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Linking Children to Services: Building on Community Assets to Pilot Test Improvement Strategies

Carrie Hanlon

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Portland, Maine Office:
10 Free Street, 2nd Floor
Portland, ME 04101
Phone: (207) 874-6524

Washington, DC Office:
1233 20th Street, NW, Suite 303
Washington, DC 20036
Phone: (202) 903-0101

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Executive Summary

Early intervention and other services that support healthy child development in the years prior to starting school can reduce the incidence of disorders that carry high costs and long-term consequences for children's health and well-being. Through the Assuring Better Child Health and Development (ABCD) project, states have identified ways to improve identification of young children with or at risk of developmental delay through appropriate screening by pediatric primary care providers, yet they also have discovered the lack of linkages at the community level among providers serving children. This document focuses on how Arkansas, Illinois, Minnesota, Oklahoma, and Oregon, through the third ABCD learning consortium (ABCD III), are building on existing local partnerships and assets to organize community pilots. It describes the preliminary lessons that have emerged from ABCD III states, including new federal opportunities to bolster community partnerships that will improve service linkages for children.

Since the task of improving linkages requires the involvement of many partners, each ABCD III state has a broad group of stakeholders and a smaller group that oversees the project. Both are comprised of state agency and private sector representatives that serve or interact with young children. Partners include Medicaid, Maternal and Child Health, Early Intervention, and mental health state agencies, pediatric primary care, family representatives, and in some cases health plans, researchers, and advocacy organizations. Each ABCD III state seeks to replicate its state-level partnership at the local level in communities that will pilot strategies for improving care coordination and linkages for young children. To help identify key stakeholders and build strong projects with potential to make statewide improvements, participating states focused on the following questions:

- How can my state inspire or require collaboration between diverse providers of children's health services?
- How do best practices spread in my state?
- Who needs to be at the table to design and pilot improvement strategies?
- Who needs to be at the table when discussing policy improvements to support/enhance the spread of best practices?
- Are these best practices applicable for other populations?
- If so, what other 'allies' exist and could or should be participating as stakeholders?

ABCD III states draw from an array of existing state and community assets including existing partnerships and organizational structures to inform their identification and organization of community pilot sites and key stakeholders. By doing so, state teams benefit from structures established to train, support, and engage medical and/or community service providers, as well as facilitate sustainability and spread. Communities already actively participating in state initiatives have a trusted mechanism for provider (and parent) communication and education, and it is easier to build on past experience and success rather than start from scratch. For example, ABCD III states are all working to support communities in which practices already use structured developmental screening during well-child care and have a primary care provider "local champion" committed to making changes in practice processes to support healthy child development. ABCD III states also use process mapping to help identify new or missing stakeholders for their state and community pilot-level partnerships; through this approach stakeholders outline the pathways providers and families now follow to identify needs, access services, and share important information.

The purpose of piloting is to test improvement strategies to determine which are successful and make adjustments before implementing them statewide. In addition to reviewing local involvement in existing programs and initiatives, ABCD III state teams consider the following community demographics when identifying pilot communities: region

or geographic location; population density; socio-economic factors; cultural diversity; workforce capacity; and technological capacity. Doing so will help teams identify the pilot strategies and lessons that are replicable in particular parts of the state, as well as those that are appropriate statewide.

ABCD III state teams are providing various types of technical assistance and support to pilot communities and will continue to do so. State-level support helps establish a consistent guiding framework and common expectations across all pilot communities. In addition to requiring regular meetings, state teams support communities via:

- Primary care provider technical assistance;
- Parent outreach and engagement;
- Material or electronic resources; and
- Quality improvement processes.

As they finalize selection of pilot sites and roll out support to community providers and stakeholders, ABCD III states are considering or taking advantage of new federal opportunities to help set the stage for statewide spread of successful interventions, specifically quality demonstration grants awarded as part of legislation reauthorizing CHIP and provisions of federal health care reform. Throughout the past year, the following preliminary lessons have emerged:

- Build pilots on existing initiatives and infrastructures.
- Involve state-level stakeholders who can help engage community counterparts to replicate partnership at the local level.
- Identify strong community advocates from various child development sectors to serve as local champions.
- Select communities to represent the diversity of the state to help in considering how pilot experiences can best be spread statewide.
- Consider using process mapping at both the state and community-level to engage stakeholders and understand how the system works from multiple perspectives.
- Develop general guidelines, but be flexible enough to accommodate and address local ideas, challenges, and lessons as they arise.
- Use creative approaches for parent engagement, which states find challenging.
- Link community pilots to emerging state and federal health reform initiatives and funding opportunities.

