

THE ENDURING INFLUENCE OF THE  
ASSURING BETTER CHILD HEALTH AND  
DEVELOPMENT (ABCD) INITIATIVE

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and Larry Hinkle*

JULY 2013

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## EXECUTIVE SUMMARY

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In May of 1999, the National Academy for State Health Policy and The Commonwealth Fund launched the Assuring Better Child Health and Development (ABCD) Program. The program was designed to assist states in improving the delivery of early childhood development services for low-income children and their families by strengthening the systems that support healthy child development of children ages 0-3. The first ABCD consortium (ABCD I) engaged four states beginning in 2000. ABCD I concluded in 2003 and has since been followed by ABCD II (2003-2007), the ABCD Screening Academy (2007-2009), and ABCD III (2009-2012).

Over the course of a decade, 25 states, the District of Columbia, and Puerto Rico made many policy changes and improvements that strengthen the systems supporting healthy child development. The ABCD states have:

- Increased identification of children with developmental delays or at risk for delays;
- Improved referral, information-sharing, and feedback mechanisms;
- Improved access to follow-up treatment; and
- Improved care coordination across systems of care.

To reach these achievements, the ABCD states tested a number of different levers and strategies. Critical factors that led to state successes include:

- State Medicaid agencies as an important driver of systems change;
- Partnerships across systems, providers, and support services to improve child development;
- Engagement and leadership of physicians;
- Engagement of families as partners in services, programs, and policies;
- Improvements at multiple levels that support and reinforce each other;
- Use of data to demonstrate results and build support for sustainability; and
- Learning collaboratives as a forum for sharing and learning across states.

This report provides a rationale for the focus and priorities of the ABCD initiative, a high-level snapshot of impact and critical success factors. It describes how states have leveraged national policies to succeed and how, in turn, states have influenced federal policies, along with areas for continued improvement.

The legacy of the ABCD program lies in the successes of the participating states in making practice, community, and policy level improvements to promote healthy child development; the improvements that have occurred at the federal level; and lessons learned about policy and practice-level quality improvement that transfer to other initiatives. As states continue to address issues related to early childhood development, the implications of the ABCD initiative and the examples from participating states offer lessons, strategies, and policies that can continue to make a difference in the health and development of young children.

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## INTRODUCTION

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Over the course of 12 years, NASHP and The Commonwealth Fund have partnered to support 27 Medicaid programs in their efforts to improve the delivery and financing of early childhood development services for low-income children. The Assuring Better Child Health and Development (ABCD) initiative brought together state Medicaid agencies and their partners to develop innovations and test models that focused on enhancing the capacity of states to: identify low-income children at risk for developmental delay through the use of standardized screening and assessment tools; connect children and their families to necessary services; and build sustainable models of coordinated care. Although ABCD is coming to an end, there are many important ideas and lessons that can help ensure that our country's youngest citizens have a chance to mature into healthy, successful, productive adults, and to improve systems of care for all populations.

This paper provides a rationale for the focus and priorities of the ABCD initiative, a high-level snapshot of impact, and identification of critical success factors. It draws on more than 27 reports originated from this project as well as a meeting that took place in February 2013 that brought together a group of federal and state leaders to discuss the impact and lessons of this work.<sup>1</sup>

### WHY FOCUS ON EARLY CHILDHOOD DEVELOPMENT?

Research shows that from birth to age five, a child's brain develops at a very rapid pace and that early experiences, whether positive or negative, can have a significant impact on their current and future development.<sup>2</sup> Children go through predictable stages of development:

- Physical — Mastering movement through use of small and large muscles, such as a baby raising his/her head to a toddler kicking a ball.
- Cognitive/Intellectual — Advances in neuroscience illustrate the importance of focusing on the intellectual needs of a child in the early years, when “the wiring of the brain,” the connections that occur between the brain's neurons, is at the highest point in a person's lifetime.<sup>3</sup>
- Social and emotional — Managing and recognizing one's own behavior and feelings, as well as those of others. Studies demonstrate that children with poor social and emotional skills are at greater risk for developing aggressive behaviors as older children and adults.<sup>4</sup>
- Speech and language — Understanding and using language to communicate.

