NATIONAL ACADEMY for STATE HEALTH POLICY

MEASURING AND IMPROVING CARE COORDINATION: LESSONS FROM ABCD III

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EXECUTIVE SUMMARY

systems of care, care coordination has become a key area of focus. Through the Assuring Better Child Health and Development (ABCD) III initiative, Arkansas, Illinois, Minnesota, Oklahoma and Oregon piloted and evaluated strategies to improve care coordination among primary care providers (PCPs) and community service providers serving Medicaid-eligible children, aged birth to three with or at risk of developmental delays. ABCD III focused specifically on improving referral and follow-up communication between PCPs and Part C Early Intervention (EI) providers. Through community pilots, states explored ways to pay for care coordination (e.g., via medical homes), to facilitate systematic communication (e.g., via standardized forms, data sharing agreements, and privacy policies), and to support and sustain coordination across systems (e.g., via structured quality improvement projects and electronic data systems that automate measurement). This report describes their evaluation methods, summarizes the results, and highlights lessons learned from their experiences evaluating care coordination.

Pediatric care coordination is patient- and family-centered, team-based, and assessment-driven activity designed to meet the needs of children.² Coordinated care, one of the seven principles of the patient-centered medical home (PCMH) approach to comprehensive primary care, is the organization of a patient's care across all health care settings and the community to ensure indicated care is delivered in a timely and culturally/linguistically appropriate manner. A number of initiatives across the country, including Medicaid PCMHs, the Affordable Care Act's health home state plan amendment option, Children's Health Insurance Program Reauthorization Act demonstration grants, and the Center for Medicare and Medicaid Innovation's State Innovation Models initiative all provide opportunities and expectations for care coordination. However, none yet has a measure for care coordination across primary medical and non-medical settings.

The measurement field for care coordination is still new, particularly for care coordination between medical and community service providers, and for children. A 2012 NQF report noted "a lack of measures that truly evaluate transitions and communication between numerous settings" and "the need for cross-cutting measures as well as measures that incorporate community-level involvement and/or examine coordination for vulnerable populations." ABCD III states have taken important first steps towards addressing these gaps.

ABCD III states all agreed to use "closing the feedback loop" as a shared outcome of care coordination, but took individualized approaches to measuring it. Each state's project focused, at a minimum, on affecting the following points of the care delivery process: PCP referral to local community service provider after identification of patient risk via a screening; community service provider follow-up (with referral feedback) to referring PCP; and documentation of referral feedback in the PCP chart or by the PCP (a "closed loop"). Participating states also selected their own additional measures to assess related aspects of the care delivery process that facilitate care coordination for children with or at risk of developmental delays: developmental screening rates, EI referral rates, referral feedback format, length of time needed to close feedback loops, and experience of care.

At the close of the three-year ABCD III initiative, participating states improved their ability to measure referrals, feedback and care coordination, and despite some limitations to the data they could collect, some states saw an increase in closed loops. The states also collected evaluation lessons with implications for any state working to foster care coordination. Three ABCD III states (Minnesota, Oklahoma and Oregon) measured how quickly loops were closed, and the two with follow-up data saw improvement. Participating

states identified improvements in rates of developmental screening and EI referral, as well as stakeholder experience.

There are a number of implications for improving care coordination between primary care and other community-based service providers:

- Information once unknowable can now be tracked.
- ABCD III interventions, including structured quality improvement protocols, peer learning, and community engagement, resulted in measurable change.
- Multi-method approaches and qualitative methods enriched evaluation.
- States effectively engaged providers and systems of care.
- Incentives facilitated evaluation.
- Electronic tracking enhanced both the intervention and the evaluation.
- Additional attention is needed to ensure that EHR adoption supports, rather than hinders, quality improvement.
- State policy can facilitate evaluation and is critical to sustainability.
- ABCD III is the tip of the evaluation iceberg.

Through ABCD III, Arkansas, Illinois, Minnesota, Oklahoma and Oregon assessed the progress and impact of piloted interventions implemented to improve care coordination for young, Medicaid-eligible children with or at risk of developmental delays. The states' experiences highlight the challenges of measuring care processes that rely on different agencies and programs. Yet their evaluation efforts also point to strategies that facilitate measurement of closed feedback loops. Given the array of federal and state initiatives designed and expected to improve care coordination, the five ABCD III states' efforts provide an important starting point for understanding how to measure one important facet of care coordination across primary care medical and community settings.

Introduction

s states and providers work to move away from siloed health care systems and toward integrated systems of care, care coordination has become a key area of focus. Through the Assuring Better Child Health and Development (ABCD) III initiative, five states tested strategies to improve care coordination among primary care providers (PCPs) and community service providers serving young children and their families.⁴ As part of their projects, they also tested methods for evaluating the impact of their improvement efforts. This report describes their evaluation methods, summarizes the results, and highlights lessons learned from Arkansas, Illinois, Minnesota, Oklahoma and Oregon's experiences evaluating care coordination.

After providing a brief overview of the ABCD III project, this report describes the current landscape of care coordination and measurement, noting that while there are many efforts to coordinate care, much less progress has been made in measuring whether or not (and how well) providers coordinate care. The report then outlines the approaches the five ABCD III states have taken to measure care coordination and related measures, including how they all have emphasized "closing the feedback loop" as a defining feature of a system that coordinates between primary care and community services. After discussion of additional, complementary measures selected by ABCD III states, the report describes how states measured closed feedback loops and other aspects of care that facilitate care coordination. Then, after summarizing states' evaluation results, the report concludes with lessons for measuring care coordination and implications for improving care coordination between primary care and other community-based service providers, particularly for children with or at risk of developmental delay.

BACKGROUND

his section describes the ABCD III project, outlining project goals and the improvement strategies implemented by participating states. It also provides an overview of what care coordination is, how state and federal initiatives seek to improve care coordination, and what efforts are underway to measure care coordination.