ABCD III states have a strong foundation to support improvement in every pilot community, each with its own assets. Participating states will continue to rely on these assets while cultivating new processes and relationships that support service provider linkages.

Introduction

Early intervention and other services that support healthy child development in the years prior to starting school can reduce the incidence of disorders that carry high costs and long-term consequences for children's health and well-being.[1] Through the Assuring Better Child Health and Development (ABCD) project, states have identified ways to improve identification of young children with or at risk of developmental delay through appropriate screening by pediatric primary care providers, yet they also have discovered the lack of linkages at the community level among providers serving children. This document focuses on how each of the states participating in the third ABCD learning consortium (ABCD III) are setting the stage to develop and test new models for improving linkages between service providers to promote healthy child development by building on existing partnerships and other community assets in pilot site communities.

Over the past 10 years, ABCD has supported states' efforts to develop and test strategies to improve the delivery and financing of services to promote healthy development for low-income children and their families. As part of previous ABCD learning consortia, participating states have increased primary care medical providers' (PCPs) use of appropriate developmental screening tools.[2] Unfortunately, even with appropriate screening by PCPs, access to follow-up or referral services remains a challenge. National data shows that months pass between a parent's report of a problem and the actual receipt of early intervention services.[3] One of the challenges to successful linkages to services and resources is the fragmentation between sectors serving children. Effective developmental interventions typically involve multiple providers and/or systems of care—particularly systems outside of health, such as early care and education, Early Intervention, and family support. It comes as no surprise that experts have identified strong cross-organizational relationships as a defining characteristic of high performance pediatric care coordination.[4] Linkages between PCPs and other service providers and resources in the community are vital to ensuring that young children at risk of developmental delay receive referral and follow-up services they need.

Experience from ABCD shows that PCPs need more familiarity with the eligibility criteria of programs (e.g. Early Intervention), along with available community resources and service providers to encourage, facilitate, and execute appropriate developmental screening, referral, and linkages. Similarly, evidence suggests that Early Intervention programs need more information about primary care processes.[5] Along with children, parents and caregivers are the focal point of all care processes; all sectors need opportunities to learn from families and share information back with them for informed decision-making. A good beginning point is to increase familiarity and understanding among community stakeholders by bringing them together for shared learning and problem-solving. As community stakeholders become more familiar with each other's strengths and challenges, they are more likely to identify opportunities to improve linkages. Through ABCD III, Arkansas, Illinois, Minnesota, Oklahoma, and Oregon are selecting and supporting pilot site communities to do just that. With the help of state-level teams, ABCD III communities will develop and implement strategies to improve communication and collaboration between PCPs, families, and other community service providers; these communities will work to help the various sectors involved in healthy child development understand each others' perspectives, strengths, and constraints to identify problems and solutions, and ultimately, implement strategies that improve coordination between PCPs, families, and other service providers.

Each ABCD III state is implementing three different kinds of improvements:

- **Primary care practice-based strategies** to redesign and reorganize care delivery (e.g. introduction of new tools, such as a registry, in a practice to support care coordination);
- **Community service provider linkages** to strengthen local relationships among the many providers serving young children and families in communities (e.g. co-location of primary care and other service providers, team-based care); and
- **Cross-system strategies** to strengthen and redesign *state-level* operations between systems that serve and interact with young children (e.g. reduction of administrative barriers for information-sharing among different agencies).

This report focuses on participatory, community-based improvement strategies, which have several strengths. Community strategies promote stakeholder involvement by providing a constructive forum to voice ideas and concerns that will shape future processes at the local level and inform state-level changes. They also enable stakeholders to build on relationships that already exist as a result of state or local initiatives. Additionally, community-based approaches are essential for successfully linking service providers in communities.[6]

Over the past year, ABCD III states have gone through an extensive planning process to set the stage for implementation of interventions to improve coordination in pilot communities. The following sections outline how ABCD III states are building on existing local partnerships and assets to organize community pilots, and describes the preliminary lessons that have emerged from or been shared with ABCD III states, including new federal opportunities to bolster community partnerships that will improve care coordination to support healthy child development.

Partnering at the State and Local Level

Since the task of improving linkages requires many partners, each participating ABCD III state has a broad group of stakeholders and a smaller group (referred to as the "state team" throughout this report) that oversees the project. Both the stakeholder group and state team are comprised of state agency and private sector representatives that serve or interact with young children. Partners include Medicaid, Maternal and Child Health, Early Intervention, mental health state agencies, pediatric primary care, and family representatives. Some also include health plans, researchers, and advocacy organizations. (See the Appendix for a more comprehensive list of each ABCD III state's partners). Although state teams and stakeholder groups are organized differently in each state, all state teams have taken on the management and allocation of responsibilities for daily ABCD III grant activities and deliverables.