If a child does not reach certain developmental milestones (skills acquired within a specific time frame) then he/she may be at risk for developmental delay.

The Centers for Disease Control and Prevention estimates that about one in six children has a developmental disability.<sup>5</sup> Children with developmental problems are at increased risk for poor outcomes in many areas important to health, well-being and success in life. Depending on severity, developmental disorders increase a child's risk for poor school performance, frequent absences from school, repeating a grade, and placement in special education programs, as well as increased health problems. It is important to identify potential developmental delays as early as possible since “the critical foundations for learning, school success, health and general well-being are established well before a child enters kindergarten.”<sup>6</sup> Nevertheless, fewer than 50 percent of these children are identified before starting school.

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## WHY LINK AN EARLY CHILDHOOD DEVELOPMENT PROJECT TO MEDICAID?

Half of the children under the age of six (11.4 million) residing in the United States live in low-income or poor families.<sup>7</sup> Numerous studies demonstrate that poverty has a significant impact on a child's development and that these children are at greater risk of developmental delay than children who are not poor.<sup>8</sup> Evidence indicates that infants from low-income families as young as nine months already lag developmentally behind their higher-income peers.<sup>9</sup> Additionally, children from low-income families, identified by their receipt of public insurance such as Medicaid or CHIP, experience Adverse Childhood Experiences, defined as childhood abuse, neglect, and exposure to other traumatic stressors, at a much higher rate than children from more affluent families on private health insurance.<sup>10,11</sup>

Medicaid plays an important role in the delivery of comprehensive health care services to young children living in poverty and is the primary source of funding for child developmental services.<sup>12</sup> One in three children under the age of six qualifies for Medicaid's benefits and services.<sup>13</sup> Through Medicaid, children under six whose families earn below 133 percent of the federal poverty level (\$31,322 for a family of four in 2013) are entitled to receive the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. EPSDT provides a wide-ranging set of age-appropriate services and benefits that includes screenings to detect physical and mental conditions as well as treatment.

## NASHP'S ROLE IN ASSURING BETTER CHILD HEALTH AND DEVELOPMENT

The Commonwealth Fund and NASHP partnered to create the ABCD initiative to assist states in improving the delivery of early child developmental services through their Medicaid programs. NASHP has administered ABCD since 1999; states began receiving funding in 2000. Since that time NASHP has supported 25 states, the District of Columbia and Puerto Rico in their efforts to enhance the capacity of Medicaid programs to support child developmental services. Each of the four ABCD projects had a distinct focus:

