.*

16 Hanlon and Rosenthal, *Improving Care Coordination and Service Linkages*, pg. 22.

NATIONAL ACADEMY for STATE HEALTH POLICY

About the National Academy for State Health Policy:

The National Academy for State Health Policy (NASHP) is an independent academy of state health policy makers working together to identify emerging issues, develop policy solutions, and improve state health policy and practice. As a non-profit, non-partisan organization dedicated to helping states achieve excellence in health policy and practice, NASHP provides a forum on critical health issues across branches and agencies of state government. NASHP resources are available at: www.nashp.org.

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