Each ABCD III state seeks to replicate this state-level partnership at the local level in communities that will pilot strategies for improving care coordination and linkages for young children. Each state team was tasked with considering the state's delivery systems and relevant key players necessary to succeed. As would be expected, and as their project activities evolve, state teams continue to identify new partners in efforts to support and promote service provider linkages. This is true particularly as state teams help pilot sites design and begin to implement interventions in their communities. To help identify key stakeholders and build strong projects with potential to make statewide improvements, participating states focused on the following questions:

- How can my state inspire or require collaboration between diverse providers of children's health services?
- How do best practices spread in my state?
- Who needs to be at the table to design and pilot improvement strategies?
- Who needs to be at the table when discussing policy improvements to support/enhance the spread of best practices?
- Are these best practices applicable for other populations?
- If so, what other 'allies' exist and could or should be participating as stakeholders?

This section highlights the existing state and community assets ABCD III teams draw from to inform their identification and organization of community pilot sites, as well as key stakeholders to involve in each one.

Building on Assets: Previous Work and Existing Organizational Structures

Selected states were required to demonstrate how the ABCD III project would fit into existing efforts to improve referral, care coordination, case management and linkages across systems that influence child development. Additionally, states were selected based on previous efforts to improve identification of children at risk of developmental delays (such as participation in ABCD I, II or the ABCD Screening Academy; or Help Me Grow, described on page 9). In fact, the need for ABCD III arose out of challenges identified during the ABCD II and Screening Academy, namely that providers were hesitant to identify issues when current service delivery systems did not (or were perceived not to) support appropriate referral and linkage processes.[7] As a result, ABCD III states are all working to support communities in which practices use structured developmental screening during well-child care and have primary

care provider "local champions" committed to making changes in practice processes to support healthy child development. By integrating ABCD III efforts with existing state initiatives, state teams benefit from structures established to train, support, and engage medical and/or community service providers, as well as facilitate sustainability and spread. Communities that are already actively participating in state initiatives have a trusted mechanism for communicating with and providing technical assistance to providers, and it is easier to build on past experience and success rather than start from scratch.

Specific examples of how ABCD III teams are identifying key stakeholders and organizing community pilots based on existing programs or infrastructure relevant to ABCD are below.

- **Arkansas'** state team is building on the existing Early Comprehensive Childhood Systems (ECCS) workgroup—tapping into an established state-level group of stakeholders already engaged in efforts to develop cross-service systems to meet the needs of all children and families.[8] The state is also structuring its community implementation strategy around the Department of Health's Hometown Health Initiative (HHI). HHI, which began in 1998, brings together an array of community stakeholders to identify health problems and create and implement solutions in the community. Although the Department of Health provides overall leadership, the initiative is "locally owned and locally controlled" and exists in all of the state's 75 counties. The ABCD III team worked with HHI to identify communities with active HHI coalitions focused on strong local-state partnerships and data-based decision-making. The team also worked with the Arkansas Foundation for Medical Care (AFMC) to identify primary care providers who are local champions in their HHI communities. Pilot sites are those with a strong HHI Coalition and an identified local champion.
- **Illinois'** state team is organized into three subcommittees and will pilot test tools and resources developed by each. The state is selecting communities in which primary care practices have participated in previous efforts. For example, the state team plans to include communities in which the local Child and Family Connections (CFC) office (the point of entry for Part C-Early Intervention services) has piloted standardized forms to improve care coordination. In choosing communities, Illinois is considering CFC capacity and CFCs with large numbers of children who are determined to be ineligible for Early Intervention services in order to pilot referral mechanisms for at-risk children. Illinois will also draw pilot sites from communities in which PCPs have participated in Enhancing Developmentally Oriented Primary Care (EDOPC). Through EDOPC primary care practices receive training and technical assistance to address screening and referral for various conditions. Participating communities are piloting models to improve communication and care coordination between primary care and Early Intervention.
- **Minnesota** is using the state's Child Health Improvement Partnership (MnCHIP) to engage stakeholders, specifically families, physicians, and staff from state agencies. Members of Minnesota's ABCD III team participate on the board of MnCHIP, a public/private partnership that works to assure optimal child health care by creating and supporting continuous quality improvement in clinical practices, in part by building and strengthening partnerships among providers and with families in communities.[9] MnCHIP meets twice a month to provide budget oversight and broader planning, while a project sub-committee meets monthly to coordinate the daily activities of the ABCD III grant. Additionally, the ABCD III team will coordinate with another existing initiative, Minnesota Health Care Homes (medical homes) created through state reform legislation to support pilot communities (see "Providing support to community pilots" section).