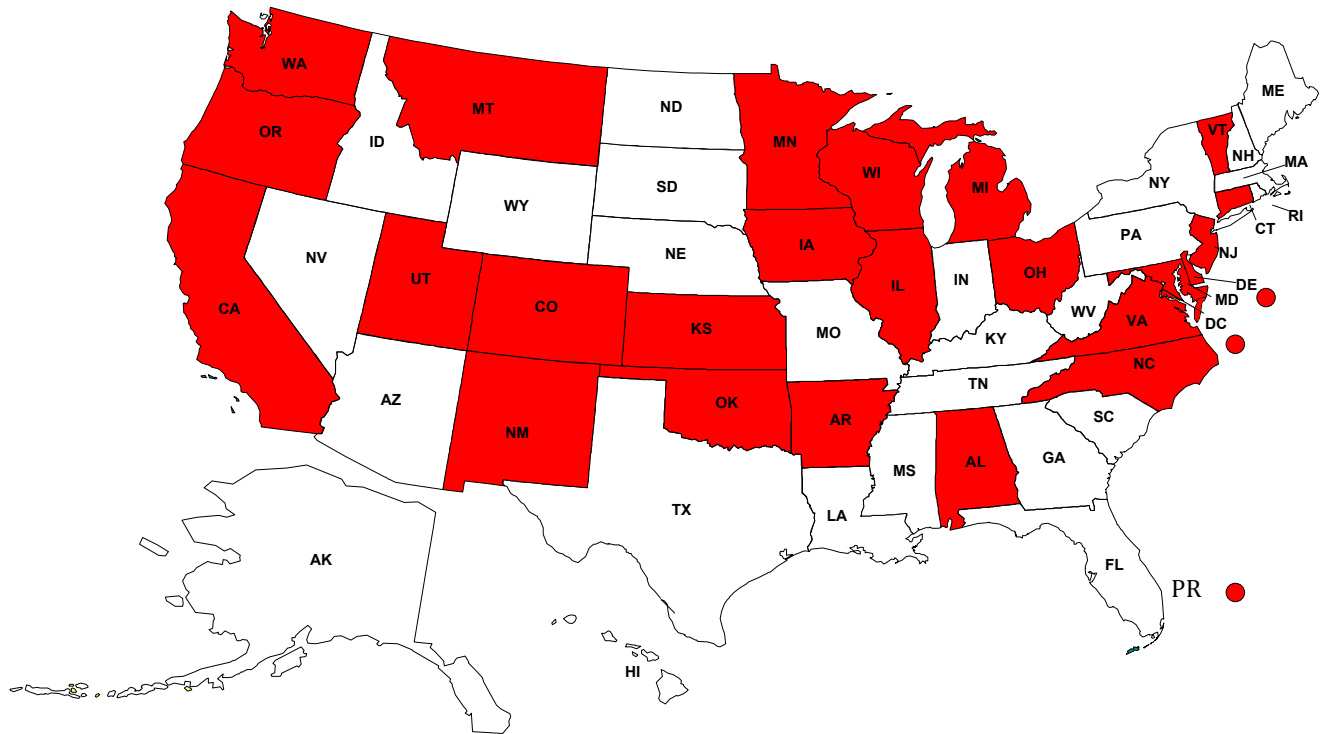
- From 2000 to 2003, the first collaborative (ABCD I) focused on developing, expanding or improving service delivery, such as designing and implementing screening and assessment tools, improving coordination across state agencies, and offering recommendations to change Medicaid policies.<sup>14</sup> Grants were awarded to four states: North Carolina, Utah, Vermont, and Washington.
- From 2003 to 2006, the second learning collaborative (ABCD II) focused on building the capacity of Medicaid programs to better support children at risk for or with social and emotional delays by identifying these children and connecting them to appropriate services. Grants were awarded to five states: California, Illinois, Iowa, Minnesota and Utah.<sup>15</sup>
- NASHP's ABCD Screening Academy supported a learning community by providing technical support to assist 19 states, Puerto Rico, and the District of Columbia in their efforts to replicate the successes of ABCD II. The Screening Academy was launched in 2007 and lasted 14 months.<sup>16</sup>
- The most recent collaborative (October 2009 – October 2012), ABCD III, sought to develop and test sustainable models for improving care coordination across different providers. Grants were awarded to five states: Arkansas, Illinois, Minnesota, Oklahoma and Oregon.<sup>17</sup>

Lessons and best practices identified throughout the course of this work have been disseminated across the country by way of in-person convenings, issue briefs, national webinars, NASHP's Annual State Health Policy Conference, a listserv for ABCD alumni, and creation of the ABCD Resource Center, located on NASHP's website.<sup>18</sup>

Figure 1 highlights those states that have participated in ABCD.

Figure 1. ABCD States

Shaded states participated in at least one ABCD initiative.





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## ABCD'S IMPACT ON EARLY CHILDHOOD DEVELOPMENT SERVICES

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**A**BCD has focused on increased identification of children with or at risk for developmental delays, referral for follow up assessment and services, improved access to treatment, and coordination across systems that care for young children. This section reviews achievements in each of those areas with specific state examples.

### INCREASED IDENTIFICATION OF CHILDREN WITH DEVELOPMENTAL DELAYS OR AT RISK OF DELAYS

The importance of identifying developmental delay in children as early as possible is widely acknowledged.

