Improving Care Coordination and Service Linkages to Support Healthy Child Development: Early Lessons and Recommendations from a Five-State Consortium

by Carrie Hanlon and Jill Rosenthal

June 2011
Improving Care Coordination and Service Linkages to Support Healthy Child Development: Early Lessons and Recommendations from a Five-State Consortium

Copyright © 2011 National Academy for State Health Policy. For reprint permission, please contact NASHP at (207) 874-6524.

This publication is available on the web at: www.nashp.org

About the National Academy for State Health Policy

The National Academy for State Health Policy 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.

NASHP provides a forum for constructive, nonpartisan work across branches and agencies of state government on critical health issues facing states. We are a non-profit, nonpartisan, non-membership organization dedicated to helping states achieve excellence in health policy and practice.

To accomplish our mission we:

• Convene state leaders to solve problems and share solutions.
• Conduct policy analyses and research.
• Disseminate information on state policies and programs.
• Provide technical assistance to states.

The responsibility for health care and health care policy does not reside in a single state agency or department. NASHP provides a unique forum for productive interchange across all lines of authority, including executive offices and the legislative branch.

We work across a broad range of health policy topics including:

• Medicaid.
• Long-term and chronic care.
• Public health issues, including obesity.
• Quality and patient safety.
• Insurance coverage and cost containment.
• Children’s health insurance and access to comprehensive services.

NASHP’s strengths and capabilities include:

• Active participation by a large number of volunteer state officials.
• Developing consensus reports through active involvement in discussions among people with disparate political views.
• Planning and executing large and small conferences and meetings with substantial user input in defining the agenda.
• Distilling the literature in language useable and useful for practitioners.
• Identifying and describing emerging and promising practices.
• Developing leadership capacity within states by enabling communication within and across states.

For more information about NASHP and its work, visit www.nashp.org

Portland, Maine Office: Washington, DC Office:
10 Free Street, 2nd Floor 1233 20th Street, NW, Suite 303,
Portland, ME 04101 Washington, DC 20036
Phone: [207] 874-6524 Phone: [202] 903-0101
Table of Contents

Acknowledgements .......................................................................................................................... 1
Executive Summary ............................................................................................................................ 2
Introduction ....................................................................................................................................... 6
About ABCD III ................................................................................................................................. 6
Overview of ABCD III State Projects ............................................................................................... 8
Table 1: ABCD III States’ Policy and System Improvement Strategies to Support Improved Linkages ................................................................................................................................. 10
Key Early Lessons ............................................................................................................................. 13
Target Interventions at Multiple Levels ............................................................................................ 13
Develop Processes that will Enable Providers to Communicate Clearly, Consistently, and Easily 14
Table 2: Comparison of State Forms Being Piloted ......................................................................... 15
Use Quality Improvement Processes to Rigorously Test New Models ............................................. 18
Incorporate Formal Methods to Involve Parents and Families ............................................................ 19
Offer Incentives for Providers to Participate ....................................................................................... 20
Identify Untapped Data-Sharing Opportunities ................................................................................. 21
Incorporate Multiple Measurement Strategies During the Planning Phase .................................... 22
Build on Existing State Partnerships and Infrastructures ................................................................. 24
Create Synergy Across State Initiatives and Priorities ...................................................................... 25
Early Recommendations .................................................................................................................. 27
Conclusion .......................................................................................................................................... 29
Appendix A: Linkage and Care Coordination/Case Management (CC/CM) Strategies to Promote Coordination Between Medical Providers and Community Referral and Resource Agencies .................................................................................................................. 31
Appendix B: ABCD III State Profiles ................................................................................................. 32
Arkansas .............................................................................................................................................. 32
Illinois ................................................................................................................................................ 33
Minnesota .......................................................................................................................................... 34
Oklahoma .......................................................................................................................................... 35
Oregon ................................................................................................................................................. 36
Endnotes .............................................................................................................................................. 38
ACKNOWLEDGEMENTS

The authors are grateful to the ABCD III project team members in Arkansas, Illinois, Minnesota, Oklahoma and Oregon for tirelessly planning, conducting, and sharing the activities that formed the basis of this document. Team members also provided valuable feedback on an earlier draft of this document; they include:

- Martha Hiett, Angela Littrell, Sonja McKinley, Sheena Olson, and Peggy Starling of Arkansas;
- Scott Allen, Juanona Brewster, Julie Doetsch, and Deborah Saunders of Illinois;
- Susan Castellano, Ruth Danielzuk, Glenace Edwall, Meredith Martinez, and Catherine Wright of Minnesota;
- Terrie Fritz, Elaine Huckabay, Dr. Laura McQuinn, Pamela Newell, Sue Robertson, and Dr. Mark Wolraich of Oklahoma; and
- Katherine Bradley, Molly Emmons, Charles Gallia, Colleen Reuland, Bruce Sheppard, and Sarah Wetherson of Oregon.

We greatly appreciate the contributions of NASHP’s Larry Hinkle, who helped draft the state summaries and tables. Finally, we thank The Commonwealth Fund, particularly Dr. Ed Schor, Vice President for State Health Policy and Practices, for supporting and guiding the ABCD III initiative. Any errors or omissions are those of the authors.
EXECUTIVE SUMMARY

Families, service providers, and policy makers are increasingly attuned to childhood development and efforts to identify and ameliorate at an early age any developmental concerns such as delays in motor, intellectual or cognitive functioning, or language or socio-emotional development. To ensure that children and families receive necessary services in a timely manner, it is critical to forge linkages between siloed service providers. Improved coordination across providers and systems may create efficiencies by reducing delay or duplication in services and improve outcomes for children. The methods used to improve linkages and care coordination between pediatric providers and community resources for young children can improve outcomes and prove to be relevant for other populations.

Through the current Assuring Better Child Health and Development (ABCD III) learning collaborative, five states (Arkansas, Illinois, Minnesota, Oklahoma, and Oregon) are developing and testing models to improve coordination in their states and provide models for others. ABCD III launched in 2009 to help participating states identify, implement, test and spread policy and system changes that create and support efficient linkages between child health primary care providers (PCPs) and providers of child and family services needed to optimize child health and development (e.g., mental health, Early Intervention, early care and education programs such as Head Start, family support such as WIC, and specialty health services). Participating states are targeting policy improvements through four approaches: maximizing the use of personnel to assure effective linkages, undertaking quality initiatives that engage clinical practice settings and networks of providers and other mechanisms for assuring and monitoring quality related to referrals, improving data, information and technology (e.g., common referral forms and data linkages); and supporting individualized care plans and cross systems planning. Selected activities and interventions in the five participating states are summarized below.

OVERVIEW OF ABCD III STATE ACTIVITIES AND INTERVENTIONS

| AR | • Developed a learning collaborative to provide technical assistance to PCPs in four pilot communities through the state’s Quality Improvement Organization (QIO).  
• Working to promote medical homes through childcare programs.  
• Testing a “fax-back” referral form to enhance communication among providers.  
• Developing a quality award for PCPs who enhance linkages.  
• Using recently established “Early Intervention Liaisons” to promote linkages with primary care. |
|---|---|
| IL | • Using a learning collaborative model to support practices and community service providers in implementing pilot activities.  
• In strong partnership between Medicaid and the Illinois Chapter of the American Academy of Pediatrics, established standardized referral forms that will be piloted (e.g., referral form, referral feedback form, and Individualized Family Service Plan (IFSP) summary form).  
• Seeking to integrate service data from Early Intervention and other programs into the electronic patient rosters used for quality assurance by Medicaid medical home providers.  
• Planning to build on an existing database for human services programs to assist PCPs in identifying referral sources for children who are found not eligible for Early Intervention services. |
| MN | • Using a combined approach of learning collaboratives and in-office training to support PCPs and other service providers in implementing protocols for sharing information and closing the information loop with families.  
• Seeking to develop service agreements between child health care providers and other service providers and empower teams to pilot several versions of team-designed referral/faxback forms.  
• Encouraging use of statewide Early Intervention referral phone line and the Minnesota ParentsKnow website and online referral request for providers and families.  
• Some pilot sites are seeking Health Care Home certification, which supports firmly established care coordination process and services. |
|---|---|
| OK | • Supporting practice implementation of interventions through Practice Enhancement Assistants (PEAs).  
• Built a referral and feedback mechanism (child referral module, known as a “web portal”) onto an existing infrastructure, the Preventive Services Reminder System. The web portal will track all referrals and completed feedback loops.  
• Helped each pilot site establish a core team representing Early Intervention, Child Guidance (health department program), Sooner Success (University of Oklahoma care coordination program) and Oklahoma Family Resource Center.  
• Supporting each county team as it determines its response and triage system for referrals.  
• Care coordination findings are intended to inform the state’s patient-centered medical home delivery model for its Medicaid program. |
| OR | • Contracting with an External Quality Review Organization-like entity (EQRO), the Oregon Pediatric Improvement Partnership, to conduct a Performance Improvement Project (PIP) that will produce an improvement model that integrates care coordination with standardized screening and referrals at the clinical level with supporting payment systems and metrics.  
• With a forum of health agencies, managed care organizations, child health care providers, Early Intervention specialists, and family members, developed EQRO criteria that build on existing early childhood primary care improvements.  
• Working with the state’s Electronic Medical Records effort and partners in EI to ensure that data are more available and linkages exist for screening, referral and follow up.  
• Added Current Procedural Terminology (CPT) code 99366 to the Prioritized List of Health Services, which enables Medicaid reimbursement for Medical team conferences with face-to-face participation by three or more qualified professionals. |

**Early Lessons**
The ABCD III states are just now reaching the mid-way point of their projects; however, they have already discovered important lessons about improving service linkages.

- **Target interventions at multiple levels.** All five ABCD III states are working to improve service linkages and care coordination by making changes at the primary care practice, community, and state system levels.

- **Develop processes that will enable providers to communicate clearly, consistently, and easily.** The five states are developing and testing common referral and follow-up forms to create mechanisms for various child-serving providers to communicate referral outcomes easily and meet state and federal guidelines for patient privacy and confidentiality, while minimizing additional reporting burden.

- **Use quality improvement processes to rigorously test new models.** The ABCD III states identify areas in need of immediate or ongoing attention through quality improvement mechanisms at the state and local level.
• **Incorporate formal methods to involve parents and families.** The five states are including Community Cafés, family-serving organizations, and parent surveys to explore system challenges from the perspectives of families, solicit parent ideas and suggestions for improvement, incorporate parent feedback into pilot interventions or design interventions that directly involve parents and families and measure change in parent perspectives.

• **Offer incentives for providers to participate.** To help set the foundation for long-term sustainability and statewide spread of changes, participating states have identified incentives for primary care providers and other service providers to participate.

• **Identify untapped data-sharing opportunities.** Participating states are pursuing interagency agreements designed to reduce barriers to information sharing among providers and systems to provide a more complete picture of a child’s identified needs and the relevant services recently received. ABCD III states are finding that small efforts can lead to significant changes.

• **Incorporate multiple measurement strategies during the planning phase.** To collect information for a common outcome across states as well as state-specific add-on measures, the five states are using a mix of quantitative and qualitative methods. New tracking and feedback tools include a web portal, database, and Performance Improvement Project metrics.

• **Build on existing state partnerships and infrastructures.** In initial planning stages and selection of community pilot sites, all five states drew from the momentum and experience of existing state partnerships and infrastructures.