Learning from Other Models: Help Me Grow

ABCD III states' efforts are informed by the work not only of each other, but of promising practices in other states. One example of an initiative that exemplifies state and community collaboration to link children and families to services is Connecticut's Help Me Grow.

Help Me Grow has developed a statewide network to help families and providers access appropriate services for young children at risk for health, developmental, or behavioral problems. A critical component of Help Me Grow is a single statewide toll-free telephone number (Child Development Infoline or CDI) staffed by care coordinators who conduct assessments, connect families to appropriate community resources, ensure successful linkages, and share referral feedback with providers. In addition, Help Me Grow includes the following community-based improvement strategies:

- Partnerships with community agencies that serve as referral resources; and
- Child development community liaisons that are the link between the CDI and community-based services.

Community liaisons are located across the state and serve as experts about available resources in their communities. These staff members develop important relationships with service providers, that enable them to help update information about the resources the CDI recommends to families and providers. Community liaisons also help CDI care coordinators identify the most appropriate resources for complex or unique situations, conduct training for service providers and facilitate networking opportunities for service providers in the community. With the support of The Commonwealth Fund, Help Me Grow has already been replicated in five states, including Oregon. Through a new grant from the W.K. Kellogg Foundation, these five states' projects will receive ongoing support, and Help Me Grow will be implemented in ten new states. Manuals are available to help guide states through the replication process.*

*See for example: P. Dworkin, et al., *Help Me Grow Replication Manual* (New York, NY: The Commonwealth Fund, September 2010). Retrieved October 28, 2010. http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Manual/2010/Sep/HELP%20ME%20GROW/HelpMeGrowReplicationWebsite_FINAL.pdf

- **Oklahoma's** community pilots are involved in both existing and new initiatives. Two of the state's four pilot communities are counties that were not only involved in, but critical to, previous ABCD projects and the state aims to build on that success. Oklahoma also considered the availability of program staff to support families and providers, specifically Sooner SUCCESS (State Unified Children's Comprehensive Exemplary Services for Special Needs) staff. Sooner SUCCESS is a project of the Child Study Center at the University of Oklahoma Health Sciences Center. Staff in a number of counties help providers and families locate services and resources for children with developmental disabilities and other health needs. Additionally, all of the selected pilots are in counties that have significant enrollment in the state's SoonerCare (Medicaid) Choice Medical Home program, in which a participating provider coordinates all health care services to eligible children. Linking pilots to SoonerCare Choice practices will enable ABCD IIII to work with practices that already have a commitment and structure in place to coordinate care for children, and to also inform potential areas for improvement in SoonerCare Choice. The state has selected two pilots that will enable it to take advantage of a new opportunity in the state: recent approval by the Centers for Medicare and Medicaid Services (CMS) of a waiver for Health Action Networks

(HANs). HANs are made up of community medicine, family medicine and pediatrics, and they build on the medical home by offering external support for practices that do not have the infrastructure they need (e.g. electronic medical records).

- **Oregon's** pilot communities are those served by six managed care organizations (MCO) that will be participating in a Performance Improvement Project (PIP). States use PIPs to meet federal regulations requiring Medicaid agencies to document how they will evaluate the quality of care for Medicaid beneficiaries in managed care plans.[10] The Oregon Pediatric Improvement Partnership (O-PIP) is the external quality review-like entity that will design the PIP and provide technical assistance to the MCOs on the PIP. Oregon's ABCD III efforts also will be informed by the state's replication of Help Me Grow (described in text box on page 8).

One of the strategies ABCD III states use to help identify important stakeholders for their state- and community pilot-level partnerships is process mapping. In process mapping, stakeholders outline the pathways providers and families currently follow to identify needs, access services, and share important information. In this case, ABCD III states map out processes for developmental screening, referral, and follow-up with referral sources. By walking through existing processes, stakeholders discover system weaknesses, such as discrepancies in stakeholder understanding of how systems currently operate. State leaders may believe or intend for the system to operate one way, but may not appreciate the barriers that keep the ideal from becoming reality. Arkansas' state team brought in a national expert to walk through process mapping with them.

Identifying Representative Pilot Communities

The purpose of piloting is to test improvement strategies to determine which are successful and make adjustments before implementing them statewide. Therefore, it is imperative that ABCD III states select pilot communities thoughtfully. In addition to reviewing local involvement in existing programs and initiatives, ABCD III state teams consider community demographics when identifying pilot communities. Each state aims to include a varied group of pilot communities to help its ABCD III project adequately represent the state's diversity. This will help teams identify the pilot strategies and lessons replicable in particular parts of the state, as well as those appropriate for statewide replication. Community demographics considered include:

- **Region or geographic location**: communities in various locations of the state to account for regional differences;
- **Population density**: both rural and urban communities;
- **Socio-economic factors**: communities with high Medicaid enrollment and/or varying levels of unemployment;
- **Cultural diversity:** communities that represent the diversity of racial and ethnic minority populations, languages, and religions;
- **Workforce capacity**: communities with varying availability and types of medical and other community service providers; and
- **Technological capacity**: communities in which providers have differing levels of experience with health information technology and electronic information sharing and ability to implement or expand the use of this technology.