Evidence indicates that pediatric primary care providers (PCPs) who use a standardized, validated, developmental screening tool more effectively identify children at risk for developmental delay than those who rely only on medical judgment.<sup>19</sup> However, not all PCPs use a standardized identification and surveillance process, including the use of validated developmental screening tools and assessments, to monitor children's development, and many solely rely on their own observations.<sup>20,21</sup> Such reliance on informal methods is a factor in the low rates of identification; only 30 percent of children with developmental delay are identified.<sup>22</sup>

The number of children receiving a screen using a validated instrument was only 30.8 percent in 2011/2012, yet the percentage has increased from a 19.5 percent screening rate in 2007, and all but one state saw improvements in screening rates.<sup>23</sup> Medicaid programs particularly have made great strides in this area, many of which participated in the ABCD initiative (see Figure 2, next page).<sup>24</sup> In 14 states, participating Medicaid providers are required to perform a standardized developmental screening as part of certain well-child exams.<sup>25</sup> In fact, research has shown that children with public insurance are more likely to receive a developmental screen than children with private insurance.<sup>26</sup>

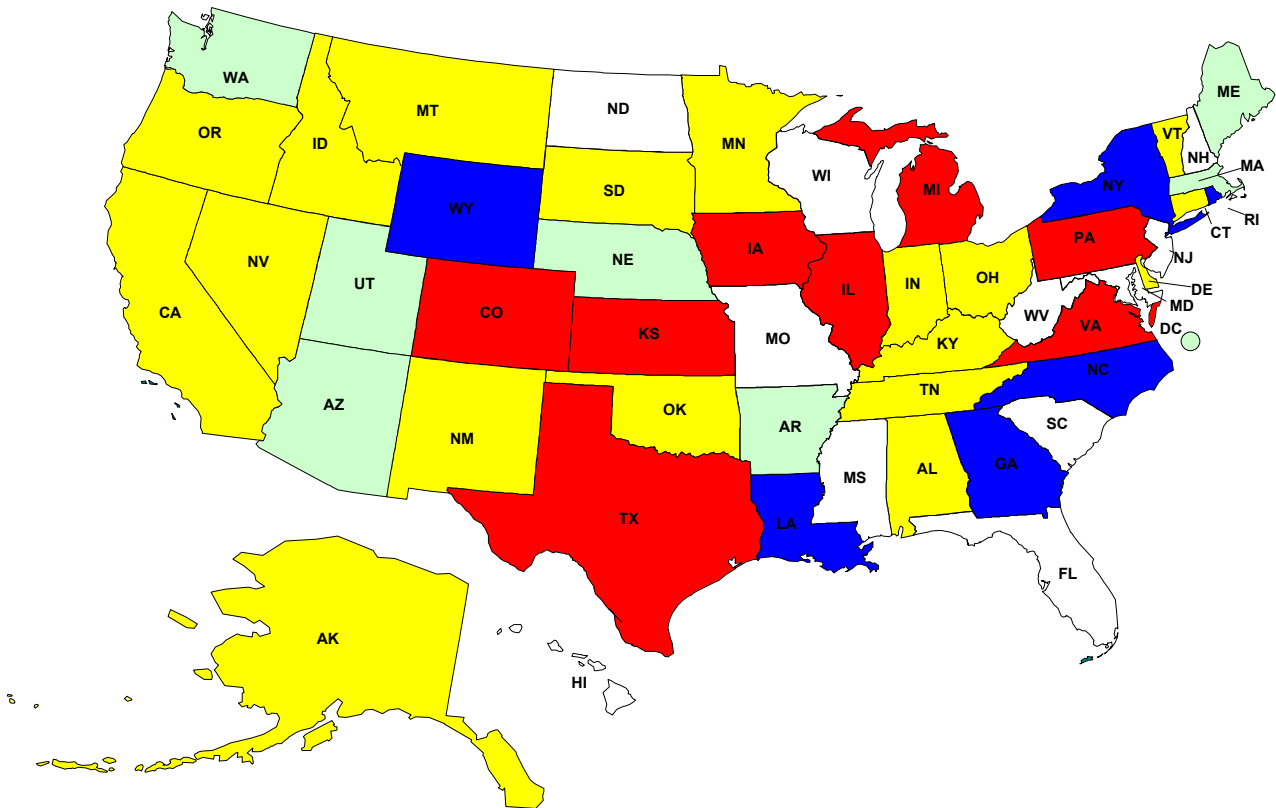
Despite the strides made in some states to require Medicaid providers to perform developmental screenings during well-child visits, only 61 percent of infants covered by Medicaid had six or more well-child visits during their first 15 months; below the Bright Future's recommended guidelines of nine well-child visits for this age range, and not every state requires that a developmental screening be conducted as part of a well-child visit.<sup>27,28</sup> However, all five states that participated in ABCD II saw primary care practices in their pilot initiatives increase their use of standardized screening tools during well-child visits and in four of these states, screening rates in the pilots exceeded 75 percent.<sup>29</sup> The two states with the highest developmental screening rates on the 2007 National Survey of Children's Health, a survey administered by the Child and Adolescent Health Measurement Initiative (CAMHI), are Minnesota and North Carolina, states that have been intimately involved in the ABCD initiative.<sup>30</sup>