• **Create synergy across state initiatives and priorities.** To expedite change processes and set the stage for sustained statewide spread of interventions, the five states are strategically integrating ABCD III into state initiatives with complementary objectives. These include medical or health home initiatives and opportunities created through national health care reform and other federal initiatives.

**Early Recommendations**

Several early recommendations emerge from ABCD III states’ experiences to date implementing interventions in pilot communities to facilitate service linkages and care coordination among diverse child-serving providers and programs.

• **Start with improving communication between primary care and Early Intervention programs.**

• **Consider models for automated data integration to encourage care coordination that is not dependent on phone- or email-based communications.**

• **Consistently support and reinforce the importance of standardized screening by primary care practices.**

• **Solicit and use stakeholder feedback to help determine what terms to use in common or template forms.**

• **Borrow from existing state templates.**

• **Consider pursuing Maintenance of Certification (MOC) for PCPs for care coordination.**

• **Relate project goals and system improvements for care coordination to existing state and federal mandates.**
• Take advantage of medical home, health information exchange, and health care reform initiatives.
• Know that paying for and implementing changes is possible in spite of limited resources.

Through their activities to date engaging families, creating and testing new provider communication tools, facilitating data sharing, and conducting baseline measurement, participating states are developing resources that are useful in broad efforts to engage multi-sector leaders and stakeholders, improve state policy, transform primary care practice, and improve population health. The ABCD III initiative creates synergy with many other state priorities. It provides an opportunity for states to draw attention to the particular needs of children in care coordination, and at the same time develop insights about coordinating care between medical and non-medical providers, which will have broad implications for other populations as important health reform and measurement initiatives roll out.
EARLY CHILDHOOD HEALTH AND DEVELOPMENT ARE CONNECTED TO SCHOOL READINESS AND EARLY SUCCESS IN SCHOOL. RESEARCH SUGGESTS THAT EARLY INTERVENTION AND PREVENTIVE SERVICES THAT SUPPORT HEALTHY CHILD DEVELOPMENT COST SUBSTANTIALLY LESS THAN LONG-TERM SPECIAL EDUCATION AND TREATMENT. FAMILIES, SERVICE PROVIDERS, AND POLICY MAKERS ARE INCREASINGLY ATTUNED TO CHILDHOOD DEVELOPMENT AND EFFORTS TO IDENTIFY AND AMELIORATE AT AN EARLY AGE ANY DEVELOPMENTAL CONCERNS SUCH AS DELAYS IN MOTOR, INTELLECTUAL OR COGNITIVE FUNCTIONING, OR LANGUAGE OR SOCIO-EMOTIONAL DEVELOPMENT.

RESEARCH ENCOURAGES THE USE OF DEVELOPMENTAL SCREENING TOOLS IN PEDIATRIC PRIMARY HEALTH CARE SETTINGS TO INCREASE IDENTIFICATION BY PROVIDERS IN THESE SETTINGS OF CHILDREN IN NEED OF FURTHER ASSESSMENT AND SERVICES FOR DEVELOPMENTAL DELAYS. ASSESSMENT AND EFFECTIVE INTERVENTIONS FOR DEVELOPMENTAL DELAYS USUALLY INVOLVE MULTIPLE PROVIDERS OR SYSTEMS OF CARE, SUCH AS PEDIATRIC PRIMARY HEALTH CARE, EARLY INTERVENTION, AND EARLY EDUCATION SERVICES. UNFORTUNATELY, YOUNG CHILDREN OFTEN FALL THROUGH THE CRACKS BETWEEN THESE PROVIDERS AND SYSTEMS. DUE TO A LACK OF REFERRAL SERVICES, INFORMATION ON EXISTING SERVICES AND MECHANISMS TO ACCESS THEM, FEEDBACK FROM REFERRAL AGENCIES, AND INTEGRATION OF PEDIATRIC PRIMARY CARE INTO COMMUNITY SERVICE COORDINATION, REFERRAL AND CARE COORDINATION REMAIN SIGNIFICANT BARRIERS. AS A RESULT, EVEN IF CHILDREN HAVE BEEN IDENTIFIED AS BEING AT-RISK FOR DEVELOPMENTAL DELAYS, THEY MAY GO WITHOUT—OR WAIT TOO LONG TO RECEIVE—VITAL SERVICES THAT COULD PREVENT OR LESSEN DEVELOPMENTAL DELAYS, AND AS A RESULT FACE CONSEQUENCES RELATED TO SCHOOL READINESS AND EARLY SUCCESS IN SCHOOL.

TO ENSURE THAT CHILDREN AND FAMILIES RECEIVE NEEDED SERVICES IN A TIMELY MANNER, IT IS CRITICAL TO FORGE LINKAGES BETWEEN SILOED SERVICE PROVIDERS. DUE IN PART TO CULTURAL, LANGUAGE, TRANSPORTATION AND OTHER BARRIERS, CHILDREN FROM LOW-INCOME OR MINORITY FAMILIES ARE MOST LIKELY TO BE HARMED BY NONEXISTENT OR INEFFECTIVE LINKAGES BETWEEN PRIMARY HEALTH CARE AND OTHER SERVICE PROVIDERS IN COMMUNITIES. CARE COORDINATION, CASE MANAGEMENT, AND SIMILAR LINKAGE ACTIVITIES CAN HELP ADDRESS THESE BARRIERS AND OFFER OPPORTUNITIES TO PROMOTE OPTIMAL HEALTH AND DEVELOPMENT FOR ALL CHILDREN.

IT IS CHALLENGING TO CREATE A SYSTEM OF COORDINATED CARE AND SERVICE LINKAGES—A SERIES OF RESPONSIVE PROGRAMS THAT, WITH MINIMAL RESOURCES, COMMUNICATE AND OPERATE EFFECTIVELY AND SEAMLESSLY ACROSS FUNDING SILOS, SETTINGS, AND TECHNICAL, LEGAL OR POLICY BARRIERS. HOWEVER, THIS WORK HAS NEVER BEEN TIMELIER, AS CARE COORDINATION IS A CENTRAL TENET OF PATIENT-CENTERED MEDICAL HOMES AND IS CRITICAL TO IMPLEMENTATION OF NATIONAL HEALTH CARE REFORM. IMPROVED COORDINATION ACROSS PROVIDERS AND SYSTEMS MAY INCREASE EFFICIENCIES BY REDUCING DELAY OR DUPLICATION IN SERVICES AND IMPROVE OUTCOMES FOR CHILDREN. THE METHODS USED TO IMPROVE LINKAGES AND CARE COORDINATION BETWEEN PEDIATRIC PROVIDERS AND COMMUNITY RESOURCES FOR YOUNG CHILDREN CAN IMPROVE OUTCOMES AND PROVE TO BE RELEVANT FOR OTHER POPULATIONS.

ABOUT ABCD III

ALTHOUGH STATES ENCOUNTER MANY BARRIERS, THEY ALSO HAVE OPPORTUNITIES TO FACILITATE ACCESS TO FOLLOW-UP CARE FOR YOUNG CHILDREN IDENTIFIED BY PEDIATRIC PROVIDERS AS EXPERIENCING OR BEING AT RISK FOR DEVELOPMENT DELAYS. STATES NEED GOOD MODELS, TOOLS, STRATEGIES AND POLICIES FOR FACILITATING REFERRALS AND REFERRAL RELATIONSHIPS. THROUGH THE CURRENT ASSURING BETTER CHILD HEALTH AND DEVELOPMENT (ABCD III) LEARNING COLLABORATIVE, FIVE STATES (ARKANSAS, ILLINOIS, MINNESOTA, OKLAHOMA, AND OREGON) ARE DEVELOPING AND TESTING MODELS THAT CAN IMPROVE COORDINATION IN THEIR STATES AND PROVIDE MODELS FOR OTHERS.

THE CURRENT COLLABORATIVE BUILDS ON PREVIOUS ABCD INITIATIVES, IN WHICH 27 STATES HAVE PARTICIPATED. WITH THE SUPPORT OF THE COMMONWEALTH FUND, THE NATIONAL ACADEMY FOR STATE HEALTH POLICY (NASHP) HAS
administered two ABCD learning collaboratives and a screening academy designed to support state efforts to create or expand service delivery and financing strategies to enhance healthy child development for low-income children and their families. The first ABCD learning collaborative (ABCD I) launched in 2000 with four participating states (North Carolina, Utah, Vermont, and Washington) and focused on general child development. Through the second learning collaborative (ABCD II), five states (California, Illinois, Iowa, Minnesota, and Utah) focused on social-emotional development. Twenty states and Puerto Rico participated in the ABCD Screening Academy to implement policies and practices to help make use of standardized screening tools a standard part of well-child care. All of these states have focused on helping providers identify children in need of follow up and intervention, establishing state policies that promote young children’s healthy development, improving referrals, and partnering with stakeholders throughout these processes. States remain engaged in ABCD and are poised to adopt and adapt strategies from ABCD III.

ABCD III launched in 2009 to help participating states identify, implement, test and spread policy and system changes that create and support efficient linkages between child health primary care providers (PCPs) and providers of child and family services needed for child health and development (e.g., mental health, early intervention, early care and education programs such as Head Start, family support such as WIC, and specialty health services). Specifically, ABCD III states are targeting three levels of improvements:

- **Primary care practice**-based strategies that transform or reorganize primary care delivery to children and families (e.g., via tools such as registries that support care coordination and including health plan-level improvement efforts);
- **Community service provider** linkages that strengthen relationships between pediatric primary care providers and other community-based providers that serve children and families (e.g., through co-location or joint trainings); and
- **Systems level** strategies that improve and redesign *state-level* operations between primary health care and other systems interacting with young children (e.g., facilitating cross-agency data sharing between Medicaid and Early Intervention).

ABCD III states also are targeting policy improvements through the following approaches:

- **Maximizing the use of personnel** to assure effective linkages (e.g., via medical homes or community-based staff);
- **Undertaking quality initiatives** that engage clinical practice settings and networks of providers and other mechanisms for assuring and monitoring quality related to referrals (e.g., through performance measurement or shared protocols);
- **Improving data, information and technology** (e.g., common referral forms and data linkages); and
- **Supporting individualized care plans and cross systems planning** (e.g., Part C Individualized Family Service Plans that link to pediatric PCPs).

Appendix A illustrates these various levels of intervention and their relationship.

ABCD III states were selected through a competitive process that took into account their previous efforts or existing Medicaid policies to improve identification of children at risk of developmental delays (e.g., reimbursement for use of a developmental screening tool), as well as their intention to test methods with a high likelihood of creating lasting systems and improvements to support high quality and efficient linkages that can be spread statewide as well as adapted by or replicated in other states. Participating states committed to the following:
• **Linkages for all young children**: State projects support high quality, efficient linkages for all young children (birth to age 3) and their families, including children with less intense needs or identified as being “at risk” for developmental delays.

• **A focus on pediatric primary health care**: Projects focus on improving linkages and coordination of care between primary care providers who serve Medicaid-enrolled children (e.g., physicians, nurse practitioners) and other child and family service providers.

• **Medicaid agency leadership and broad stakeholder engagement**: Proposals were submitted by state Medicaid agencies that committed to working in active partnership with key stakeholders in formalized roles to achieve project objectives. Each state engages a broad stakeholder group with pediatric primary care and family leadership representation. Other stakeholders include decision makers and champions from Maternal and Child Health/Title V, Part C Early Intervention agencies, early education and other children’s service providers or advocacy groups.