ABCD III states aimed to include pilot sites that represent variations among some or all of the above characteristics. For example, Arkansas selected pilot sites located in the Northeast, North Central, Delta (Eastern), Central, and South Central regions of the state. The state's five pilot communities represent a variety of provider types, including a Federally Qualified Health Center (FQHC), two large pediatric practices, one small to mid-size practice, and a health education center. Similarly, Illinois hopes to include one or more FQHCs, a large practice, and private practices in urban, rural, and suburban settings. The state team is also assessing community activation of family involvement and is surveying Child and Family Connections offices to determine their technological capacity. Illinois is interested in pilot sites that represent various religious beliefs, racial and ethnic populations, and languages in the state. In recognition of differences in screening rates and referral by ethnicity in its state, Oregon will include sites with Hispanic populations. Oklahoma's pilot sites include three rural and one more urban county. Two of Minnesota's sites are in the Minneapolis/St. Paul metropolitan area and two others are in smaller cities in the state's northern and southern areas.

Providing Support to Community Pilots

Having identified pilot communities, ABCD III state teams are providing various types of technical assistance and support and will continue to do so for the duration of the project. State-level support helps establish a consistent guiding framework and common expectations across all pilot communities in order to facilitate service provider linkages. State teams ask or require pilot communities to participate in regular meetings to enable peer learning and information sharing. For example, Oregon expects its community teams to convene monthly to discuss progress and challenges; at least one state team member will also attend. In addition to regular meetings, state teams provide vital support to pilot communities through primary care provider technical assistance, parent outreach and engagement (Community or Parent Cafés), material or electronic resources, and quality improvement processes.

Primary Care Practice Technical Assistance

ABCD III state teams are providing training or resources in a variety of formats to support practice change. For example, in Oklahoma, the University of Oklahoma's Health Sciences Center will oversee Practice Enhancement Assistants (PEAs), who will work with each of the pilot communities to outline each entity's role and responsibilities, from identification of needs through delivery of follow-up services. Minnesota hosted a technical assistance webinar about care coordination for pilot communities without care coordinators already in place. The state team realized that these practices had different definitions for care coordination and wanted to ensure pilot communities have a shared understanding and definition of care coordination. Additionally, Minnesota is working to ensure that the project is compatible with the guidelines for Minnesota Health Care Homes to provide support to pilot practices to help them potentially achieve state certification as medical homes if they do not already have it.

Parent Engagement

Many ABCD III states find it challenging to meaningfully engage parents in pilot communities. Several states 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. Both Arkansas and Oregon are holding Community Cafés to engage parents and families, serve as parent resource meetings, and provide a forum to elicit suggestions for potential policy improvements.[11] Child care programs in all five of Arkansas' community sites have agreed to conduct cafés. Recently, the Division of Child Care and Early Education and Arkansas Child Abuse Prevention conducted a successful Community Café in collaboration with the Arkansas Children's Trust Fund. The Café resulted in a blog about their progress (www.arcafes.blogspot.com). The Café focused on a different topic (child abuse prevention) but will serve as a resource as Arkansas develops its ABCD III Cafés. Oregon's state team has invited a representative of Strengthening Families, a national initiative that uses Cafés to engage families in building protective factors to reduce child abuse, neglect and promote healthy child development, to provide training on hosting cafés. Additionally, Illinois has previous experience with Community Cafés.[12]

The Oklahoma ABCD team is using a different approach to engage families. The Oklahoma Family Network (OFN), a statewide parent-to-parent mentorship and referral network, is partnering with the ABCD initiative to provide support for families interested in speaking with other parents about their experiences

accessing services. OFN will identify family members in each of four communities to help lead pilot activities. OFN also was recently awarded a contract with the Oklahoma Health Care Authority to provide technical assistance, support, advice and expertise to the OHCA in the development and implementation of a Member Advisory Task Force (MATF) to gain knowledge, feedback and input from SoonerCare (Medicaid) members and families.