### Colorado

"Since the inception of ABCD [in Colorado], we have increased the number of pediatric practices that use a standardized developmental screening tool as a routine component of well child visits from less than 5% to 70%."

*Eileen Bennett, Colorado ABCD State Coordinator, "Seven Years of ABCD In Colorado," National Academy for State Health Policy, ABCD Electronic Resource Center: [Colorado Page](#), November 2012.*

**Figure 2. State Medicaid Requirements and Reimbursement Policies On Developmental Screening, April 2011**



**Figure 2 Key:**

**Red:** State Medicaid program requires standardized developmental screening as part of well-child exams and pays an additional fee beyond the usual well-child care reimbursement for this screening.\* (8)

**Blue:** State Medicaid program requires standardized developmental screening as part of well-child exams, but does not pay an additional fee beyond the usual well-child care reimbursement for this screening. (6)

**Yellow:** State Medicaid program pays an additional fee beyond the usual well-child care reimbursement for standardized developmental screening, but does not require this screening as part of well-child exams. (18)

**Light Green:** State Medicaid program does not require standardized developmental screening as part of well-child exams and does not pay an additional fee beyond the usual well-child care reimbursement for the screening. (7 states and D.C.)

**White:** State did not respond. (11)

\* The **Colorado** Medicaid program requires the use of a standardized screening tool, but the screening is not required to be completed at a well-child check. It can be completed at other times of the year (e.g. sick-child visits). It is paid under a separate code.

North Carolina's participation in the first cohort of ABCD states has propelled the state to lead the nation in developmental and behavioral health screenings for children up to age 5. Seventy-five percent of EPSDT exams for children up to 5 include a developmental screen, and the state requires the use of standardized screening tools during specific well-child visits in order to receive Medicaid reimbursement.<sup>31</sup> North Carolina involves parents in identifying developmental delay by having them complete an Ages and Stages Questionnaire, a standardized screening tool, while waiting to see the child's PCP. This approach has helped open the lines of communication between a child's family and primary health care provider.<sup>32,33</sup>

Some of the states participating in the ABCD initiative sought to improve the identification and treatment of children at risk for or with developmental delay by improving their payment policies. States employ different financing incentives to increase the use of standardized screening tools, as shown in Figure 2. In 26 states, the Medicaid program pays an additional fee for standardized screening. Some states reimburse for more than one type of screen during a well-child visit. For example, Minnesota's Medicaid program reimburses providers who conduct a social emotional developmental screen, in addition to a general developmental screen, to help identify infants and toddlers experiencing mental health concerns.<sup>34</sup>

States are also exploring opportunities to incorporate screening practices into developing delivery system models, including Accountable Care Organizations, medical homes, and others. North Carolina started by implementing screening through its Community Care of North Carolina (CCNC) networks. In Oklahoma, the state is pursuing changes that will make developmental screening and follow-up a requirement for all three tiers of medical home recognition in the state.<sup>35</sup> Oregon has made developmental screening a "must pass element" in its revised Patient Centered Primary Care Homes (PCPCH) standards to be released in October 2013 and an incentive metric for its Coordinated Care Organizations (CCOs). As one of 17 incentive measures for which the Oregon Health Authority collects and reports data, CCOs must reach benchmarks on these measures to receive quality pool funding.<sup>36</sup>