ABCD III: A Focus on Care Coordination for Young Children

Through the three-year ABCD III project, five states sought to improve care coordination between PCPs and community service providers of Medicaid-eligible children, aged birth to three, who were identified via screening as having potential developmental delay. Community service providers refer primarily to Part C Early Intervention (EI) providers, but also include providers of mental health, home visiting, family support, physical or speech therapy services. With support from The Commonwealth Fund, participating states targeted improvements at the practice, community, and state levels. Their improvement strategies encompassed four main approaches:

- Identifying personnel to assure effective linkages among providers (e.g., via community-based staff, medical homes);
- Developing quality initiatives to engage providers in assuring, improving, and monitoring referrals and follow up information (e.g., performance measurement);
- Creating common referral forms and data linkages across care systems; and
- Monitoring and improving individualized care plans and cross systems planning (e.g., via Part C Early Intervention Individual Family Service Plans.⁵

ABCD III focused specifically on referral and follow-up communication between PCPs and EI providers. Every state has an EI program administered by a state agency, authorized and funded by the federal government, and guided by both state and federal policies. EI programs provide children with in-depth evaluation and assessment and (if eligible) intervention for developmental disabilities and delays, development of service plans, and coordination of health and social services. PCPs are a regular source of care for young children, and PCPs increasingly screen for and identify developmental delays among young children. Young children who are identified as having disabilities or delays must be referred for further assessment and, if indicated, services or intervention by EI. Improving communication and care coordination between PCPs and EI providers, who are key members of the care team for children with potential developmental delays, is an opportunity to help children and their families access needed services in a timely manner and support healthy child development.

As with previous ABCD initiatives, one of the ABCD III selection criteria was a commitment to work with the National Academy for State Health Policy (NASHP), administrator of the project, throughout the grant period to refine and implement an evaluation plan. ABCD has required states to evaluate their projects as a mechanism for documenting progress, which can help sustain and spread efforts post grant funding. Selected states agreed to collectively identify and use at least one measure to assess project impact. The overarching ABCD III project goals were to identify a variety of state approaches for improving and measuring care coordination for children with or at risk of developmental delays and highlight promising practices and challenges for the benefit of others. The purpose of sharing states' evaluation findings is to present workable options and lessons, not to compare state performance.

Table 1: Overview of ABCD III Improvement Strategies, By State

	State				
Strategy	Arkansas	Illinois	Minnesota	Oklahoma	Oregon
Developed Consistent Tools and Processes		,			
Referral and feedback form(s)	1	1	1	1	1
Referral tracking document or spreadsheet		1	1		
Individual Family Service Plan (IFSP) and/or Part C Early Intervention (EI) evaluation	1	1		1	/
summary form(s) or report(s)					
Statewide referral processes	/	/			/
Provider and/or community toolkit	/	/	/	1	
Incentivized Primary Care Providers (PCPs)	<u> </u>	1		Γ	
Maintenance of Certification (MOC) credit		1	1		
Assistance in seeking medical home certification		1	1	1	1
Recognition status to leaders	1				
Stipend			1		
Medicaid managed care organization incentive pool measure (developmental screening)					1
Implemented Continuous Quality Improvement					
Process mapping	1		1	1	
Medicaid managed care Performance Improvement Project (PIP)					1
Community-tailored referral protocols			1	1	
PCP training and support in Plan-Do-Study-Act rapid cycle change		1	1	1	1
On-site practice coaching		1	1	1	
Managed care organization training and support					1
Learning collaboratives			1	1	1
Performance feedback	1	1	1	1	1
Enhanced Existing or Built New Data Systems					-
Web-based referral tracking and communication system				1	
New EI data system fields or features			1		1
Integration of EI service data into medical home provider patient rosters (pending)		1			
Provision of data about EI services received to Medicaid managed care organizations					1
New data sharing between EI and Medicaid programs					1
Engaged Communities					
Local, multi-sector pilot teams of providers and programs	1	1	1	1	1
State team of cross-sector agencies, programs, and organizations	1	1	1	1	1
Community meetings	1		1		1
Integrated Activities and/or Lessons into State Reform Initiatives					
Medical home	1	1	1	1	1
Accountable care entities (Coordinated Care Organizations)					1
Wraparound support to medical home (Health Access Networks)				1	
Early learning system transformation			1		1

As detailed in other NASHP publications, ABCD III states pursued a variety of strategies to improve care coordination for Medicaid-eligible children with or at risk of developmental delays.⁷ The states selected communities to participate in pilots, and then served as conveners of PCPs, other providers and partners in each community, helping them identify, implement, and evaluate improvement strategies.⁸ Through the community pilots, states explored ways to pay for care coordination (e.g., via medical homes), to facilitate systematic communication (e.g., via standardized forms, data sharing agreements, and privacy policies), and to support and sustain coordination across systems (e.g., via structured quality improvement projects and electronic data systems that automate measurement).⁹ Table 1 (previous page) briefly outlines the improvement strategies each ABCD III state pursued.

THE CURRENT LANDSCAPE OF CARE COORDINATION AND MEASUREMENT

To set the broader context for ABCD III states' evaluative activities, this section briefly describes what care coordination is, its role in current health care delivery reform initiatives across the country, and the state of care coordination measurement.

Care Coordination Defined

There are numerous definitions for care coordination; pediatric care coordination has been defined as a patient- and family-centered, team-based, and assessment-driven activity designed to meet the needs of children. One of the seven principles of the patient-centered medical home (PCMH), an approach to comprehensive primary care, is coordinated care, described generally as the organization of a patient's care across all health care settings and the (non-medical) community to ensure indicated care is delivered in a timely and culturally/linguistically appropriate manner. Communication among providers serving a patient is key to effective care coordination.