• **Two or more demonstration sites**: Participating states agreed to secure participation from at least two communities with sufficient family, pediatric primary health care, and other service provider involvement to serve as pilot sites where interventions could be implemented and change measured to inform and achieve statewide improvement.

• **Evaluation**: Each state is creating and implementing an evaluation plan to assess whether their interventions are having the desired effect and to gather the evaluative information needed to shape improvements and support plans for statewide spread. Additionally, ABCD III states committed to selecting a common outcome that all collaborative states would produce twice during the project to demonstrate impact.

**Overview of ABCD III State Projects**
The five ABCD III states share the aforementioned goals of identifying, implementing, testing and spreading primary care practice-based, community service provider, and systems level changes that create and support efficient linkages between child health primary care providers and other child and family service providers. Additionally, each ABCD III state project has its own specific objectives. The objectives share many common components, such as:

• Encouraging and promoting the use of standardized tools and systematic processes for referring and tracking services for children and their families;

• Identifying sustainable practices for ensuring effective referrals and linkages are made across screening, referral and treatment programs;

• Supporting providers in implementing effective protocols for sharing information with each other as well as closing the information loop with families;

• Advancing systemic changes to improve outcomes for young children with and at risk for developmental delays; and

• Strengthening the relationship between systems of care.

Brief descriptions of each project follow. More detailed descriptions are in Appendix B.
Arkansas
Arkansas has developed a learning collaborative to provide technical assistance to PCPs in four pilot communities through its Quality Improvement Organization (QIO) – the Arkansas Foundation for Medical Care (AFMC). The Arkansas Department of Health’s Hometown Health Initiative (HHI), which assists communities in developing health strategies that are locally designed and sustained, is involved in each pilot. The project has also partnered with the Arkansas Early Childhood Comprehensive Systems Initiative (AECCS), and is working to promote medical homes through childcare programs.

Some of the key components of the Arkansas project include the testing of a “fax-back” referral form to enhance communication among providers, plans to develop an online service directory for children identified with developmental delays, a quality award for PCPs who enhance linkages, and the use of recently established “Early Intervention Liaisons,” who have been designated by the Early Intervention agency to promote linkages with primary care.

Illinois
Illinois’s ABCD III initiative seeks to identify the best sustainable practices for ensuring effective referrals and linkages across screening, referral and treatment programs, and that all children are linked to the services that best fit their unique needs. With input from PCPs obtained through a strong partnership between the state Medicaid and Illinois Chapter of the American Academy of Pediatrics, the state has established standardized referral forms that will be tested during the pilot phase. These piloted forms include a referral form, referral feedback form, and Individualized Family Service Plan (IFSP) summary form.

Illinois also seeks to integrate service data from Early Intervention and other programs into the electronic patient rosters used for quality assurance by Medicaid medical home providers. The database and rosters will allow tracking and follow-up of referrals so that children who are at risk, but do not qualify for EI or Special Education, will be referred to other appropriate preventive child development services. Illinois also plans to build on an existing database for human services programs (Statewide Provider Database) to assist PCPS in identifying these referral sources.

Minnesota
Minnesota is using a combined approach of learning collaboratives and in-office training to support PCPs and other child and family service providers in implementing effective protocols for sharing information and closing the information loop with families. The Minnesota Child Health Improvement Partnership (MnCHIP), a public/private partnership, provides project oversight. The project assists designated care coordinators in pilot PCP offices in implementing referral protocols, incorporating information provided by child and family service providers into clinic work flow, integrating practices established by the Minnesota Medical Homes Project, and co-locating services.

At the community level, Minnesota seeks to develop service agreements between child health care providers and other child and family service providers and empower teams to pilot several versions of team-designed referral/faxback forms. Minnesota is also encouraging use of its statewide Help Me Grow (Minnesota’s Early Intervention Program) referral phone line and the Minnesota ParentsKnow website and online referral request for providers and families. Some pilot sites are seeking Health Care Home certification, which supports firmly established care coordination process and services.
Oklahoma

Oklahoma has built a referral and feedback mechanism (child referral module or “web portal”) onto an existing infrastructure, the Preventive Services Reminder System (PSRS). PSRS is an open-source academic development designed and maintained by the University of Oklahoma Health Sciences Center Department of Family and Preventive Medicine, partially funded by the Oklahoma Health Care Authority, and used by PCPs for improving preventive and longitudinal care in primary practices. Most ongoing data collection in Oklahoma’s project will occur through electronic monitoring of web portal usage, as the portal will track all referrals and completed feedback loops. Each of Oklahoma’s pilot counties has a core team representing Early Intervention, Child Guidance (health department program), Sooner Success (University of Oklahoma care coordination program) and Oklahoma Family Resource Center. Each team will determine its response and triage system for referrals to allow for individual personnel, workflow, and population needs. As part of a multi-faceted “Facilitated Change” strategy to continually uncover needs and problem solve, the state is using Practice Enhancement Assistants (PEAs) who provide technical assistance to practices.

Oklahoma’s care coordination findings are intended to inform its patient-centered medical home delivery model for its Medicaid program. Effective strategies identified through the ABCD III initiative will inform changes to tiering criteria for medical homes.

Oregon

Oregon is contracting with an External Quality Review Organization-like entity (EQRO), the Oregon Pediatric Improvement Partnership (OPIP), to conduct a Performance Improvement Project (PIP). The PIP will produce an improvement model that integrates care coordination with standardized screening and referrals at the clinical level with supporting payment systems and metrics. A forum of health agencies, managed care organizations, child health care providers, Early Intervention specialists, and family members have developed EQRO criteria that build on existing early childhood primary care improvements. The EQRO will also evaluate the level to which each Managed Care Organization (MCO) participates in the PIP, provide technical assistance to MCOs, and report a comprehensive summary of its findings to Medicaid.

The team is also working with the state’s Electronic Medical Records effort and partners in EI to ensure that data is more available and linkages exist for screening, referral and follow up. ABCD III team members have successfully made treatment, referral and awareness of outcomes for developmental screenings a part of the medical-home model the state is developing. Oregon has added Current Procedural Terminology (CPT) code 99366 to line three of the Prioritized List of Health Services, which enables Medicaid reimbursement for Medical team conferences with face-to-face participation by three or more qualified professionals.

Table 1 provides a comparison of each state’s primary interventions.

<p>| Table 1: ABCD III States’ Policy and System Improvement Strategies to Support Improved Linkages |
|-----------------------------------------------|---|---|---|---|---|
| Developing consistent instruments, tools and processes | AR | IL | MN | OK | OR |
| Piloting new referral and feedback forms | ✔ | ✔ | ✔ | ✔ | ✔ |
| Creating Individualized Family Service Plan (IFSP) summary forms | ✔ | ✔ | ✔ | ✔ | ✔ |
| Developing reporting templates to document linkages between primary care and other child and family service providers | ✔ | ✔ | ✔ | ✔ | ✔ |
| Describing referral consent requirements that exist in statute and law | ✔ | ✔ | | | |
| Standardizing referral processes statewide | ✔ | ✔ | | | ✔ |</p>
<table>
<thead>
<tr>
<th>Activity</th>
<th>AR</th>
<th>IL</th>
<th>MN</th>
<th>OK</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning joint Human Services and Education Department trainings</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defining ‘care planning’ and shared care coordination resourcing</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Using provider incentives</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Considering reimbursing for care coordination and linkages activities</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>separately</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Securing professional maintenance of certification (MOC) credit for participants</td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Testing how to tie model to medical home accreditation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Providing special recognition status to leaders</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allowing health plans to conduct ABCD III improvement work as part of their required Performance Improvement Projects</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Implementing continuous improvement strategies</strong></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Using process mapping to identify and refine practice and policy</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>improvement opportunities</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Implementing a Performance Improvement Project (PIP) with community and stakeholder feedback</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Planning to use a PDSA-like cycle to monitor quality of model</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><strong>Linking existing or building data systems</strong></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Testing new web portals or patient registries</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Developing a statewide system to track developmental screening and referrals</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Developing new or capitalizing on existing data sharing agreements</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Developing linkages to share EI data with health plans for care coordination and management of enrolled clients by plans</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><strong>Improving systems</strong></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Refining Early Intervention policies and practices</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Standardizing requirements for well child screens, child health exams, and EPSDT across program/service lines</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Revising MCO contract language to include linkages strategies</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Defining roles and responsibilities for services within blended/braided funding streams</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Linking community pilots to emerging state and federal health reform initiatives and funding</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><strong>Building consensus and/or shared visions to promote spread and ensure sustainability</strong></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Paralleling Health Care Home requirements and measures in care plan, data fields, reporting requirements, etc.</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Using Community Cafés to strengthen community engagement</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Building pilots on existing infrastructures and initiatives</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Using community liaisons (“utilities”) to strengthen and support linkages</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Considering a single statewide referral mechanism (e.g., 211)</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ABCD III state projects receive funding and technical assistance over three years: year one of the project is for planning, year two for pilot implementation, and year three for statewide spread of activities and interventions. As of this writing, participating states are halfway through year two of their projects. ABCD III states have completed planning activities, which included defining stakeholder roles, securing participation agreements from pilot sites, identifying a process for addressing state policy and system changes, designing intervention tools and resources, and convening stakeholder groups. The five states are now immersed in pilot implementation; they are providing technical assistance to community pilot sites, helping pilots assess what processes are working, identifying policy, infrastructure and system changes to support improvement, and testing measurement approaches to produce and share preliminary results.

In the final year of their projects, ABCD III states will begin to spread practice changes statewide. They will complete systems improvements that do not require legislative action, communicate completed systems improvements to critical partners, finalize training materials, begin to conduct training to spread the practice improvements developed in the pilots to other areas of the state, and finally, produce concluding evaluation reports.

The following sections (1) highlight early lessons from the five ABCD III states’ experiences to date and (2) provide recommendations for other states seeking to improve care coordination and service linkages for children with developmental delays or for other populations.
KEY EARLY LESSONS

The ABCD III states are just reaching the mid-way point of their projects; however, they have already discovered important lessons about improving service linkages. Detailed in this section, these lessons include:

- Target interventions at multiple levels;
- Develop processes that will enable providers to communicate clearly, consistently, and easily;
- Use quality improvement processes to rigorously test new models;
- Incorporate formal methods to involve parents and families;
- Offer incentives for providers to participate;
- Identify untapped data-sharing opportunities;
- Incorporate multiple measurement strategies during the planning phase;
- Build on existing state partnerships and infrastructures; and
- Create synergy across state initiatives and priorities.

TARGET INTERVENTIONS AT MULTIPLE LEVELS

ABCD III states are working to improve service linkages and care coordination by making changes at the primary care practice, community, and system levels. Improvement at any one of these levels is bolstered by (and often depends upon) complementary policies and procedures being in place at the other levels. This means, in terms of support for data, information and technology that facilitate linkages, for example, that practices’ ability to track referral and follow up through patient registries or other tools works in tandem with the use of common forms among PCPs and community service providers to routinely communicate referral and feedback information. In turn, this is made possible by state systems that limit administrative barriers for sharing this pertinent information for service linkages.8 Below are examples of participating states’ strategies to improve linkages at each level.