### **IMPROVED REFERRAL, INFORMATION-SHARING, AND FEEDBACK MECHANISMS**

Once primary care providers identify children as at risk for or experiencing developmental delay, they often need to refer their families to community resources or Early Intervention agencies for follow-up assessment or additional services. However, some primary care providers are unsure of where to refer children in need of additional supports and doubt their ability to conduct further assessments.<sup>37</sup>

A critical need exists for strategies that ensure appropriate and timely referral by primary care providers after screening and subsequent communication of referral results back to the primary care provider. ABCD states have fostered information sharing between medical and non-medical providers by developing standardized referral and feedback forms and protocols, simplifying practices to meet state and federal health and education privacy and consent requirements (the Health Insurance Portability and Accountability act (HIPAA,) and the Federal Educational Rights and Privacy Act (FERPA,) respectively), and creating mechanisms for closing the referral feedback loop once a primary care provider refers a child to

## **North Carolina**

"As a result of ABCD [in North Carolina], children with developmental needs are identified earlier. Referrals to the Early Intervention program are on average made at an earlier age, and have more than quintupled since 2004."

*Marian Earls, MD, Lead Pediatric Consultant, Community Care of North Carolina, "Comments: 12 Years of ABCD," National Academy for State Health Policy, ABCD Electronic Resource Center: [North Carolina Page](#), November 2012.*

Early Intervention.<sup>38</sup> Having standardized forms and processes in place allows for improved communication between those involved in caring and nurturing a young child.

For example, Illinois developed standardized referral and feedback forms, as well as a summary version of an individualized family service plan<sup>39</sup> to help facilitate communication between medical and non-medical providers. In addition, the state is seeking to create an electronic exchange of data between the state's Early Intervention program that serves children age birth to 36 months and the child's primary care medical home. This exchange of information systematizes and standardizes communication from Early Intervention to the PCPs about the result of a referral and ensures that the PCP is notified of the referral outcome.<sup>40</sup> The objective of this effort is to ensure that the child's primary health care provider is aware of the services being provided to that child in order to better coordinate care. Illinois is currently expanding its cross-agency electronic data sharing system to include referrals to Family Case Management for high-risk pregnant women.<sup>41</sup>

## Illinois

"Throughout Illinois' involvement in ABCD, we have created system changes to improve early childhood developmental screening rates among providers through public/private partnerships, and greatly improved communication and referral processes between primary care providers and Early Intervention offices. I am very pleased with our progress."

*Theresa Eagleson, Administrator, Division of Medical Programs, Illinois Department of Healthcare and Family Services. Quote Provided for NASHP State Health Policy E-News, "Success in ABCD: Spotlight on Illinois," March 12, 2013.*

Oklahoma built a referral and feedback mechanism into an existing Web portal, the Preventive Services Reminder System (PSRS), originally designed to improve preventive care among primary care practices. The state's ABCD III project added a new component — "Request for Early Childhood Services" — to the

## Oklahoma

"In the portal's first 16 months, we've seen on average over a month's time shaved off closing the communication loop. The portal also showed us that the right children are being referred (~75% were found eligible for EI)."

*Laura McGuinn, MD, Associate Professor of Pediatrics, University of Oklahoma Health Sciences Center. Quote Provided for NASHP State Health Policy E-News, "Success in ABCD: Spotlight on Oklahoma," March 26, 2013.*

PSRS that allows a PCP participating in the pilot to request that a child be assessed for developmental delay. The request is then emailed to a county-based team who determines which agency will assess the child. Once the child is assessed and eligibility for state services is determined, the agency that assessed the child will input all relevant information to the Web portal and the PCP will be notified by email and will be able to review the information sent by the county team, which can be added to the child's medical records.<sup>42</sup>

### IMPROVED ACCESS TO FOLLOW-UP TREATMENT

Once a child is identified with a developmental delay or at risk for developmental delay, it is

important to connect the child and the family to appropriate supportive services. However, there is a dearth of resources available for young children and their families, particularly for early childhood mental health services. In addition, many children who are found to be ineligible for Early Intervention services according to state guidelines fall through the cracks. As a result, many ABCD states have attempted to expand access to services or create new services for children and families.