Care Coordination in Delivery Reform Initiatives

Nearly all states are advancing the PCMH within their Medicaid programs¹² as one of several state delivery reform initiatives that rely upon or seek to promote care coordination. The PCMH supports care coordination and team-based care in part through enhanced payment.¹³ States also are taking advantage of the Affordable Care Act's health home state plan amendment option, which provides matching funds for services that promote care coordination for Medicaid beneficiaries with chronic conditions and includes an evaluation of states' efforts. 14 Through demonstration grants awarded as part of the Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 (P.L. 111-3), 18 states are working to improve child health quality, with most of the states implementing care coordination models. Early, broad lessons from the national evaluation of the grant program were published this year.¹⁵ Through the Center for Medicare and Medicaid Innovation (CMMI)'s State Innovation Models (SIM) initiative, states recently were awarded grants to transform their health care delivery systems by integrating community health into multipayer models. 16 Not surprisingly, care coordination is explicitly referenced in each of the selected testing states' applications.¹⁷ Through SIM, Arkansas, for example, will promote team-based care coordination and provide per-member per-month payment for care coordination.¹⁸ States also participate in several CMMIled accountable care organization (ACO) programs designed to improve care quality and value while reducing costs by coordinating care for Medicare beneficiaries. 19 (Other accountable care-like initiatives are spreading in state Medicaid and CHIP programs as well.)²⁰ As a final example, CMMI's Comprehensive Primary Care Initiative focuses on strengthening primary care and provides resources and bonus payments to improve care coordination, particularly for Medicare patients. Primary care practices in four states and three regions were selected for this initiative, which includes other public and private insurers.²¹

Gaps in Care Coordination Measurement

In 2009, when ABCD III states began their measurement journeys, there were few resources available to measure care coordination across primary medical and non-medical settings. Today, in 2013, most, if not all, of the above health care delivery reform initiatives promoting and expecting care coordination include evaluation components, but none yet has a measure for care coordination across primary medical and non-medical settings. In the past few years, there has, however, been new activity related to measuring care coordination.

A 2011 blog post from The Commonwealth Fund highlighted how organizations such as the National Quality Forum (NQF), National Committee for Quality Assurance, and federal Agency for Healthcare Research and Quality (AHRQ) have created guidelines for evaluating care coordination.²² A 2012 NQF report referenced many of those resources and summarized findings from an environmental scan identifying 124 measures of care coordination:

"... [T]here is a lack of measures that truly evaluate transitions and communication between numerous settings...most were measures of patient experience and did not examine critical care coordination activities such as the establishment of accountability and the communication of critical information. The findings of the scan, though not surprising, highlighted the need for cross-cutting measures as well as measures that incorporate community-level involvement and/or examine coordination for vulnerable populations." 23

In the report, NQF endorsed a framework for care coordination measurement with five domains: healthcare home; proactive care plan and follow up; communication; information systems; and transitions.²⁴ NQF also endorsed 12 care coordination measures, which mostly relate to medication management and care transitions for acute/emergent care, home health care, or patients aged 65 or older, leaving primarily one relevant measure for children in primary care settings: "Medical Home System Survey." This composite measure is based on provider self-reported responses to the survey (Medical Home System Survey) that determines eligibility for NCQA patient-centered medical home program recognition. The survey assesses six domains of the patient-centered medical home, including communication and test and referral tracking.²⁶

Prior to NQF's report, the Affordable Care Act required the Secretary of the U.S. Department of Health and Human Services to create a National Strategy for Quality Improvement in Health Care to guide improvement and measurement of health and health care quality. One of the six initial priority areas of the National Quality Strategy is "promoting effective communication and coordination of care," and as of 2012, one of the two key measures identified for this priority area is the percentage of children needing care coordination who receive effective care coordination, 27 an item from the National Survey of Children's Health (NSCH). The 2007 NSCH found that 68.8 percent of children who needed it received effective care coordination services. This measure asks about children needing referrals for any doctor or service, problems getting needed referrals, family need for (and receipt of) help with coordinating a child's health care, and receipt of all needed extra help with care coordination. The National Quality Strategy will track improvement after developing an aspirational target for this and other key measures.

The National Quality Strategy priority areas will soon drive measurement in federally funded initiatives, such as the Medicare and Medicaid Electronic Health Record (EHR) Incentive Programs, established by the American Recovery and Reinvestment Act (ARRA) of 2009. The EHR Incentive Programs provide incentive payments to hospitals and health professionals for using certified EHR systems to improve care coordination and patient safety. Participants must report on a subset of clinical quality measures provided by the federal government. Beginning in 2014, eligible providers will need to select measures from at least

three of the six priority strategies outlined in the National Quality Strategy. One of the available measures for adults will be "closing the referral loop: receipt of specialist report," which refers to the "percentage of patients with referrals, regardless of age, for which the referring provider receives a report from the provider to whom the patient was referred."^{30,31,32} This measure also is a required measure for CMMI's aforementioned Comprehensive Primary Care Initiative.³³

In short, the measurement field for care coordination is still new, particularly for care coordination between medical and non-medical providers, and for children. As the next sections describe, ABCD III states have taken important first steps towards addressing some of the measurement gaps identified by NQF in 2012.

STATE-SELECTED CARE COORDINATION MEASURES

ith many aspects of the care delivery process potentially contributing to and affecting care coordination, ABCD III states could have selected any number of items to measure care coordination. However as noted above, when ABCD III states were beginning their projects, the absence of preferred, standardized care coordination measures, particularly for children and primary care settings put participating states in the position of innovatively identifying and developing their own measures to test. Experience from previous ABCD initiatives showed that there needs to be both a shared outcome measure across all participating states, as well as individualized, state-specific measures to assess project performance.³⁴ This section outlines the various items ABCD III states opted to measure to assess improvement in closing the feedback loop and other measures critical to coordinating care.

CLOSING THE FEEDBACK LOOP

Since the process of tracking referrals and care coordination across primary care medical and community service systems such as El is less straightforward than measuring a discrete service such as a developmental screen, ABCD III states agreed to measure "closing the feedback loop" as a shared outcome of care coordination, but took individualized approaches to measuring it, tailored to their projects. Each participating state's project focused, at a minimum, on affecting the following points of the care delivery process:

- PCP referral to local community service provider after identification of patient risk via a screening;
- Community service provider follow up (with referral feedback) to referring PCP; and
- Documentation of referral feedback in the PCP chart or by the PCP (a "closed loop.")

States engaged both PCPs and community service providers (primarily Part C Early Intervention) as part of ABCD III, but the primary audience for intensive, hands-on assistance and support was primary care medical providers and staff. (ABCD has historically focused on PCPs because they are the primary source of care for young children). For this reason, the states agreed to the following common outcome to serve as their shared proxy for care coordination: a closed feedback loop (via PCP receipt of EI referral feedback). As Table 2 shows, each state defined this common outcome slightly differently, tailoring it to fit interventions (noted in Table 1) and data collection capabilities. All states' projects focused on Medicaid-eligible children birth to age three, however, as noted in Table 2, only two states defined the age range in their measures. The value of states having taken a variety of approaches is that there are richer, more diverse experiences to share.