- **Arkansas** is working to improve practice-based linkages through the development of referral tools for PCPs and via practice liaisons from the state’s quality improvement organization (Arkansas Foundation for Medical Care) that provide technical assistance to PCPs on referral, follow-up and care coordination. At the community level, the Part C Early Intervention program within the Department of Human Services’ Division of Developmental Disabilities has designated regional “Early Intervention liaisons” with supporting completion of referrals and general care coordination in the pilot sites. Liaisons are responsible for facilitating coordination between primary care and developmental service providers. At the systems level, Arkansas is linking an initiative that supports developmental screening within child-care settings with the ABCD III initiative to support primary care and early education linkages.

- **Minnesota** is focused on care coordination based in primary care practice offices with the goal of increasing communication between primary care and other child and family service providers. Some participating pilot sites had staff with care coordination responsibilities prior to joining this project, whereas other sites have added these responsibilities. The state encouraged participat-
ing sites to put in place practice-based coordinator staff and hosts in-person and online technical assistance events for participating community sites about a variety of topics, including referrals and care coordination. Through events like these, the state has provided a common definition of care coordination (and care plans) to participating practices to ensure common understanding. Minnesota’s baseline data shows that the amount of time devoted to care coordination varies greatly by practice (from 1.5 hours to 32 hours per week), as most of the coordinators wear multiple hats and also serve as office administrators or nurses. In addition to supporting care coordinators in primary care offices (a practice-based strategy), Minnesota is piloting referral and feedback forms between EI (Help Me Grow) and PCPs to support community-based improvement and to enhance the communication and feedback loop, and at the systems-level, strengthening the state’s existing Help Me Grow referral network.

- **Oregon** is leveraging managed care level requirements around quality improvement so that eight participating plans will be working with primary care providers on improving screening, referral and care coordination as part of their required performance improvement project. The eight participating plans cover 1 in 3 children in Oregon. As part of this improvement work, the state is spreading the use of common referral forms piloted and developed through the ABCD Screening Academy and the START (Screening Tools and Referral Training) program led by the Oregon Pediatric Society. Additionally, Oregon is working with the Early Intervention system to incorporate flags and tracking systems that notify EI providers to send information back to the referring primary care provider and to allow tracking of feedback to the PCP via the EI data systems. Some of the counties where the plans work are linking to and coordinating with the state’s effort to implement a Help Me Grow Referral Network and a 211 phone line for parents, providers and others in the communities to contact about resources. Oregon is also exploring CPT claims that providers can use when coordinating and communicating with EI. Lastly, Oregon has included an explicit focus on developmental screening and care coordination with community-based systems in the state-specific medical home definition being developed with the goal of having 75 percent of Oregonians in a medical home that meets the outlined standards.

As the following sections will describe, Arkansas and Minnesota, like all ABCD III states, are simultaneously exploring the above interventions in conjunction with other practice, community, and system-level changes to support linkages for children. The next section details how ABCD III states are piloting the use of common forms to inform system-level improvements.

**Develop Processes that will Enable Providers to Communicate Clearly, Consistently, and Easily**

Past and present experience from ABCD states indicates that PCPs and other service providers from programs such as Early Intervention (EI) communicate sporadically and inconsistently. The information they share is often driven by protocols and processes that are unique to their individual program and do not facilitate concise sharing of pertinent information necessary to execute appropriate child developmental screening, referral, and service linkages. Through this project the teams have been able to come together to define what data points are needed and how to best communicate this to each of the unique and diverse entities (community, clinics, schools, etc.). By developing and testing common referral and follow-up forms, the five ABCD III states are creating opportunities and mechanisms for various child-serving providers to communicate referral outcomes easily, while minimizing any additional reporting burden (See Table 2).
**Table 2: Comparison of State Forms Being Piloted**

<table>
<thead>
<tr>
<th>Form component</th>
<th>Arkansas</th>
<th>Illinois</th>
<th>Minnesota</th>
<th>Oklahoma</th>
<th>Oregon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form Name(s)</td>
<td>ARLinks Provider Feedback to PCP DEMO Form</td>
<td>1. Standardized Illinois EI Referral Form 2. Illinois EI Program Referral Fax Back Form</td>
<td>Child Referral Status Information</td>
<td>Request for Early Childhood Services</td>
<td>Common Referral Form – Birth to Age 5</td>
</tr>
<tr>
<td>Form is Used for Referral to Which Community Resources?</td>
<td>EI only</td>
<td>EI/Early Childhood Special Education only</td>
<td>Any</td>
<td>El. Care Coordination (Sooner SUCCESS), Family to Family Network (Oklahoma Family Network) and State Department of Health Early Childhood Services (Child Guidance)</td>
<td>El / Early Childhood Special Education (ECSE) only</td>
</tr>
<tr>
<td>Referral and Parent Consent are Combined in Same Form or in Separate Forms?</td>
<td>Separate</td>
<td>Same (Both are in form (1) above)</td>
<td>Separate³</td>
<td>Separate (Request form has checkboxes to indicate that consent is on file)</td>
<td>Same</td>
</tr>
<tr>
<td>Number of Parent Signature Spots for Release (and HIPAA/ FERPA Language Included)</td>
<td>1 (HIPAA, FERPA)</td>
<td>1 (HIPAA, FERPA)</td>
<td>1 (HIPAA, FERPA)</td>
<td>2 (HIPAA, FERPA) (The plan-recommended tool will include FERPA only)</td>
<td></td>
</tr>
<tr>
<td>Child / Parent Contact and Demographic Information</td>
<td>Child name, date of birth</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Parent/guardian name</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Address, phone number(s)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>County</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Primary language</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Interpreter needed</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Insurance type</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>Race</td>
<td></td>
<td>Foster parent/guardian, if applicable</td>
<td></td>
</tr>
<tr>
<td>Form Component</td>
<td>Arkansas</td>
<td>Illinois</td>
<td>Minnesota</td>
<td>Oklahoma</td>
<td>Oregon</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>-----------</td>
<td>----------</td>
<td>--------</td>
</tr>
<tr>
<td>Does Form Specify the Information to be Sent Back to PCP?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No (It specifies information that is allowed to be sent)</td>
<td>Yes</td>
</tr>
<tr>
<td>Information about Reason for Referral</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening tool used?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Domains of concern</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Risk factor/diagnosis</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Family awareness of referral</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Feedback Information to be Completed by EI / Community Agency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whether child was evaluated; whether child was determined to be eligible/not eligible</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whether child was screened; whether child was determined to be eligible; and any recommended follow up with PCP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation date; whether child was determined to be eligible / not eligible; provider referred to; and county contact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation date; evaluation outcome including eligibility; services the child will receive; care coordination notes; county team contacts; other relevant information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With consent of parent/guardian, the referral source (community service providers as well as PCP) receives information from EI regarding eligibility determination outcome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other referrals being made are noted.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The states are engaging programs such as child care, early Head Start, mental health, and home visiting, other care coordination programs (e.g., Oklahoma SoonerSuccess, Oregon CaCoon), and Help Me Grow, but for most states, the relationship between EI and PCPs is at the forefront of their efforts to improve linkages for children with or at risk of developmental delays. PCPs see children at regular intervals for well-child visits and can collaborate with community resources in treatment planning by approving or signing off on care plans developed through the EI-required Individualized Family Service Plan (IFSP). EI is an obvi-
ous partner, as early intervention services “[a]re designed to meet the developmental needs” of eligible children along with family needs “related to enhancing the child’s development.” Estimates are that approximately 13 percent of children have a developmental delay that would make them eligible for Early Intervention services. Past experience is that PCPs may be unfamiliar with EI program eligibility criteria or with the resources and service providers available to children and families in the community. This lack of familiarity affects PCP willingness to screen children, for fear of identifying issues for which they cannot ensure services, and it reduces the quality of referrals made to programs such as EI for further assessment of children at risk for developmental delays. In a national survey, more than two-thirds of responding EI programs cited primary care practices’ lack of knowledge about EI as a challenge. At the same time, programs such as EI lack information about primary care processes, which often results in PCPs receiving unwieldy reports with follow-up information about children referred to EI. This means that even when providers try to share information, they do not always get what they need in an easily understood format. By convening stakeholders representing Medicaid, Early Intervention, and primary care practices—and in many cases including other agencies and families—ABCD III states are identifying ways that providers can share critical information about children in a single form that meets various providers’ and families’ needs as well as state and federal guidelines for patient privacy and confidentiality. Arkansas, Illinois, Oklahoma and Oregon are piloting standard forms for use across all community sites, whereas Minnesota provides a template form that pilot communities can tailor to fit each community’s needs. States are working to balance community desire to tailor forms to fit local needs with state interest in standardizing forms as much as possible for statewide spread. However, in each case, the various kinds of providers work together (either on the state or community level) to agree on a common format for communication. This process involves designing, testing, and revising forms until they meet the needs of all parties.

- **Illinois** pilot sites are testing a “Standardized Illinois Early Intervention Referral Form” and a referral fax back form. The 2-page referral form facilitates information sharing about referrals from PCPs as well as from other sources (such as community service providers) to Early Intervention. This abbreviated form provides Early Intervention with authorization to release information, so that each child’s medical home is updated using the fax-back form, even if the PCP is not the referral source. Illinois has also developed an IFSP summary report, which provides the PCP with a succinct summary of the assessment in a format PCPs can digest and use. The Early Intervention agency hopes to convert the summary form to an electronic version that will self-populate in the future based on the IFSP.

- **Oklahoma** established a form for “Referral for Early Childhood Intervention.” After discussion with county SoonerStart (Early Intervention) personnel, Oklahoma decided to revise this wording to “Request for Early Childhood Services.” The change reflects the fact that some children will be “at risk” but will not meet the criteria for Early Intervention (EI) referral. The Department of Education requires all referrals to its system to undergo the full eligibility determination (and evaluation) process for EI services; having clearly ineligible children go through the lengthy evaluation process created a bottleneck in the system. The seemingly small clarification in wording enables providers and EI coordinators to directly refer children clearly not eligible for EI to other early childhood service organizations without undergoing unnecessary evaluation. The team initially planned to use a fax-back format of the request form, but shifted to an electronic format (see “Incorporate Multiple Measurement Strategies” section).

In addition to enhancing the PCP/EI connection, states are looking to improve communication and coordination with other service providers. States continue to try to ensure that the many children found to be
ineligible for EI receive the supports they need to address risk factors and support healthy development. Improving communication between EI and mental health programs, for example, is critical but difficult, due in part to limited numbers of behavioral health providers who treat young children.

- **Arkansas** has a pilot project in which childcare providers in communities identified as being high users of vouchers for care are trained by childcare resource and referral agencies to conduct developmental screening. The childcare providers who receive parental consent send the results to PCPs. The trainers visit the PCPs and prepare them for requests for referrals. This process enables parents to discuss results with trained childcare providers that they trust.

- **Illinois**' form also provides a direct connection between Early Intervention and other service providers, and then closes the loop with the medical home. Some community-based service providers in Illinois cannot be reimbursed by Medicaid until the child is first found to be ineligible for EI services. These providers may use the new referral form to refer to EI. With the consent of the parent/guardian, EI informs both the PCP and the community service provider of the eligibility determination outcome.

- **Oregon** is working to enhance communication between EI providers and PCPs about additional community-based services EI recommends for the child (as part of EI's service coordination requirements). Data integration is being explored so that managed care plans contracted for children receiving EI services are informed about children's receipt of EI and then charged with identifying additional services the child may be eligible to receive through the managed care contract.