Material and Electronic Resources

ABCD III state teams also are providing communities with both material and electronic resources to pilot test communication and measurement strategies. For example, in Illinois, pilot sites will test two forms: a receipt of referral form and an Individualized Family Service Plan summary form. The forms were piloted under another project (EDOPC), but will be slightly tailored for ABCD III to allow for information sharing about referrals to Early Intervention as well as to other community providers. This will enable primary care and other community providers to better understand the services children receive or perhaps have yet to receive. Arkansas' state team is adapting Illinois' forms (and associated training materials) for use in its pilot communities. Minnesota's team also is piloting consent and referral communication forms for participating providers to use in sending information to the Early Intervention system, along with a Patient Registry database to track care coordination and linkage activities across providers in pilot communities. The state team in Oklahoma 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.

Quality Improvement Processes

In addition to conducting state-level process mapping to understand current care coordination processes, ABCD III states are helping community pilots undertake process mapping at the local level. Such exercises allow for a more accurate picture of missing links and areas in need of clarification or support in order to successfully improve linkages while simultaneously bringing key stakeholders to the table. After conducting state-level process mapping with a national expert, Arkansas identified several areas for improvement and now plans to help each pilot community conduct the same process at the local level in conjunction with learning collaborative meetings among community stakeholders. Similarly, Minnesota's state team used the Model for Improvement to assist pilot sites in developing PDSA (Plan-Do-Study-Act) change cycles to plan how they will implement coordinated services and referral systems.[13] The state worked with staff in each of its pilot sites to map referral pathways and identify key players. As a result, the team identified local variations in processes, which is a challenge in terms of standardizing an approach across all pilots, but also an opportunity to learn how interventions fare in slightly different systems.

As previously mentioned, ABCD III states are building on community assets and selecting communities carefully so that as they test improvement strategies, they will be able to implement successful strate gies for linking children to services in *every* community. As they roll out support to community providers and stakeholders, ABCD III states are considering or taking advantage of new federal opportunities to help set the stage for statewide spread of successful interventions.

CHIPRA Quality Grants

The federal government awarded ten demonstration grants to states as part of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), which reauthorized the State Children's Health Insurance Program (CHIP). The grants will support efforts in 18 states to enhance medical home initiatives, implement or strengthen health information technology or exchange, measure provider performance, and evaluate models of care coordination to improve child health quality. Illinois and Oregon partnered with other states to receive grants, and ABCD III teams in both states are working to integrate project efforts and CHIPRA grant activities. Members of Illinois' ABCD III team participate in a CHIPRA subcommittee informing decisions about the data that will be shared with medical homes and within electronic medical records. Through this effort, ABCD III team members are working to ensure that social service data (e.g. immunization, case management) from key child-serving systems, in addition to clinical data, are shared. ABCD III pilot communities in Oregon will collect and validate measures related to standardized developmental screening developed through the CHIPRA grant as well as the use of health information technology to improve care coordination and linkages between primary care providers and follow-up services for the delivery of care to children covered by Medicaid and CHIP.

Federal Health Reform

The Patient Protection and Affordable Care Act of 2010 (ACA or PL 111-148) offers states several opportunities to support coordination and linkages among community providers serving children. ABCD III states may be able to draw from these opportunities to help facilitate statewide spread.[14]

- **Community Health Teams (Section 3502):** Through the creation of a new Center for Medicare and Medicaid Innovation—which will test health care delivery and financing models—ACA establishes a grant program for states to create "community health teams" to support the medical home. These teams will be made up of an array of health care providers and may include social workers and mental health professionals to help primary care practices collaborate with community-based resources, share information, and create a coordinated system of early identification and referral for children at risk of developmental or behavioral problems.
- **Community-based Collaborative Care Networks (Section 10333):** ACA authorizes funding for five years for a second grant program to support networks of health care providers (e.g. federally qualified health centers) in providing coordinated, integrated services for low-income populations. These networks will be responsible for providing case management and helping individuals access a medical home.

- **Health Homes (Section 2703)**: ACA gives states an option to implement "health homes" for Medicaid beneficiaries with chronic conditions through a state plan amendment. This appears to provide an opportunity for states to implement medical homes for children with two chronic conditions, one serious and persistent mental health condition, or one chronic condition and risk factors for a second condition. The option becomes available January 1, 2011, and offers 90 percent federal matching for medical home provider reimbursement for the first two years it is in effect.
- **Maternal, Infant, and Early Childhood Home Visiting Programs (Section 2951):** ACA also authorizes funding for five years for a Title V grant program to put in place evidence-based home visiting programs. Through these programs, nurses, social workers, or other professionals meet with at-risk families in their homes and connect families to health care, early education, child abuse prevention, and other services a family may need to support healthy child development. In July 2010, the federal government awarded $88 million in grants for these programs; 49 states will receive funding.

Preliminary Lessons

ABCD III states are just beginning roll-out of community pilots; however, throughout their planning year, several preliminary lessons about stakeholder engagement and pilot community organization to support care coordination and service linkages have emerged.