Table 2: ABCD III Common Outcome: Closed Feedback Loops between PCPs and EI

5		Common Outcome Specification (N-Numerator; D-Denominator)			
State					
Arkansas	N:	Number of Medicaid/CHIP children referred for developmental services whose PCP knows			
		the results of the referral			
	D:	Number of Medicaid/CHIP children referred for follow-up by the PCP for developmental			
services					
Illinois	N:	Number of referrals EI responded to by using referral fax-back form sent to referring			
		medical home			
	D:	For children with positive developmental screens, the number of referrals made to El			
		during the Maintenance of Certification,	Part 4* period		
Minnesota**		Baseline	Follow Up		
	N:	Number of children referred to EI,	Number of children ages 0-2 referred to El		
		whose medical provider received	for whom the eligibility status was known and		
		feedback from the EI agency	marked in the child's electronic medical record		
			at the referring clinic		
	D:	Number of children referred for EI	Number of children ages 0-2 referred to El		
		services			
Oklahoma	N:	Number of children less than 34 months	of age referred for EI services whose PCP knows		
		of the services received within 80 days			
	D:	D: Number of children kess than 34 months of age whose PCP referred for EI services more			
		than 80 days ago			
Oregon	N:	N: Number of children referred to EI, whose PCP received feedback from EI that was			
		incorporated into the chart			
	D: Number of children referred for follow-up by PCP for EI services				

^{*} Maintenance of Certification Part 4 is continuing education credit for PCPs toward maintaining board certification. See page 13 for more information.

OTHER MEASURES CRITICAL TO COORDINATING CARE

In addition to the common outcome (closed feedback loops between PCPs and EI), participating states used state-specific supplemental measures to assess related aspects of the care delivery process that facilitate care coordination for children with or at risk of developmental delays (See Table 3). States selected these additional measures based on their interventions, respective evaluation priorities and the type(s) of data readily available to state agencies and stakeholders. Two states (Illinois and Oregon) tracked developmental screening rates since the screen is most often the impetus for referral and communication between the PCP and EI provider. Four states (Illinois, Minnesota, Oklahoma and Oregon) measured the EI referral rate. Two states (Arkansas and Oregon) collected information about the format in which referral feedback was provided, and three states (Minnesota, Oklahoma and Oregon) assessed how long it took to close feedback loops. Additionally four states (Arkansas, Illinois, Minnesota and Oregon) assessed the experience of care for stakeholders ranging from providers to parents and families to managed care plans.

^{**}Minnesota adjusted its outcome measure midway through the project to more clearly track what the medical provider did with feedback information, rather than track only whether the information was received.

Table 3: ABCD III State-specific Measures

	Arkansas	Illinois	Minnesota	Oklahoma	Oregon
Rate of developmental screening among eligible children:					
State rate					1
Participating Managed Care Organization rate					1
Participating PCP rate		1			1
PCP referral rate to El		1	1		1
Receipt of El services			1	1	1
Format of referral feedback to PCP (e.g., evaluation report summary,	1				1
Individual Family Service Plan, specific form, notes, etc)					
Time needed to close the feedback loop:					
 Average number of days to close the feedback loop 				1	
Average number of days between referral and follow-up			1		1
communication					
Care experience:					
Parent/caregiver satisfaction			1		
Stakeholder experience	1	1	1		1

METHODS TO ASSESS PROGRESS AND IMPACT

articipating states used a mix of quantitative and qualitative methods to assess the progress and impact of their projects; details varied from state to state. This section shows the different ways states measured closed feedback loops as well as the supplemental measures they identified as critical to coordinating care: screening, referral, timeliness and experience of care.

Whenever states were able, they collected data at baseline and again after implementation of improvement strategies to assess any change. States collaborated with evaluation contractors or partners listed below:

- Arkansas Foundation for Medical Care;
- Chapin Hall (Illinois);
- Oregon Pediatric Improvement Partnership;
- University of Oklahoma Health Sciences Center; and
- Wilder Research (Minnesota).

The Oregon Pediatric Improvement Partnership served as the external quality review-like organization for Oregon's ABCD III performance improvement project (PIP), developed the evaluation tools and metrics implemented by participating managed care organizations (MCOs) and evaluated overall MCO performance on the ABCD III PIP.

As described in the following sections, states, in partnership with their evaluation partners, used chart review, claims data analysis, newly established data tracking tools, and stakeholder surveys, interviews and meetings to track progress.

Assessing "Closed Feedback Loops"

The states relied on two main methods—use of new data tracking tools or claims data analysis coupled with chart review—to measure the common outcome (closed feedback loops between PCPs and EI). In Illinois and Minnesota, PCPs documented closed loops via new data tracking tools (run charts and an Access database, respectively) created for ABCD III. Participating PCPs used these tools to document referrals made to EI and to indicate whether and/or when feedback was received from EI. In Minnesota, participating clinics monitored and reported screening, referral, care coordination and communication information in the Access database and submitted it to evaluators every six months. In Oklahoma, PCP offices checked a box in an electronic system acknowledging receipt of referral feedback for a child referred.35 Two states (Arkansas and Oregon) used Medicaid and/or El data to identify children for whom EI claims were submitted and whose charts should be randomly sampled to identify evidence of PCP receipt of El referral results. Oregon's project was under the rubric of a managed care organization (MCO) performance improvement project and had each participating MCO pull a sample of continuously enrolled children who turned 1, 2 or 3 years old in the last calendar year and who had a 9, 18 or 24 or 30 month well-child visit. Additionally, Oregon made modifications within its EI data system to allow tracking of whether EI reported feedback information to referring providers. In Arkansas, the state's Quality Improvement Organization developed a chart abstraction tool and led chart review.³⁶ In Oregon, the Oregon Pediatric Improvement Partnership (OPIP) developed the chart abstraction tool and guidance for collecting and submitting requested data; collection was timed to coincide with MCOs' Healthcare

Effectiveness Data and Information Set (HEDIS) data collection. Additionally, the State Medicaid agency provided a data file of children for whom Medicaid had been billed for EI services; MCOs then guided practices in examining those medical charts.