Navigating consent requirements can also be challenging for providers in participating states. To clarify staff responsibilities for acquiring consent from families when initiating and completing referrals to Early Intervention, Minnesota’s Department of Human Services and Department of Education are jointly developing a document to describe referral consent requirements (per existing statute and law).

**Use Quality Improvement Processes to Rigorously Test New Models**

ABCD III states identify areas in need of immediate or ongoing attention through quality improvement mechanisms such as process mapping and the Model for Improvement championed by the Institute for Healthcare Improvement. The Model for Improvement is a change model in which ABCD III participants set aims, establish measures to determine if a change is an improvement in care coordination and service linkages, select changes to implement, and conduct Plan-Do-Study-Act (PDSA) cycles to test and implement the changes. By using tools like these in conjunction with team meetings, participating sites are constantly refining their processes and procedures.

- **Arkansas** conducted state-level process mapping, through which ABCD III stakeholders walked through existing state developmental screening, referral, and follow-up pathways to assess gaps or areas of confusion or duplication. Through that process, the state identified areas for improvement and plans to test ways to clarify the state’s multiple Early Intervention system entry points.

- In **Illinois**, PCPs are conducting several PDSA cycles, including increasing the number of children referred using the Standardized Illinois Early Intervention Referral Form and following up with children referred within 36 hours. Early Intervention regional intake agencies are conducting PDSA cycles as well, to increase the use of the newly-designed Referral Fax Back Form which provides information to the PCP and the community service provider (if they initiated the referral) on the status of the referral.

- **Minnesota** hosted a full-day, quality-improvement advisor-facilitated learning collaborative session for its pilot sites to learn about using PDSA cycles to make small tests of change (initial site-specific learning collaboratives and site visits occurred before this session). Community pilot site teams develop at least
one PDSA cycle at each regular team meeting, and to date, many have focused on ensuring referrals get to the appropriate person and communication comes back to the referring provider. The state encourages PCPs in participating pilot sites to use the statewide electronic referral system through the state’s Early Intervention program (known as Help Me Grow). The Minnesota Department of Education (MDE) has already reported a significant increase in the number of referrals through the online referral system, most of which have been from PCPs; MDE attributes this increase to the efforts of the state’s ABCD III project. From January 2010 - March 2011 there was a 54 percent increase in on-line referrals to Help Me Grow. Referrals from professionals accounted for 76 percent of those referrals.

• Similarly, Oklahoma is using a multi-faceted “Facilitated Change” strategy to continually uncover needs and brainstorm creative solutions as needed with community teams each month. The strategy includes, among other things, the use of practice facilitators or Practice Enhancement Assistants (PEAs) who support practice implementation of interventions. PEAs are providing technical assistance to practices on the use of centralized referral resources (such as a web portal) and helping practices conduct PDSA cycles.

• Oregon is facilitating a Learning Collaborative among the eight managed care plans participating in the ABCD III Performance Improvement Project (PIP). Each participating managed care organization has quality improvement staff charged with implementing and supporting the quality improvement strategy developed and refining the strategy based on ongoing lessons.

Process mapping and quality improvement models are proving to be valuable mechanisms for communities to identify gaps and implement changes to fine-tune processes, yet participating states also are finding informal methods, such as regular meetings and contact with pilot sites, to be useful for identifying areas in need of attention. For example, after meeting with different pilot communities, several states have observed local variation in familiarity with standardized developmental or mental health screening. Some PCP sites have prior training and regularly use screening tools; in other communities they do not. Participating states recognize that statewide spread of ABCD III depends upon PCP readiness for change and new or continued commitment to standardized screening along with effective referral and follow up. One Minnesota pilot site developed a PDSA for mental health screening, and Oklahoma’s PEAs have met with several participating clinics to continue to work on making developmental screening a routine part of patient care.

Incorporate Formal Methods to Involve Parents and Families

Because child health and development is deeply rooted in the environment that parents create, engaging parents as active partners with providers is essential. ABCD III states are committed to engaging families of Medicaid-eligible children to ensure service linkages occur for their children. Several states note the challenge of involving families with young children who are Medicaid-eligible, at risk for delays, and whose parents are not professionally involved in early childhood. Parents and families have responsibility for following through with recommended or scheduled referrals and follow-up care for children, so participating states consider options for involving parents from the outset. States are including Community Cafés, family-serving organizations, and parent surveys to explore system challenges from the perspectives of families, solicit parent ideas and suggestions for improvement, incorporate parent feedback into pilot interventions or design interventions that directly involve parents and families, and measure change in parent perspectives.

• Arkansas and Oregon are helping communities foster relationships with parents through Parent Cafés (or Community Cafés). Cafés are structured, small group conversations hosted by trained
leaders in which parents (or other community members) discuss issues that are important to them to establish relationships and identify areas in need of change.17 Through Parent Cafés, states provide a forum to elicit parent suggestions for potential policy improvements and to engage parents in a leadership role.

- Childcare programs in each of Arkansas’ community sites will conduct Cafés for parents and families. By organizing the Cafés through childcare programs, the project believes it can effectively target and promote the Cafés to the appropriate families. These Cafés will be informed by a previous Community Café that was conducted by the state’s Division of Child Care and Early Education and Arkansas Child Abuse Prevention in collaboration with the Arkansas Children’s Trust Fund. That Café resulted in a blog (www.arcafes.blogspot.com) and will serve as a resource for ABCD III Cafés.

- With the help of a representative of Strengthening Families, a national initiative that uses Cafés to engage families in building protective factors to reduce child abuse and promote healthy child development, Oregon held three regional trainings for pilot communities on hosting Community Cafés. Local Early Intervention programs organized and promoted Cafés. Additionally, Oregon is facilitating a group-level process that will engage parents with primary care providers, community providers and Early Intervention to define a quality improvement strategy for each participating community. This will test whether the group-level process of identifying strengths and opportunities helps build the community-level engagement needed for a quality improvement project that requires public/private partnership and buy-in.

- As part of its evaluation strategy, Minnesota, with the help of Wilder Research, is conducting telephone interviews with parents of young children served at participating primary care clinics. The interviews assess parents’ perceptions of clinic practices for screening, referral, communication, and care coordination. Baseline interviews were completed with 95 parents; interviews will be repeated during the project to evaluate changes in parent feedback about clinic processes.

- Oklahoma’s project team partners with the Oklahoma Family Network (OFN), a statewide parent-to-parent mentorship and referral network, to ensure families receive support to speak with other parents regarding their experiences in accessing services. OFN helped identify family members to help lead project activities in each of the state’s pilot communities. Through a contract with the state, OFN also provides technical assistance to the Oklahoma Health Care Authority with a Member Advisory Task Force (MATF) to solicit feedback from Medicaid beneficiaries and families. OFN representatives are also present at each county’s monthly meetings.

**Offer Incentives for Providers to Participate**

Given their commitment to long-term sustainability and statewide spread of ABCD III interventions, participating states are identifying incentives for provider participation in care coordination and service linkage activities for children with or at risk of developmental delays. States focus on incentives to PCPs, but are also exploring incentives for other providers. The specific approaches states are pursuing for PCPs include maintenance of certification (MOC), special recognition, and Medicaid reimbursement for care coordination and service linkage activities.

- This year Arkansas plans to develop a quality measurement system to identify primary care practices that demonstrate commitment to assuring healthy child development. The leading practices
will receive an award and be honored at an event; the team plans to continue the recognition program, which will be replicable and adaptable by other states and for other provider types.

- Three states (Illinois, Minnesota, and Oklahoma) plan to submit applications to the American Board of Pediatrics or the American Board of Family Medicine for Part 4 Maintenance of Certification credit. Approval would enable physicians to count participation in ABCD III linkage activities toward the requirements to maintain Board Certification. Certification requires demonstration of competency through a Performance in Practice module, also known as Part 4. In order to meet this requirement, providers must demonstrate they have undertaken a quality improvement initiative and used data to assess their practice. Designing a PDSA cycle around care coordination and linkages can meet this criterion.

- **Oregon** has added CPT code 99366 to the Oregon Health Plan (Medicaid)’s Prioritized List of Health Services; this addition enables Medicaid reimbursement for medical team conferences with face-to-face participation by the patient and three or more qualified professionals. The addition was possible because, the state Medicaid agency periodically has an opportunity to make technical changes to the list. The next steps include actuaries costing out the service to determine the amount of reimbursement. Oregon will track the use of the CPT code and also plans to recommend a similar CPT code (99368, for team conferences in which the patient is not present) for inclusion on the list.

One challenge states face is identifying comparable incentives for Early Intervention staff participation in care coordination and service linkage activities. Like PCPs, EI staff have multiple responsibilities and serve many infants, toddlers, and their families. Like Medicaid, public health, and other agencies, EI agencies may face budget and staff cuts that compromise their ability to meet program requirements. ABCD III states continue to work to identify incentives to effectively make the case for participating in activities that support care coordination such as completing common forms. For example:

- **Illinois** is in the process of identifying incentives for other providers. For instance, one incentive for community-based organizations is an opportunity to strengthen a connection to primary care providers. Early childhood providers may not have easy access to PCPs; this project provides a rationale for PCPs to engage community service providers in a way they may not have previously. Community agencies may also find that demonstration of community linkages obtained by participating in the ABCD III initiative and resulting efficiencies or reduced duplication is appealing to their funders. Early intervention providers may find that the common forms reduce their paperwork and standardize their processes resulting in higher job satisfaction or reduced stress.

- Early Intervention programs in Oregon can use ABCD III as an improvement activity to improve federal Child Find indicators for increasing the number of birth-to-three children they serve in their communities.  

**IDENTIFY UNTAPPED DATA-SHARING OPPORTUNITIES**

Siloed state programs usually have separate data systems that do not “talk” to each other, even though they may contain important information about the same children. Sharing information through state agency resource databases can help ensure that children receive coordinated care by offering providers a more complete picture of a child’s identified developmental or socio-emotional needs and the relevant services she or he has recently received. Participating states are pursuing interagency agreements designed to reduce barriers to information sharing among providers and systems. Despite the difficulties posed by disconnected data systems, such as differing vendors and administrative barriers, ABCD III states are finding that small efforts such as informal conversations between agencies can result in significant changes.

---

*Improving Care Coordination And Service Linkages To Support Healthy Child Development: Early Lessons And Recommendations From A Five-State Consortium*  
National Academy for State Health Policy
• The Illinois project team reviewed an existing interagency data sharing agreement among three state agencies and found it covered the data they sought to exchange as part of this ABCD III project, but a new mechanism would be required to be able to aggregate and share it. Through conversations with various data sharing and collection entities, the team discovered there were opportunities to add new variables by modifying file layouts. Much of the data needed to track EI referrals and outcomes is collected in the Department of Human Services (DHS)’ Cornerstone system, a statewide data management information system that helps integrate community maternal and child health services provided by DHS to measure health outcomes, provides a single point of enrollment for multiple state programs, and builds a file for each individual that includes a comprehensive needs assessment and care plan. Regional EI system points of entry (Child and Family Connections Offices) use Cornerstone to coordinate EI assessments and track completion of referrals. The Cornerstone EI data are being transferred to the Enterprise Data Warehouse (EDW) in the Department of Healthcare and Family Services (HFS), which administers the state’s Medicaid program. EDW staff will work to make it possible to aggregate, analyze and share the EI referral data. Future steps include providing the EI referral data to the state’s medical homes via a secure portal so medical home providers can tell if a child has received an EI assessment or services. Illinois has discovered that the data sharing process need not be as cumbersome or difficult as expected.