- **Build pilots on existing initiatives and infrastructures** such as health promotion programs (e.g. Hometown Health Initiative in Arkansas), primary care support programs (e.g. MnCHIP in Minnesota), and/or community-building programs (e.g., Help Me Grow in Oregon). This strategy enables state teams to benefit from established structures and trusted mechanisms for training, supporting, and engaging medical and/or community service providers.
- **Involve state-level stakeholders who can help engage community counterparts to replicate partnership at the local level.** State team members represent key sectors and have knowledge about leading activity at the local level, including connections to particularly active individuals who can support or champion a community pilot. In short, state teams are able to bring in their local counterparts to form or enhance stakeholder groups.
- **Identify strong community advocates from various child development sectors to serve as local champions.** Involving local champions from each of the sectors that need to partner more effectively can help garner and sustain momentum. It also gives the activity a local voice that carries credibility and creates buy-in, rather than relying on state partners for implementation. ABCD III states have had much success identifying champions within the PCP community who are already committed to improvement.
- **Select communities to represent the diversity of the state to help in considering how pilot experiences can best be spread statewide.** ABCDE III states considered factors such as region or geographic location, population density, socio-economic factors, cultural diversity, workforce capacity, and technological capacity.
- **Consider using process mapping at both the state and community-level to engage stakeholders and understand how the system works from multiple perspectives**. By being able to discuss how the current systems hinder linkages among health care, Early Intervention, family support, and other stakeholders, communities are able to 1) make the case for stakeholders to participate in efforts to improve the system and 2) help identify policies that impede or could enhance linkages (e.g., data linkages).
- **Develop general guidelines, but be flexible enough to accommodate and address local ideas, challenges, and lessons as they arise.** ABCD III state teams play a critical role in providing a consistent guiding framework and common expectations for pilot communities. However, they are already seeing that communities are at different levels of readiness, and therefore will need slightly different types of technical assistance and support.
- **Use creative approaches for parent engagement, which states find challenging**. ABCD III states continue to seek out and test models for engaging parents (e.g. Parent Cafés, family networks) to ensure interventions meet the needs of families.
- **Link community pilots to emerging state and federal health reform initiatives and funding opportunities** (e.g. medical home or Health Access Networks). Doing so provides a way to drive change more quickly, as the pilot becomes a part of something much broader that has additional dedicated resources, and a structure for sustaining change long-term.

Conclusion

ABCD III states have gone through a year-long planning process to set the groundwork for implementing interventions to improve service provider linkages and care coordination for young children, particularly those with or at risk of developmental delay. To organize their community pilots, ABCD III states have identified and built on state and local strengths, including existing early childhood infrastructure, initiatives, and local champions. They also have considered important community demographic differences to ensure pilots represent the states' diversity. Through quality improvement processes, ABCD III states and communities are identifying new or missing stakeholders as well as referral and follow-up processes in need of improvement. State teams face challenges in engaging parents, but they are trying new strategies, such as community cafés, to ensure community interventions meet the needs of children and families. Despite challenges, ABCD III states have a strong foundation to support improvement in every pilot community, as each community has its own strengths. Participating states will continue to draw from and rely on these assets, while cultivating new processes and relationships that support service provider linkages.

Appendix

Appendix: Partners in ABCD III States

	Families	PCPs	Early Education and Intervention	State Agencies
Arkansas	Family courts/child welfare system; family representatives; AR Advocates for Children and Families; Connect Care; Partners for Inclusive Communities	AR AAP; Arkansas AAFP; Arkansas Foundation for Medical Care; Community Health Centers of Arkansas	AR Early Childhood Association; AR Children's Behavioral Health Commission; AR Early Childhood Commission; Head Start	Division of Child Care and Early Childhood Education; Department of Human Services; Medicaid, Division of Behavioral Health, Division of Developmental Disabilities (EI and Children with Special Health Care Needs); Office Of Policy and Planning; Department of Health: Title V and Local Public Health; Department of Education, Special Education and Coordinated School Health; University of Arkansas for Medical Sciences
Illinois	EDOPC; AOK Network; EI local interagency councils; local Child and Family Connections offices; the DSCC Title V Family Advisory Council; the DCFS Strengthening Families project; the DMH Family Consumer Specialists; and Voices for Illinois Children	Illinois AAP	Advocate Health Care Healthy Steps Program; The Ounce of Prevention Fund; the Illinois Children's Mental Health Partnership	Medicaid / Department of Healthcare and Family Services; Department of Human Services' Divisions of Mental Health; Community Health (Early Intervention; WIC and Family Case Management); and Human Capital Development (Head Start/Early Head Start)
Minnesota	Minnesota ParentsKnow; Minnesota's statewide Help Me Grow; MnCHIP	Minnesota Medical Home Project; AAP; National Association of Pediatric Nurse Practitioners	Local Interagency Early Intervention Agencies	Medicaid and Children's Mental Health/ Department of Human Services; Head Start, Early Childhood Screening and Help Me Grow/ Department of Education; Maternal and Child Health Title V Program/ Minnesota Department of Health
Oklahoma	The Oklahoma Family Network	OK AAP; University of Oklahoma Department of Pediatrics Child Study Center; University of Oklahoma Department of Family Medicine	Oklahoma Partnership for School Readiness; Sooner SUCCESS	Medicaid / The Oklahoma Health Care Authority; Department of Health-Child Guidance; Department of Education SoonerStart (EI) program
Oregon	Family representatives from CYSHN and EI services	Medical Directors of Oregon Health Plan, Managed Care Organizations; OR Pediatric Society and Quality Improvement Committee; OR START Project; Oregon Pediatric Improvement Partnership	Help Me Grow Project; United Way of Lane County; Regional EI contractors	Medicaid; Department of Human Services; Maternal and Child Health Title V Program; Department of Education, Early Intervention; Oregon Center for Children and Youth with Special Health Needs; Oregon Health and Science University