Types of Referral Feedback Indicating a Closed Feedback Loop

ABCD III states documented closed feedback loops if the following information was sent by EI to the referring PCP:

- **El eligibility information** indicating whether the child is eligible to receive any Part C services (eligibility guidelines vary by state).
- **El evaluation report** with all findings from an assessment of the child's needs, as well as identification of appropriate early intervention services to address the needs; and/or
- **El Evaluation report summary** with key elements from the evaluation report, such as specific tests and results and next steps needed;
- Individual Family Service Plan (IFSP) outlining the early intervention services a Part-C eligible child will receive and an action plan for the child's family and team of care providers (IFSP guidelines vary by state).
- IFSP summary form highlighting IFSP findings and clinically pertinent action plan items for PCPs; and/or
- Standardized referral feedback form (created by states during ABCD III), which PCPs used to
 initiate a referral and indicate desired feedback, and EI subsequently completed and returned to
 the referring PCP.

Chart reviewers in Arkansas and Oregon searched for evidence of receipt of the above information in sampled medical records, and primary medical care office staff in Illinois, Minnesota, and Oklahoma documented every referral made by a participating PCP with a standardized referral feedback form and receipt of above information back from EI.

All states promoted the use of standardized referral feedback forms as part of their ABCD III projects. Some states (IL, OK, OR) only counted closed loops towards their common outcome if the feedback was provided via a standardized feedback form. Both Arkansas and Oregon (through their chart review processes) tracked the type of referral feedback provided by EI.

Assessing Screening, Referral, and Timeliness

In addition to measuring referral feedback to PCPs, states gathered data for supplemental screening, referral, and timeliness measures to help in understanding, assessing, and facilitating care coordination. To measure developmental screening, Oregon used one of the 24 Medicaid/CHIP child core measures (proportion of children screened in the first three years of life), which the Medicaid agency voluntarily reports to CMS.³⁷ Oregon analyzed this data at the state-level and created a complementary measure of screening examining children who had a well-child visit at which screening was recommended, and then analyzed this information at the MCO level. Providers in Illinois and Minnesota logged the screenings and referrals they provided to children. Minnesota also tracked referrals made via its online EI referral system, which the state promoted throughout ABCD III.

Minnesota and Oklahoma used the new data tracking tools they created for ABCD III to assess timeliness via the length of time needed to close feedback loops. Oklahoma's electronic early childhood services

system automatically tracks the date of each referral and subsequent communication, which allowed the team to document the average number of days it took for each referral to be closed, which meant the PCP had clicked a box indicating review and receipt of the referral feedback or communication from El. Similarly, Minnesota used its Access database to assess the average number of days between clinic referral and follow-up communication from El. Oklahoma also used its electronic system to determine the percentage of referrals entered that were completed in 80 and 160 days. The Oklahoma team selected these ranges based on the fact that in most cases, El has 45 calendar days to complete its initial assessment/evaluation of a referred child.³⁸ Oklahoma wanted to provide a window of time that allowed for PCP review of feedback information received from El.

Assessing the Care Experience

ABCD III states undertook a variety of qualitative methods to capture and gauge the care experience of involved stakeholders ranging from parents and families to local EI staff. These qualitative strategies included Community Cafés, surveys, interviews, focus groups and community meetings.

To engage parents and families of children with developmental delays, both Arkansas and Oregon used Community Cafés, structured, small group conversations hosted by trained leaders in which participants discuss issues that are important to them to establish relationships and identify areas in need of change.³⁹ The Cafés provided a forum for families to discuss their experiences in navigating the multiple programs involved in serving their children. Oregon conducted one Café with Spanish-speaking families. Minnesota conducted two rounds of telephone interviews with a random sample of parents from each participating clinic whose children received a developmental screening.

To assess provider experience, states used surveys, interviews and focus groups. Minnesota introduced a PCP survey to assess medical provider experience. Arkansas convened a focus group of EI providers and two focus group sessions with members of community teams who help children ages 0-5 with disabilities and their families access a range of services, from child care, Head Start, and family support to early childhood special education. Illinois and Oregon conducted interviews and surveys with an array of stakeholders, including medical and non-medical providers, to help identify system challenges and potential solutions.

Oregon's multi-pronged community engagement process included community meetings of stakeholders including medical providers, MCO staff, parents, El providers, and home visiting nurses to identify challenges and inform the development of the state's ABCD III Medicaid performance improvement project.

RESULTS

t the close of the three-year ABCD III initiative, participating states improved their ability to measure referrals, feedback and care coordination, and some experienced improvement. They also collected evaluation lessons with implications for any state working to foster care coordination. This section describes ABCD III evaluation findings—improved measurement of communication and closed feedback loops, feedback loops closed more quickly, and improved screening, referral and experiences of care—and summarizes ABCD III state, community, and practice-level lessons about the measurement experience.

IMPROVED MEASUREMENT OF COMMUNICATION AND CLOSED FEEDBACK LOOPS

There were some limitations to the common outcome data ABCD III states could collect, but overall, all states improved their measurement of closed feedback loops and some states saw an increase in closed loops. At the beginning of ABCD III, two states did not have a mechanism to track referral feedback information (Illinois and Oklahoma) and one state (Oregon) was unable to assess the information until midway through the project. As a result, the baseline common outcome for these three states are "missing." The other two states initially had moderate rates of referral feedback: 53 percent in Arkansas and 63.6 percent in Minnesota. Since states simultaneously planned improvement interventions and evaluation, it is possible early outreach and support to stakeholders affected baseline rates in Arkansas and Minnesota. (Oregon captured a comparable referral feedback rate of 60 percent midway through its project). At follow-up one to two years later, rates were: 66 percent in Illinois, 68.3 percent in Minnesota, 78 percent in Oklahoma, and 88 percent in Arkansas, indicating increased communication between PCPs and EI providers in at least Arkansas. Table 4 summarizes ABCD III states' data for closed loops. As previously indicated, Minnesota refined its method of measuring referral feedback so its baseline and follow-up indicators differ slightly.