• Oklahoma developed an interagency agreement between The University of Oklahoma Health Sciences Center (OUHSC) and Oklahoma Health Care Authority (OHCA) that allowed data sharing to create a database of the children ages 0-5 enrolled in Medicaid in the participating pilot counties. The state team is rolling out a secure, web-based referral portal to facilitate information sharing between primary care and community service providers, maintain a historical record for each child, and provide a mechanism to remind providers if follow-up for a child is not yet completed.

• Oregon has developed an interagency agreement between Early Intervention and Medicaid that allows data sharing in order to view and analyze EI data for evaluation and tracking. Oregon is exploring data transfers of EI data to Medicaid for publicly insured children to allow analysis of EI services in coordination with Medicaid services. Additionally, Medicaid is exploring options for how these data can then be transferred to the managed care organizations responsible for managing children’s care and used as part of MCO care coordination and health promotion efforts.

States’ data-sharing lessons have implications for many more programs and populations. According to one ABCD III state leader, “ABCD is leading the way as an illustrative example of data sharing. It will open doors for more collaboration and data sharing so providers have tools.” States have not found legislative changes to be necessary to support data sharing agreements. However, states understand that long-term sustainability may depend on formal policy change to maintain continuity as staff leave or join state agencies.

**Incorporate Multiple Measurement Strategies During the Planning Phase**

Measuring care coordination is complex for the same reason care coordination itself is challenging—it involves multiple, segregated programs and data systems. As they work to create responsive, communicative systems through ABCD III, participating states must determine how they will know care coordination has improved. For this project, teams needed to decide on a common outcome (see Table 3 below)
they all would measure to show improvement; teams collectively agreed to demonstrate evidence of a feedback loop. States are also collecting data for specific, individual add-on measures to, for example, assess parent or provider satisfaction. To collect information for the common outcome and add-on measures, states are using a mix of quantitative and qualitative methods, ranging from chart review to claims data analysis, and interviews, surveys and community meetings.

Table 3: ABCD III Common Outcome

<table>
<thead>
<tr>
<th>State</th>
<th>Specification for Common Outcome</th>
</tr>
</thead>
</table>
| Arkansas| **Numerator:** Number of Medicaid/CHIP children referred for developmental services whose PCP “knows the results” of the referral  
**Denominator:** Number of Medicaid/CHIP children referred for follow-up by the PCP for developmental services |
| Illinois | **Numerator:** Number of Department of Healthcare and Family Services (HFS) child beneficiaries receiving EI services whose PCP knows of the services  
**Denominator:** Number of HFS child beneficiaries receiving Early Intervention Services |
| Minnesota| **Numerator:** Number of children referred, whose PCP knows the results of the referral and takes necessary action  
**Denominator:** Number of children referred for follow-up by PCP for EI services |
| Oklahoma | **Numerator:** Number of children referred for EI services whose PCP knows of the completed status of the referral  
**Denominator:** Number of children referred for Early Intervention Services |
| Oregon  | **Numerator:** Number of children referred, whose PCP knows the results of the referral and documents interpretation  
**Denominator:** Number of children referred for follow-up by PCP for EI services |

As the following examples show, in addition to creating new forms to communicate referral and follow-up information, states are implementing new tracking and feedback tools to facilitate ongoing data collection to assess improvement.

- Pilots in Minnesota are beginning to track referrals and outcomes through two new tools. Pilot practices will use a new Access database created for this project, and local Early Intervention (Help Me Grow) staff will be using an Excel spreadsheet to keep track of information on referrals, eligibility, and communication between EI and clinics. The Access database will help practices work on improving care coordination services, an element of health care home (described further in next section). One county has already found the database to be so beneficial for tracking information that it is now also using it for an unrelated adult depression screening project. In addition to these tools, Minnesota has contracted with Wilder Research to assist in conducting surveys or interviews with care coordinators, PCPs, EI staff, and parents. These qualitative methods will be repeated throughout the project.

- Ongoing data collection in Oklahoma will occur through a newly established child referral module (“web portal”), which was built into an existing Preventive Services Reminder System (PSRS). The PSRS is an open-source, academic development for improving care in primary practices; it has been funded since 2002 by AHRQ and funding is expected to continue indefinitely. To measure change, the team will electronically monitor web portal usage; the portal will enable tracking of referral rates and outcomes as it will
show completed feedback loops. The web portal also will provide screening and referral documentation that can be used for billing purposes.

- **Oregon**’s team has contracted with an External Quality Review Organization (EQRO) to conduct a Performance Improvement Project (PIP) to produce an improvement model, along with supporting payment systems and metrics. States use PIPs to meet federal regulations requiring Medicaid agencies to show how they will evaluate the quality of care for beneficiaries in managed care plans. Oregon’s EQRO-like entity leading the PIP is the Oregon Pediatric Improvement Partnership (OPIP). OPIP has proposed a multi-pronged community engagement approach that will inform the PIP development and solicit qualitative metrics via strategic interviews with managed care plans, EI service providers, PCPs, parent leaders, and a town hall meeting with all of these stakeholders. OPIP will be responsible for evaluating improvement and developing the measurement tools and strategies the managed care organizations will use for reporting. OPIP will be summarizing the data across all eight of the plans. Additionally, OPIP will be analyzing and evaluating and referral and feedback at the county-level via the Early Intervention data system (called EC data) to evaluate the MCO efforts in those counties. Lastly, Medicaid will use MCO claims data to evaluate efforts.

**Build on Existing State Partnerships and Infrastructures**

In initial planning stages and selection of community pilot sites, states drew from the momentum and experience of existing state partnerships and infrastructures. States looked to include communities and stakeholders where partners were engaged and had demonstrated a readiness for change, as evidenced by prior experience with screening initiatives or active local or county representation in statewide programs focused on healthy child development. These communities already have momentum and mechanisms in place to support information sharing and improvement.

- **Arkansas** worked with the Department of Health’s Hometown Health Initiative (HHI) to identify pilot communities for ABCD III. HHI is a more than decade-old, “locally owned” initiative with coalitions in every county. Through HHI, community stakeholders work together to identify local health concerns and create and implement solutions. With the help of HHI, the ABCD III team was able to select pilot communities that have strong local-state partnerships and share a commitment to data-based decision-making.

- **Illinois** selected pilot communities based in part on the capacity of local Child and Family Connections (Early Intervention) offices; the state also sought out communities where primary care practices had previously received technical assistance on screening and referral through a project called Enhancing Developmentally Oriented Primary Care.

- To help in engaging stakeholders such as parents, PCPs and state agency staff, **Minnesota** has linked its ABCD III project to the state’s Child Health Improvement Partnership (MnCHIP), a public/private partnership that promotes optimal child health care by creating and supporting continuous quality improvement in clinical practices. Members of Minnesota’s ABCD III team are members of MnCHIP, which provides project oversight.

- **Oregon**’s pilot communities are served by eight managed care organizations (MCO) participating in the ABCD III PIP. EI/Early Childhood Special Education programs also serve the pilot communities organized on the county level and contracted through the Oregon Department of Education. In addition, county Public Health home visiting nurse programs also have a role. One goal of the PIP is to build a learning collaborative in each MCO-community to cement relationships among entities that serve children at risk for developmental disabilities.
CREATE SYNERGY ACROSS STATE INITIATIVES AND PRIORITIES

To expedite change processes and set the stage for sustained, statewide spread of community interventions, participating states are being strategic in integrating ABCD III into state initiatives with complementary objectives. States focus on care coordination not only through ABCD III, but also as part of medical or health home initiatives and while taking advantage of opportunities created through national health care reform and other federal initiatives. ABCD III projects are advancing family engagement in care decisions, population health improvement, and strengthened local and state system capacity for data sharing and communication across settings of care and programs; these issues are central to broad-reaching state and national health care goals such as improving the value of health care and eliminating health disparities.

- **Illinois** is exploring ways to expand and enrich the patient data shared with PCPs through the state's medical home program (Illinois Health Connect, or IHC). IHC providers receive a patient panel roster each month with information about every patient assigned to their practice. The panel roster includes information about demographics, clinical indicators, and screening. Illinois has assessed medical providers for input to determine how they use the panel roster and what additional data might be helpful to include. Illinois is working to integrate other types of data (e.g., Early Intervention service claims data) into the panel roster to improve linkages. According to an ABCD state leader, "ABCD will put more mass behind the flow of data," so that insight from the initiative can help PCPs use the IHC panel rosters more effectively.

- A member of **Minnesota**’s team staffs both ABCD III and the state’s Health Care Home initiative, which supports firmly established care coordination process and services. The team consistently takes care to create synergy between the two projects. For example, the project provides technical assistance and tracking tools to participating pilot practices to help them increase care coordination and tracking, which are elements of Health Care Home certification from the state.

- **Oklahoma**’s project team is linking efforts to two complementary state initiatives: medical homes and Health Action Networks (HANs). First, the team selected pilot communities in counties that have high enrollment in the state’s SoonerCare (Medicaid) Choice Medical Home program. Through SoonerCare Choice, a participating provider coordinates all health care services to eligible children. SoonerCare Choice has three medical home tiers; each tier requires a minimum set of care coordination services (e.g., track tests and referrals) and some optional care coordination services that result in additional payment. Higher tiers have more requirements but are eligible to receive higher payments. The team will use lessons and effective strategies from ABCD III to inform changes to the tiering criteria. The state team also selected two pilots in communities with HANs. The Centers for Medicare and Medicaid Services approved a waiver for HANs, comprised of family and community medicine and pediatrics, which build on the medical home by offering external support for practices that do not have the tools they need, such as electronic medical records.

State teams have found that ABCD III can inform state initiatives in several important ways. First, as governors and state agencies roll out medical home or health information exchange initiatives that affect patients of all ages, ABCD III teams call attention to the particular needs of children. These state initiatives may initially focus on the needs of adult populations or assume that adult needs apply across all age groups; ABCD III teams can reinforce the unique developmental and socio-emotional needs of children to help ensure initiatives consider incorporating components, such as electronic health record fields, that would be unique to children.

- Members of **Oregon**’s ABCD III team have helped make treatment, referral and awareness of outcomes for developmental screenings a part of the medical home model currently under development in the state.
• Both Illinois and Oregon partnered with other states to receive federal grants awarded as part of the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), which reauthorized the State Children’s Health Insurance Program (CHIP). These CHIPRA quality grants support state efforts to enhance medical home initiatives and health information exchange or technology, and evaluate models of care coordination to improve child health quality. Project teams in both states are integrating ABCD III and CHIPRA grant activities. Members of Illinois’ ABCD III team participate in a CHIPRA subcommittee and are working to ensure that social service data from key child-serving systems will be shared within electronic medical records and with medical homes. Illinois is also one of two CHIPRA grantee states that will develop new measures. One of these measures, identified by PCPs as a top priority, focuses on care coordination. Measure development will capitalize on lessons from the ABCD III initiative. In Oregon, ABCD III pilot communities will collect and validate standardized developmental screening measures developed through the CHIPRA grant and inform the use of health information technology to improve care coordination and linkages for child Medicaid and CHIP beneficiaries.