AAP – American Academy of Pediatrics; AAFP – American Academy of Family Physicians; AOK – All our Kids Early Childhood Network; CYSHN – Children and Youth with Special Health Needs; EDOPC –Enhancing Developmentally Oriented Primary Care Project; EI – Early Intervention; START – Screening Tools And Referral Training; WIC –Special Supplemental Nutrition Program for Women, Infants, and Children

Endnotes

1 J. Shonkoff and D. Phillips (Eds.), Committee on Integrating the Science of Early Childhood Development, *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: National Research Council and Institute of Medicine, 2000.

2 See for example, N. Kaye and J. May, *State Strategies to Support Practice Changes that Improve Identification of Children at Risk for or with Developmental Delays: Findings from the ABCD Screening Academy*. (Portland ME: National Academy for State Health Policy (NASHP), March 2009), and N. Kaye and J. Rosenthal, *Improving the Delivery of Health Care that Supports Young Children's Healthy Mental Development: Update on Accomplishments and Lessons from a Five-State Consortium* (Portland ME: NASHP, February 2008).

3 K. Hebbeler et al., *Early Intervention for Infants and Toddlers with Disabilities and their Families: Participants, Services, and Outcomes*, Final Report of the National Early Intervention Longitudinal Study (NEILS). (Menlo Park, CA: SRI International, 2007).

4 R.C. Antonelli,, J.W. McAllister, and J. Popp. *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework*. (New York, NY: The Commonwealth Fund, May 2009), vii.

5 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.

6 K. Johnson and J. Rosenthal, *Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States* (Portland, ME: The Commonwealth Fund and NASHP, April 2009).

7 N. Kaye and J. Rosenthal, *Improving the Delivery of Health Care that Supports Young Children's Healthy Mental Development.*

8 For more information on Arkansas' Early Comprehensive Childhood Systems workgroup please visit: Arkansas Department of Human Services Division of Child Care and Early Childhood Education. "Arkansas Early Childhood Comprehensive Systems Initiative." Retrieved October 28, 2010. http://www.arkansas.gov/childcare/services/aeccsi/.

9 Minnesota Chapter American Academy of Pediatrics. "Projects: Minnesota Child Health Improvement Partnership." Retrieved October 28, 2010. http://www.mnaap.org/projects/improvementpartnership.htm

10 Federal law requires states where Medicaid beneficiaries must enroll in MCOs to carry out a number of activities to assess the quality of care that beneficiaries receive including hire an External Quality Review Organization (EQRO) or EQR-like entity for certain activities, and have the MCOs conduct PIPs to measure and implement interventions to improve performance.

11 National Alliance of Children's Trust and Prevention Funds. "Effective Partnerships with Parents: Community Cafés." Retrieved October 28, 2010. https://www.msu.edu/user/nactpf/initiative_parents-2.htm

12 http://www.strengtheningfamiliesillinois.org/index.php/line/category/parent_cafe/

13 For more information on Model for Improvement and PDSA please visit: Institute for Health Care Improvement. "How to Improve: Improvement Methods." Retrieved October 28, 2010. http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/HowToImprove/.

14 For additional information, see: Cover Missouri. "Grant or Pilot Program Opportunities in Federal Health Reform with a Primary Care or Patient Centered Medical Home Component" St. Louis, MO: Missouri Foundation for Health, 2010. Retrieved October 28, 2010. http://www.mffh.org/mm/files/Grant%20Opportunities%20-%20Primary%20Care.pdf