Table 4: Results for Closed Loops

		Rate of Closed Feedback Loops			
		(Percent of referrals where PCP Received Referral Feedback or Knew of Referral Results)			
State	Number of Primary Care Practices				
State	or MCOs Represented in Findings	Baseline	Mid-	Follow-up	
		(Numerator/	Project*	(Numerator/	
		Denominator)		Denominator)	
Arkansas	7 practices (27 PCPs)	53 percent		88 percent	
	in 5 counties	(76/143)		(167/189)	
Illinois	18 practices (23 PCPs)	Missing		66 percent	
	in 6 counties			(55/83)	
Minnesota**	10 practices (10 PCPs)	63.6 percent	68.3 percer		
	in 4 counties	(49/77)		(97/142)	
Oklahoma	8 practices (22 PCPs)	Missing		78 percent	
	in 4 counties			(288/364)	
Oregon	8 MCOs (contracting with □70	Missing	60 percent	In process for	
	practices) covering 15 counties		(76/127)	select MCOs	

^{*}Oregon is the only state that collected and reported mid-project data.

^{**}Specification changed from baseline to follow up.

CLOSING THE LOOP MORE QUICKLY

Timely identification of needs and provision of services are critical for children because their brains develop very quickly in the first five years of life. ⁴⁰ Research is not yet available to demonstrate whether closing a feedback loop more quickly affects child health outcomes, but ABCD III states assumed an increase in timeliness would correlate with more timely provision of services, and therefore be beneficial for children and families. Three ABCD III states (Minnesota, Oklahoma and Oregon) measured how quickly feedback loops were closed, and the two with follow-up data saw improvement (see Table 5).

In the first six months of electronic data tracking in Oklahoma, it took an average of 85 days for the feedback loop to be completed—from initial referral by the PCP to EI to review of EI feedback by the referring provider. In the last 10 months of the project, it only took an average of 51 days, representing a decrease of 34 days in the time it took to complete referral feedback. Minnesota also saw a decrease in the average number of days between clinic referral and follow-up communication from EI services, from an average across sites of 153 days at baseline to an average of 56 days across the sites at follow up. This represents a decrease of 97 days.

Oklahoma found that its data were most accurate when collected/analyzed in a way that assured sufficient time had passed for it to be reasonable to expect a feedback loop to be closed. For example, if a referral just occurred yesterday, it would be misleading to count it as "not completed" if referral feedback had not been sent, received, and noted in the chart today. For this reason, they tracked feedback for referrals within a set number of days. Oklahoma compared the percent of referrals completed within 80 and 160 days during the first six months and last 10 months of data collection, and saw improvement in both measures. For the first six months of data collection in Oklahoma, 43 percent of referrals were completed within 80 days and 79 percent within 160 days. In Oklahoma's last 10 months of data collection, 73 percent were completed within 80 days and 98 percent completed within 160 days.

IMPROVED IDENTIFICATION, REFERRAL, AND CARE EXPERIENCES

A benefit of ABCD III state support to practices and communities was improvement in the related components of the care process. Each state found that improving care coordination relied upon practices and communities implementing changes in protocols and processes beginning with screening and going all the way through documentation of referral feedback. As a result, participating states identified improvements in rates of developmental screening and EI referral, as well as stakeholder experience.

- **Screening.** In Oregon the proportion of children screened for developmental delay in the first three years of life increased from 9.6 percent to 19.6 percent. Overall in Illinois, 86 percent of (or 112 of 131) 9-, 12-, and 18-month old children seen by participating physicians during the pilot period received a developmental screening.
- Referral and receipt of El services. There was a 100 percent referral rate among participating PCPs in Illinois; all 83 children with a positive screen were referred to El. Across participating plans in Oregon, there was an average referral rate of 30 percent for children identified with risk. Over the course of Oregon's project, El reported increases in the number of referrals from providers in counties in which the MCO efforts were more intense. Participating providers in Minnesota made a total of 180 referrals to El, for which the majority (81 percent) were children found to be eligible for El. As a result, the state increased the number of children receiving El services. The Department of Education was able to attribute an overall increase in PCP referrals through the state's online El system partly to ABCD III. A school district in one participating county increased the number of children served by El by 44 percent over the three years of the project.

Table 5: Results for Time Needed to Close the Loop

State	Measure	Baseline	Follow up
Minnesota	Average number of days between PCP referral and EI referral feedback for children ages 0-2 (all sites)*	147 days	56 days
	Site A	139 days	53 days
M: Ei	Site B	203 days	51 days
	Site C	98 days	63 days
*	Average number of days for the feedback loop to be completed	85 days	51 days
Oklahoma**	Feedback loop completed in 80 days or less	43 percent of the time	73 percent of the time
ð	Feedback loop completed in 160 days or less	79 percent of the time	98 percent of the time
	Of those who received a report back from EI, average number of days between PCP referral and EI referral feedback	133 days	n/a***
	Of those for whom the feedback loop is completed, percent completed in 80 days or less	61 percent	n/a***
L C	Of those with a referral, percent completed in 80 days or less	32 percent	n/a***
Oregon	Of those for whom the feedback loop is completed, percent completed in 160 days or less	74 percent	n/a***
	Of those with a referral, percent completed in 160 days or less	38 percent	n/a***
	Of those with a referral, percent with some type of information back	52 percent	n/a***

^{*}Wilder Research did not calculate baseline and follow up averages for Minnesota's fourth site due to insufficient data. The average for all sites includes the three sites listed.

Care experience. In Minnesota, a slightly higher percentage of parents in 2012 reported that
they were "very satisfied" with how their child's provider handled screening than in 2011 (83
percent compared to 80 percent). Similarly, the percent of parents reporting that the PCP or
office staff provided advice or plans for next steps following a screening went from 65 percent in
2011 to 71 percent in 2012.

The four states that conducted Community Cafés, focus groups and community meetings to gather stakeholder feedback did not repeat them to assess changes in perception; rather, the feedback informed development of state projects to ensure attention to stakeholders', particularly families', needs and priorities. Oregon leveraged community engagement findings to sustain project momentum, continuously reminding stakeholders of parents' and others' feedback. The information also guided states' strategies for spreading improvement strategies to new communities. For example,

^{**}For these measures in Oklahoma, "baseline" refers to the period from which data could be tracked, which was post-introduction of the web-based referral system.