Teams also can inform state initiatives by sharing lessons and insights about coordinating care between medical and non-medical providers, which will have broad implications for other populations. Although much attention has focused on the need to improve coordination among primary and specialty medical services, ABCD III illustrates the need to stress coordination among providers of developmental services for children, many of whom exist outside the traditional health care system (i.e., early care and education or family support services). The focus on community service provider coordination with PCPs is critical to services for adults as well. According to one ABCD III state leader, “This project is a learning module to help medical homes interface with community services,” in that it will provide a model for learning how medical homes can better coordinate with mental health, substance abuse, and other community service providers. Once states have developed effective policies, models, programs, and tools through this initiative, and have tested data flows, they can apply them to other vulnerable populations covered by Medicaid and other publicly-funded health care programs, including low income adults, the elderly, and racial and ethnic minority populations, all of whom would likely benefit from improved care coordination and service linkages.

By leveraging federal grants and existing initiatives, states are maximizing resources and supporting interventions with limited resources. ABCD III states have completed a great deal of planning and begun implementation of interventions in participating communities with very little new funding and often in the face of daunting budget and staffing cuts to partnering agencies.
Several recommendations emerge from ABCD III states’ experiences so far implementing interventions in pilot communities to facilitate service linkages and care coordination among diverse child-serving providers and programs:

- **Start with improving communication between primary care and Early Intervention programs.** Primary care and EI are obvious partners in supporting healthy child development, and their relationship is likely one of the easier and most critical places to begin. As part of this effort, identify the shared goals and priorities and a “common language” that can be used to improve community.

- **Consider models for automated data integration to encourage care coordination that are not dependent on phone- or email-based communications.** In the interest of minimizing provider burden and maximizing efficiency, ABCD III states are exploring ways to automate data integration, by, for example, having summary forms self-populate based on data in long reports.

- **Consistently support and reinforce the importance of standardized screening by primary care practices.** Referrals are more meaningful when based on and tied to developmental or mental health screening results. States are finding that there is always a need for training, refresher, or reminders about screening in primary care settings. In some states, there is added value if providers use the same screening tools that EI uses to evaluate children for eligibility; it provides a common language and helps smooth referral and transition process (e.g., in Oregon, EI uses the Ages and Stages Questionnaire (ASQ) to evaluate children; if a PCP also uses the ASQ, the intake process is easier).

- **Solicit and use stakeholder feedback to help determine what terms to use in common or template forms.** ABCD III states have learned that specific terms like “universal” and “referral” have different meanings to different programs and may carry unintended legal responsibilities or consequences. Clarifying terms early on with stakeholders can help avoid subsequent confusion.

- **Borrow from existing state templates.** Although each state is unique, there are opportunities for states to benefit from each other’s experiences. Several ABCD III states have used each other’s forms either as a starting point to avoid creating a new form from scratch or as a tool to help modify an existing form.

- **Consider pursuing Maintenance of Certification (MOC) for PCPs for care coordination.** ABCD III states are finding that submission of an MOC application is an extra incentive for PCPs to participate in activities that promote service linkages.

- **Relate project goals and system improvements for care coordination to existing state and federal mandates** (e.g., child find requirements). Connecting care coordination and service linkage activities to related mandates is one way to help encourage EI and other community service providers to participate in improvement activities; it also offers a pathway to sustainability, as systemic changes can be continued to help meet state and federal requirements.

- **Take advantage of medical home, health information exchange, and health care reform initiatives.** Each of these initiatives is an opportunity to highlight and integrate the unique needs of children with or at risk of developmental delay; they are also a chance to share and apply lessons from child-serving providers with a broader audience, for a wider patient population.
• **Know that paying for and implementing changes is possible in spite of limited resources.** By leveraging existing initiatives and federal grants, ABCD III states have completed a great deal of planning and begun implementing interventions in participating communities with very little new money and often in the face of daunting budget and staffing cuts to partnering agencies.
Conclusion

ABCD III states are not yet quite halfway through their efforts to implement and pilot interventions to improve service linkages and care coordination for children with or at risk of developmental delays, yet they have already discovered important preliminary lessons that can apply to improvement efforts with other populations and providers. Through their activities to date engaging families, creating and testing new provider communication tools, facilitating data sharing, and preparing for baseline measurement, participating states are developing resources that are useful in broad efforts to engage multi-sector leaders and stakeholders, improve state policy, transform primary care practice, and improve population health. The ABCD III project creates synergy with many other state priorities and is an opportunity to draw attention to the needs of children in care coordination as important health care reform and measurement initiatives roll out.
## Appendix A: Linkage and Care Coordination/Case Management (CC/CM) Strategies to Promote Coordination Between Medical Providers and Community Referral and Resource Agencies

<table>
<thead>
<tr>
<th>Role of State Fiscal and Administrative Support</th>
<th>Primary care practice-based strategies</th>
<th>Service provider linkage strategies</th>
<th>Systems change and cross-system strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategies that transform the way pediatric primary care practices are organized to deliver care</td>
<td>Strategies that strengthen relationships between pediatric primary care and other providers</td>
<td>Strategies that enhance or transform operations between health and other service systems at state level</td>
<td></td>
</tr>
<tr>
<td>Medical homes that use care planning and care coordination approaches.</td>
<td>Community-based staff that assist providers and families in completing referrals and linkages.</td>
<td>Care coordination utilities that operate across a state (e.g., EPSDT coordinators statewide, coordination networks.</td>
<td></td>
</tr>
<tr>
<td>Staff assigned to assure referrals and linkages, including onsite care coordinators.</td>
<td>Co-location of primary health care and other service providers (e.g., child development, social work, mental health).</td>
<td>New structures to organize CC/CM personnel and programs (e.g., public health nurses, community social workers, MCO staff, CSHCN coordinators).</td>
<td></td>
</tr>
<tr>
<td>Resource and referral strategies to help medical providers and families learn about/link to resources, including parent-to-parent approaches.</td>
<td>Health and mental health consultants in early care and education programs who provide referral and linkages to other providers.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Support for strategies that maximize use of linkages and CC/CM

<table>
<thead>
<tr>
<th>Support for quality improvement initiatives and other mechanisms for assuring and monitoring quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality improvement efforts within clinical practice settings which can address gaps in knowledge and behavior (e.g., introduce new tools, quality measurement).</td>
</tr>
<tr>
<td>Quality improvement initiatives that engage networks of providers in measuring and changing performance.</td>
</tr>
<tr>
<td>Macro data and information strategies (e.g., surveys, early childhood information systems, shared resource data base) that guide planning for early childhood health and related services.</td>
</tr>
<tr>
<td>Monitor and provide incentives for quality of care coordination, including completion of referrals, care plans, etc.</td>
</tr>
<tr>
<td>Public-private payer quality initiatives.</td>
</tr>
<tr>
<td>Cross-system professional training.</td>
</tr>
</tbody>
</table>

### Support for data, information, and technology that facilitates linkages and communication among families and providers

<table>
<thead>
<tr>
<th>Support for individualized care plans and cross-systems planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adoption of technology such as electronic medical records that facilitate linkages and CC/CM</td>
</tr>
<tr>
<td>Data, information, and technology strategies that support linkages (e.g., common referral forms, telephone consultation, telemedicine).</td>
</tr>
<tr>
<td>Macro and information strategies (e.g., surveys, early childhood information systems, shared resource data base) that guide planning for early childhood health and related services.</td>
</tr>
<tr>
<td>Practice-based follow-up systems (e.g., practice registries, tracking systems).</td>
</tr>
<tr>
<td>Electronic medical/health records that support patient-centered care.</td>
</tr>
<tr>
<td>Strategies to reduce administrative barriers for sharing information.</td>
</tr>
</tbody>
</table>

### Support for individualized care plans used by primary care providers/medical homes.

| Care plans that incorporate multiple provider perspectives and recommendations. |
| Part C Individualized Family Service Plans (IFSP) that link to pediatric primary care providers. |
| Planning for improved integration of early childhood services and systems with support for local implementation (e.g., early childhood comprehensive systems initiatives). |

---

*Improving Care Coordination And Service Linkages To Support Healthy Child Development: Early Lessons And Recommendations From A Five-State Consortium*

*National Academy for State Health Policy*
Appendix B: ABCD III State Profiles

Arkansas

Background

Arkansas is implementing Linkages Improve Networks and Knowledge of Services (AR LINKS), its ABCD III program. Arkansas Medicaid designed AR LINKS with the idea of building on current initiatives and partnerships, many of which were created through the state’s participation in the ABCD Screening Academy. As a part of its project, the Arkansas Medicaid program has developed a learning collaborative to provide technical assistance to primary care providers (PCPs) in four pilot communities through its Quality Improvement Organization (QIO) – the Arkansas Foundation for Medical Care (AFMC). AR LINKS has also partnered with the Arkansas Early Childhood Comprehensive Systems Initiative (AECCS), and is working to promote medical homes through childcare programs.

Objectives

Arkansas’ team conducted a mapping process of its current linkage system and identified a series of issues that impede linkages. These issues include: PCPs lack knowledge about community resources, multiple conduits for referrals, ineffective referral and follow up processes at the state and community levels, lack of coordination among programs serving children with developmental problems, and lack of care coordination capacity. To improve upon these issues the state seeks to develop an online service directory for children identified with developmental delays; modify the Medicaid provider website to allow PCPs to search for service providers according to criteria; and develop a tool kit for PCPs and educational materials/brochures for child care programs. Arkansas has also partnered with the Arkansas Department of Health’s Hometown Health Initiative (HHI). HHI, “is a locally owned and locally controlled initiative that stresses: collaboration, coalition building, community health assessment, prioritization of issues, and the development and implementation of community health strategies that are locally designed and sustained.”

Hometown Health is present in each of Arkansas’ 75 counties and, given its objectives, makes for an ideal partner to ABCD III. Arkansas also plans to implement a quality measurement system and will define the role of the recently established “Early Intervention Liaisons,” who have been designated by the EI agency to promote linkages with primary care. The EI Liaisons are meant to help ensure communication and collaboration with EI providers and services at the local level.

Project Activities

- Arkansas has developed a “fax-back” referral form and training/resource manual for use by PCPs and other community providers.
- Arkansas is also working to strengthen the partnership with Early Intervention/Division of Developmental Disabilities Services (DDS), partner with HHI and develop new collaborative efforts with the state’s System of Care Initiative in the Division of Behavioral Health Sciences (DBHS). Through these partnerships Arkansas expects to develop a comprehensive statewide spread strategy that can be successfully implemented and sustained.
ILLINOIS

Background

Illinois has developed Illinois Healthy Beginnings II: Coordinating Medical Homes and Community Services (IHII) to build on the success of its ABCD II program in developing coordination and collaboration among Medicaid, Title V and Women, Infants, and Children (WIC) programs, the public health infrastructure, and many additional stakeholders. Illinois looks to build on this work and as a part of IHII, Illinois Medicaid delegated the project administration to the Illinois Chapter, American Academy of Pediatrics (ICAAP) through a subcontract. As a part of ABCD III the state seeks to identify the best, sustainable practices for ensuring that effective referrals and linkages are made across screening, referral and treatment programs, and ensure that all children are linked to services that best fit their unique needs.

Objectives

Illinois plans to build on an existing database for human services programs (the Department of Children and Family Services’ Statewide Provider Database [SPD]) for referrals that will integrate existing resources. Through ABCD III, the managers of the SPD and Illinois Health Connect (Medicaid medical home initiative) are working with the Department of Healthcare and Family Services (HFS) and ICAAP staff to develop strategies to ensure that children with less complex needs do not fall through the cracks, receive services when referred, and reach the resources available. Illinois also seeks to integrate service data from Early Intervention and other programs into the electronic patient rosters used for quality assurance by Medicaid medical home providers. The database and rosters will allow tracking and follow-up of referrals so that children who are at risk but do not qualify for EI or Special Education will be referred to other appropriate preventive child development services.

Project Activities

- Illinois is in the process of completing an Illinois Chapter of the American Academy of Pediatrics (ICAAP) developmental screening Maintenance of Certification (MOC) application for its medical practices. The parameters for measuring effectiveness of Plan-Do-Study-Act (PDSA) activities are established for medical homes and EI and are being discussed for community service providers.
- The state has established standardized referral forms that will be tested during the pilot phase. These piloted forms include a referral form, referral feedback form, and IFSP summary form.
- Illinois is working to establish electronic exchange of data between medical home and EI offices about objective developmental screening and referral outcomes.
- The Illinois Department of Human Services’ (DHS) Cornerstone data system and HFS’ Enterprise Data Warehouse will expand existing data exchange files to populate provider panels and panel rosters with additional EI data to enhance communication between EI and PCPs.
MINNESOTA
Background

Minnesota’s Communities Coordinating for Healthy Development is building on the progress it has made in recent years in the development and coordination of early childhood services and systems. At the outset of ABCD III, Minnesota already had well-established partnerships between public agencies as well as between public and private entities; an overlap in staff who work on the various initiatives provide a sound infrastructure for promoting linkages. The strong role of counties in delivering care has enabled communities to tailor services to their unique needs and created wide variability in the operation of early intervention services and access to resources across communities.

Objectives

Minnesota combines learning collaboratives and in-office training to provide support for primary care and other child and family service providers in implementing effective protocols for sharing information with each other as well as closing the information loop with families. The Minnesota Child Health Improvement Partnership (MnCHIP), which is a public/private partnership, provides project oversight. The project assists designated care coordinators in pilot PCP offices to implement referral protocols, incorporate information provided by child and family service providers into clinic workflow, incorporate practices established by the Minnesota Medical Homes Project, and co-locate services. At the community level, Minnesota seeks to develop service agreements between child health care providers and other child and family service providers and assist in the development of standard referral, consent and fax-back forms and resource listings. Minnesota is also working to increase awareness and encouraging use of its statewide Help Me Grow (Minnesota’s Early Intervention Program) and referral phone line and the Minnesota ParentsKnow website and online referral request for providers and families.

Project Activities

- The state is empowering teams to pilot several versions of team designed referral/faxback forms between clinics and Help Me Grow.
- The ABCD III State Interagency Workgroup is discussing how the state Help Me Grow website and the database used by teams can support information exchange at the local level.
- The state is working with the Minnesota Department of Education (MDE) to develop trainings around funding streams and billing guidelines for Help Me Grow Services, as well as supporting the use of the statewide Help Me Grow online and telephone referral systems.
- Pilot sites are encouraged to use the statewide electronic referral system through Help Me Grow, and MDE has seen a significant increase in referrals through this system, most of which have been from PCPs. MDE attributes this increase to the efforts of ABCD III. The state is working with MDE to strengthen the referral webpage.
- The Department of Human Services and MDE are collaborating on several items: they are jointly developing a document that describes referral consent requirements in statute and law; developing a standard consent form; and working to make sure that messages around referral protocol are consistent and meet the HIPPA and FERPA guidelines.
- MnCHIP has drafted a MOC4 (Maintenance of Certification) application for the ABCD III project in collaboration with the Minnesota Chapter of the American Academy of Pediatrics to be submitted as an incentive for providers to fully participate, especially in the data gathering and tracking activities, and to assist in the spread of ABCD III in subsequent years.
• A sub-group of the Interagency Workgroup will meet several times to outline which EI services can be funded by designated funding streams.

• On the practice level some of the state's pilot sites are seeking Health Care Home certification – which supports firmly established care coordination process and services; including follow up care coordination and communication.

**Oklahoma**

**Background**

Through Connecting the Docs: Improving Care Coordination and Delivery of Developmental Screening and Referral Services in Oklahoma, Oklahoma seeks to advance systemic changes to improve outcomes for young children with and at risk for developmental delays. Oklahoma's initiative builds on existing infrastructure to establish new and strengthen existing linkages among entities serving children and families.

**Objectives**

Oklahoma identified four issues it will seek to address in ABCD III. First, there is no infrastructure to coordinate isolated initiatives designed to ensure follow-up for referrals, linkage of subsystems, and monitoring of process and outcome measures. Second, there is no consistent single point of contact or consistent service provision infrastructure across communities. Third, there is no process to assure that families of children at risk for delay are connected with appropriate services. Finally, resources in many rural areas are sparse, and existing programs and services lack visibility. Oklahoma's Department of Health and Medicaid agency are working in four communities to evaluate and implement Connecting the Docs. County core teams mirror the state-level project team and include partners from EI (SoonerStart), Child Guidance, SoonerSuccess (care coordination program), and the Oklahoma Family Network. The pilots will test a number of new practice policies designed and implemented through the project. Oklahoma has extended its existing Preventive Services Reminder System (PSRS) to include a child referral module (the “web portal”). The PSRS is an open-source academic development for improving preventive and longitudinal care in primary practices. Most ongoing data collection in Oklahoma's project will occur through electronic monitoring of web portal usage, as the portal will track all referrals and completed feedback loops. The web portal will also provide screening and referral documentation that can be used for billing purposes.

**Project Activities**

• The state has built its referral and feedback mechanism (child referral module or the “web portal”) into an existing infrastructure (PSRS), which will facilitate long-term sustainability. The state is in early discussion phases of including the feedback referral as part of casework for every child in every county.

• The team is using a multi-faceted “Facilitated Change” strategy to continually uncover needs and brainstorm creative solutions as needed with community teams each month. The strategy includes, among other things, the use of practice facilitators or Practice Enhancement Assistants (PEAs) who support practice implementation of interventions. PEAs provide technical assistance to practices on the use of centralized referral resources (such as the web portal) and help practices conduct PDSA cycles.

• After discussion with the pilot counties, the state has decided that each county can respond differently to the referral. One commonality will be that once the PCP enters the child's information in
the web portal, it will be viewable by the entire county team. From there, counties can independently decide who is the “catcher” of the referral for initial triaging. This allows counties to respond to their individual personnel, workflow, and population needs.

- Oklahoma is pursuing a MOC4 application to help incentivize providers to participate in the project as part of their quality improvement requirements. The state expects to submit this application in July 2011.
- The state has forged an interagency agreement between OHCA and OUHSC to share patient demographic data.
- Effective strategies identified through the ABCD III initiative will inform changes to tiering criteria for SoonerCare Choice plan medical homes.

**OREGON**

**Background**

Oregon’s ABCD III project: ABCD for Oregon’s Healthy Kids is engaged in a number of initiatives designed to promote the healthy development of children. Oregon, through its previous work, found itself in excellent position to undertake ABCD III – the legislative and executive branches have placed priority on covering all of Oregon’s children and have created an integrated Health Authority. Additionally, Oregon’s work in the ABCD Screening Academy catalyzed practice and policy improvements across systems by bringing together primary care, early intervention, and public health.

**Objectives**

Oregon intends to accomplish its objectives via an External Quality Review Organization (EQRO), which will conduct a Performance Improvement Project (PIP). Under federal Medicaid managed care rules, states must contract with an EQRO and conduct PIPs, but states do have flexibility in the topic and approach used to conduct each PIP. These activities are eligible for enhanced federal matching funds. The PIP will produce an improvement model that integrates care coordination with standardized screening and referrals at the clinical level with supporting payment systems and metrics. A forum of health agencies, managed care organizations, child health care providers, EI specialists, and family members will develop EQRO criteria that build on existing early childhood primary care improvements. The EQRO will also evaluate the extent to which each Managed Care Organization (MCO) participates in the PIP, provide technical assistance to MCOs, and report a comprehensive summary of its findings to Medicaid.

**Project Activities**

- An interagency agreement with the Oregon Pediatric Improvement Partnership (OPIP) as the EQRO-like entity was executed on November 8, 2010.
- OPIP is using a multi-pronged community engagement strategy to inform development of the PIP. Feedback from parents has been solicited via Community Cafés. Interviews with EI staff, PCPs, and other providers and a town hall forum with these stakeholders and MCOs will round out the community engagement approach.
- The team is working with its partners in EI to make IT changes that will make Medicaid and EI data more available and easy for practitioners to use. The team is working with the state’s Electronic Medical Records effort to ensure that linkages exist between primary care and EI for screening, referral and follow up. The team met with the Oregon Community Health Information Network (OCHIN), which provides...
Electronic Health Record technical assistance to FQHCs and safety net clinics, to ensure it has the level of detail necessary to share information with EI.

- **Oregon** has added Current Procedural Terminology (CPT) code 99366 to line 3 of the Prioritized List of Health Services. Including this code enables Medicaid reimbursement for Medical team conferences with face-to-face participation by 3 or more qualified professionals. Oregon plans to recommend CPT code 99368 (similar except the patient is not present) be included as well.

- Oregon is in the midst of redesigning the Medicaid delivery system. Of prime importance is basing the reimbursement strategy on a medical-home model. ABCD III team members have successfully made treatment, referral and awareness of outcomes for developmental screenings a part of the state's medical-home model.

- The state has modified contract language with its managed care plans to reflect that they can choose to join the ABCD III project in Oregon as a way of meeting their obligation to run two PIPs a year.
Endnotes


5 A national workgroup developed a systems graphic to represent the results that an early childhood system should deliver; the graphic includes health, early learning and development, and family leadership and support. See: “Early Childhood Systems Working Group (ECSWG).” Accessed May 24, 2011. http://www.buildinitiative.org/content/early-childhood-systems-working-group-ecswg.

6 AL, AK, AR, CA, CT, CO, DE, DC, KS, MD, MI, MN, MT, NJ, NM, OH, OR, PR, VA, WI

7 Under federal Medicaid managed care rules states must contract with an EQRO and conduct PIPs. The states do, however, have flexibility in the topic and approach used to conduct each PIP. These activities are eligible for enhanced federal matching funds.


9 A “Consent for Use, Disclosure and/or Release of Personal and Health Information For Purposes of Developmental and Mental Health Care Coordination” form is in development for future use.

10 HIPAA refers to Health Insurance Portability and Accountability Act and FERPA to Family Educational Rights and Privacy Act provisions.

11 34 CFR 303.12 (a)


14 S. Allen, Coordinating Care Between Early Intervention and the Primary Care Medical Home.” Presentation at the ABCD III Learning Collaborative Kick-Off Meeting, New Orleans, LA January 19, 2010.


18 To learn more about Child Find, visit http://www.childfindidea.org/overview.htm.


20 This measure includes all referrals to Early Intervention, regardless of source. Illinois may add an additional measure that is more similar to the other states in that it is limited to EI referrals by PCPs.


23 Johnson, K. and J. Rosenthal, Improving Care Coordination, Case Management, and Linkage to Service for Young Children: Opportunities for States.3.