^{***}Data not available. Oregon conducted chart reviews mid-project and was not able to collect follow up data during the project.

Arkansas team members learned that mothers and grandmothers are the major source of child development information yet they were not aware of Part C EI services.

LESSONS ABOUT THE MEASUREMENT PROCESS

Understandably, ABCD III states encountered challenges with collecting data for their common outcome and supplemental measures, but as they tested evaluation methods and models for care coordination, they learned important lessons about the measurement process.

- States likely need to develop a mechanism to track closed feedback loops. Early on, it became clear that collecting baseline data about referral feedback from EI (non-medical) providers to primary care medical providers would be a complicated, if not impossible, task for states given there are not specific claims that are tied to referral, and the services that are being referred are outside of the traditional health system and health databases. None of the states had a statewide or local mechanism in place to track feedback loops. There was no way to definitively or globally identify referrals (much less PCP referrals) using Medicaid claims data, and states' EI system data did not include reliable information on referral sources. Two states opted to identify populations for the common outcome based on EI service claims (Arkansas and Oregon) and/or MCO data about well-child visits (Oregon), which enabled them to identify children who could or should have received screenings and referrals. MCOs in Oregon had no reliable, valid data from which to sample children who were receiving EI, and therefore could not tell which children were receiving EI services. All participating states—those with and without chart review or suitable claims data to assess referral feedback—found it necessary to introduce new paper or electronic systems and/or augment existing data systems to enable tracking.
- Chart reviews and claims data are imperfect yet provide important information. Only a few of the states had the resources to conduct chart reviews, which require extensive time and labor, and those states that were able had to time the reviews in such a way as to reduce provider burden. For this reason, during the course of this project Oregon was only able to complete one round of chart reviews, and did so midway through the project. However, Oregon has included developmental screening as part of its required performance measures for its MCOs, which provides opportunities for future medical chart reviews to be conducted as part of external quality review activities. States found charts to contain more accurate and meaningful data than claims data for the topic of referral and feedback from community-based providers. States also identified several limitations of claims data. Providers can wait for up to one year to bill for services, creating a time lag. PCP confusion remains about billing for developmental screening (using CPT code 96110), there is a lack of incentive to bill for a 96110 in a capitated environment, and some PCPs do not bill because private insurers do not cover the service. Despite these flaws, states found claims and charts to contain critical, complementary clues to understanding the care process.
- Valid measurement relies on use of standardized referral tools, community provider communication to PCPs regardless of referral source, and verification of family follow through. Through chart reviews, Oregon identified instances of referral feedback but no evidence of referral. Part of the reason for this is that some local El contractors in the state are inquiring about the child's PCP and sending information about El services received, regardless of whether the child was referred to El by their PCP. Secondly, through community engagement it was found that some providers do not use the common referral form or indicate at the time of referral that they would like to receive feedback from El. Additionally, some states assumed that each family

acted upon a referral, but they had no way to verify it. As a result, the common outcome data might underestimate closed loops by counting referrals in which the family never went to El, and for which El could not have provided feedback. Oklahoma was able to track this information through its electronic referral feedback system, which included family support providers who could follow up with families.

- Providers can only be held accountable for that which they can control. Some states provided participating PCPs with continuing education credit toward maintaining board certification (specifically Maintenance of Certification Part 4 or MOC4) for ABCD III care coordination efforts.⁴¹ To meet MOC4 standards, physicians must continuously seek to improve an outcome or process (and measure it), which requires physicians to be able to influence the outcome being measured. In the case of ABCD III, PCPs needed to be able to measure the extent of referral feedback without being held accountable for another provider's behavior (e.g., return of a referral feedback form). As a result, Minnesota needed to ensure it explicitly tracked items within the PCP's control. Minnesota's measure for the common outcome originally assessed PCP receipt of feedback, but the state modified it to track PCP marking feedback in the child's record.
- EHRs need to be able to track referral feedback and guardian consent forms. Although intended to simplify office processes, electronic health records (EHRs) posed a challenge. None of the participating providers or clinics had an EHR with a sufficient way to track referral feedback, yet the new referral feedback forms states introduced in ABCD III were not compatible with EHRs. The forms require parent consent via signature, which means they can only be uploaded as PDF attachments and therefore are not searchable fields. In short, the attachments live in the EHR but are not fully integrated into the patient record.
- Providers who receive referrals must be engaged in improvement efforts with PCPs. Much of the practice-based support in ABCD III went to PCPs, however, EI staff and providers were important partners in returning forms or using shared data systems. States found that it was more difficult to get feedback from EI to the PCP than to increase referral to EI. One state (Minnesota) created a data-tracking tool explicitly for EI staff, but discontinued its use due to low participation. By engaging EI, local teams learned how ABCD III tools sometimes duplicated EI work. A local EI staff person might have to enter eligibility, evaluation and IFSP information into the EI system, and then enter it into a second system so it could be accessed by PCPs.
- Providers need support balancing intervention and evaluation efforts. As with most quality
 improvement efforts, participating staff and providers simultaneously implemented interventions
 and tracked those efforts to support evaluation. A couple of states found that participants
 needed assistance in balancing the two types of activities, noting that participants at times
 emphasized evaluation at the expense of intervention or vice versa. In order to reduce burden on
 participating stakeholders, states sometimes found it necessary to modify evaluation methods in a
 way that limited the amount or type of evaluative information they had (e.g., by reducing required
 fields in tracking tools).

IMPLICATIONS

Participating states used their evaluation data to: create clinic-specific screening, referral, and communication timeliness data summaries; identify suggestions for future enhancements to the project; relay progress and results to state agency leadership; and identify common system-level concerns that state agencies needed to address. There are a number of implications for improving care coordination between primary care and other community-based service providers:

- Information once unknowable can now be tracked. Half of the ABCD III states initially were
 unable to assess closed feedback loops because there was no mechanism to do so. By creating
 and implementing use of standard forms, privacy policies, databases and care coordination logs,
 all ABCD III states are now able to track referral feedback, which is critical to ongoing efforts to
 improve care coordination.
- ABCD III interventions, including structured quality improvement protocols, peer learning, and community engagement resulted in measurable change. States that tracked the length of time needed to close the loop found that it occurred more quickly at the end of the evaluation period compared to the beginning, which is critical for developmental issues but also important in any efforts to coordinate care. The findings suggest that ABCD III states' improvement strategies (learning collaboratives offering training in quality improvement processes and peer learning opportunities coupled with efforts to bring key community partners together) can improve care coordination for children.
- Multi-method approaches and qualitative methods enriched evaluation. All participating states used a mix of quantitative and qualitative methods to evaluate their projects, and states found qualitative strategies to be a powerful way to fill in gaps or better understand quantitative data as well as engage and motivate key stakeholders in quality improvement.
- States effectively engaged providers and systems of care.
 - At the practice-level, participating states successfully engaged primary care offices and systems in process improvements. ABCD III focused more intensively on PCPs than other (EI) providers and as a result states found that PCPs engaged more in ABCD III evaluation and improvement efforts. All providers needed quality improvement coaching, but PCPs were more familiar with rapid cycle improvement processes than were EI providers.
 - At the state level, El data were important to assess progress. ABCD III states identified
 ways to strengthen El data systems by adding fields for referral sources and automated
 responses for referring providers. Sharing El data, and by implication other data
 sources, with Medicaid and MCOs is a way to motivate and clarify expectations for care
 coordination.
- Incentives facilitated evaluation. The two states (Illinois and Minnesota) that provided board
 certification credit (MOC4) for PCPs participating in ABCD III fine-tuned their evaluation
 measures as part of the MOC4 approval process. The refinements helped in tracking PCP
 improvement processes as part of care coordination. MOC4 also provided additional motivation
 for board-certified PCPs to participate in evaluation activities.

- Electronic tracking enhanced both the intervention and the evaluation. The state (Oklahoma) with a shared electronic tracking system was able to collect and analyze a wealth of data much more quickly and easily than the other states. Through the tracking system, medical and community service providers could communicate in new ways, accessing the same, real-time patient information and exchanging electronic messages related to care. Illinois and Minnesota implemented electronic tracking tools that also facilitated data collection, however, each provider had to maintain its own tool rather than contribute to one shared tool, which made real-time (aggregate) data analysis impossible. Electronic systems are only as helpful as the data included in them though; in every state all El data except feedback information lived in a separate data system from the primary care data system. Analyzing data from the two systems still requires much work, which is why, as a result of ABCD III, Illinois is linking separate data systems to automate referral communication.⁴²
- Additional attention is needed to ensure that EHR adoption supports rather than hinders
 quality improvement. EHRs need a mechanism to track screening, referral and feedback for this
 population. None of the participating PCPs had an EHR that could adequately track referrals or
 referral feedback for children with or at risk of developmental delay. Screening and evaluation
 results could only be uploaded as attachments or be re-typed into free text or numeric fields.
- Measuring multiple aspects of the care process—screening, referral and closed feedback loops—enables prioritization of quality improvement efforts. Through their evaluation data, states could tell which aspects of the care process seemed to go better than others and which aspects could be the focus of future efforts. For example, Illinois had an 86 percent screening rate, a 100 percent referral rate to El and documented closed feedback loops for 66 percent of those referrals, indicating that future improvement efforts focusing on closing feedback loops would be most beneficial.
- State policy can facilitate evaluation and is critical to sustainability. Through their evaluation efforts, states identified areas where state policy (data sharing agreements, MCO contract language) could facilitate measurement of closed loops and care coordination. At least one state highlighted the importance of identifying opportunities to institutionalize interventions and evaluative efforts in broader delivery system reform so that improvement becomes a long-lasting goal and priority linked to state-level sustainability.
- ABCD III is the tip of the evaluation iceberg. Participating states' evaluations only begin to
 dive into questions of measuring care coordination between primary care medical and community
 service providers. For the most part ABCD III answers whether a part of care coordination
 occurred, but not whether health outcomes improved as a result. The latter is an important,
 even more difficult question to answer, particularly within a short timeframe. ABCD III states'
 experiences offer insights for moving forward.

Conclusion

Inrough ABCD III, Arkansas, Illinois, Minnesota, Oklahoma and Oregon's assessed the progress and impact of piloted interventions implemented to improve care coordination for young, Medicaideligible children with or at risk of developmental delays. The states' evaluation of referral and follow up communication between primary care medical and non-medical community providers (EI) highlight the challenges of measuring care processes that rely on different agencies and programs—a dearth of data and referral tracking tools, data silos, and providers with very diverse evaluation experience. Yet their evaluation efforts also point to strategies that facilitate measurement of closed feedback loops: date stamping of referral and subsequent communication to track timeliness; use of mixed methods such as chart review, claims data analysis, provider referral tracking tools, and family surveys, meetings or interviews; and, if possible, electronic, real-time tracking systems. In particular, ABCD III experience highlights the need for continued attention to EHRs to ensure they meet the developmental needs of children and, more generally, support referral tracking. With an array of initiatives—accountable care organizations, medical homes, health homes, and demonstrations for CHIP enrollees and other populations—designed and expected to improve care coordination, the five ABCD III states' efforts provide an important starting point for understanding how to measure one important facet of care coordination across primary care medical and community settings.

ENDNOTES

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- 36 Arkansas Foundation for Medical Care and Arkansas Department of Human Services, AR Links Program Evaluation Report (Little Rock, AR: 2012): 10.
- 37 As a result of CHIPRA, the federal government identified an initial set of children's health care quality measures that state Medicaid and CHIP programs voluntarily report. To learn more, see: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/CHIPRA-Initial-Core-Set-of-Childrens-Health-Care-Quality-Measures.html.
- 38 34 CFR §303.310
- 39 National Alliance of Children's Trust and Prevention Funds. "Effective Partnerships with Parents: Community Cafés." Retrieved May 23, 2013. http://www.ctfalliance.org/initiative_parents-2.htm.
- 40 National Research Council. From Neurons to Neighborhoods: The Science of Early Childhood Development. (Washington, DC: The National Academies Press, 2000): 5.
- 41 Mary Henderson, Maintenance of Certification: ABCD III State Efforts to Capitalize on an Incentive for Quality Improvement (Portland, ME: NASHP, 2012). http://www.nashp.org/publication/maintenance-certification-abcd-iii-state-efforts-capitalize-incentive-quality.
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