One aspect of Minnesota's ABCD II project focused on expanding mental health treatment for children who were screened and identified as at risk. The project led to the creation of the Children's Therapeutic Services and Support benefit, which seeks to provide a wide range of mental health services to children diagnosed with emotional disturbances. The benefit includes skill-building services for the child and the child's family. The state also tested a potential new Medicaid service tailored for children whose social emotional development was identified at risk but who did not have a diagnostic label.<sup>43</sup>

Since there is strong scientific evidence demonstrating that the physical and mental health of a mother impacts the development of her child, Illinois enacted the Perinatal Mental Health Disorders Prevention and Treatment Act in 2008. This act provides information to women and their families about perinatal mental health disorders, develops procedures for assessing women for such disorders during prenatal and postnatal visits, and promotes early detection in order to promote early care and treatment and, when medically appropriate, to avoid medication. Although rules have not yet been promulgated, the act clarified that primary care providers may bill Medicaid for screens used to identify mothers for perinatal depression. If the mother is not herself eligible for Medicaid, Illinois allows the screening to be billed as a risk assessment for the infant, under the infant's identification number for up to one year postpartum. Iowa, Minnesota, and Utah clarified that providers may use the DC:0-3 diagnostic classification system\* to diagnose young children, crosswalk that diagnosis to a DSM diagnosis and bill Medicaid for treatment services. This diagnostic system is specifically designed for young children and enables providers to bill Medicaid for treating young children whose conditions are not adequately reflected in existing classification systems for adult mental health diagnoses.<sup>44</sup>

In Vermont, much of the state's initial ABCD work laid a foundation for Children's Integrated Services, a comprehensive system for prenatal/postpartum mothers, and infants and children birth to six.

## Minnesota

"The ABCD series of projects in Minnesota has been utterly transformative in strengthening the role of primary care and establishing connections between primary care and community agencies to improve services for young children and their families. Needed referrals have increased across sectors, and productive new working relationships have emerged within Minnesota communities."

*Glenace Edwall, Psy.D, Ph.D, MPP, Director, Children's Mental Health Division, Minnesota Department of Human Services. Quote Provided for NASHP State Health Policy E-News, "[Success in ABCD: Spotlight on Minnesota](#)," January 15, 2013.*

## Vermont

"The ABCD community has been a valuable resource to Vermont, and we are very grateful for having had the opportunity to participate."

*Russell Frank, CHIP Director, Vermont Department of Health Access. Quote Provided for NASHP State Health Policy E-News, "[Success in ABCD: Spotlight on Vermont](#)," December 18, 2012.*

\* The Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood (DC:0-3) is designed to help mental health and other professionals recognize mental health and developmental challenges in young children and use diagnostic criteria effectively for classification and intervention. For more information please visit: <http://www.zerotothree.org/child-development/early-childhood-mental-health/dc-0-3-revisions.html>.

## CARE COORDINATION ACROSS SYSTEMS OF CARE

The care that a child receives from the PCP and non-medical providers frequently occurs in silos and is not coordinated. ABCD states recognized that in order to ensure that children are identified, referred, and receive care, it is critical to find ways of promoting and providing incentives for care coordination. Many states sought to make improvements resulting in better coordination to create a “seamless system of care” across providers and other state and local services. ABCD states leveraged policies that provide incentives for cross-system care coordination and embedded care coordination for children within broad statewide, federally supported initiatives such as medical homes, accountable care organizations and managed care performance improvement projects (PIPs).<sup>45</sup> The goal of the ABCD III states in particular was to create an environment where care coordination activities occur as part of routine practice.

Some states have used dedicated staff that can assist in care coordination activities to ensure that children receive follow-up assessment and services. Arkansas has used designated regional “Early Intervention liaisons.” These liaisons support the completion of referrals and facilitate coordination between primary care providers and developmental service providers.<sup>46</sup> Colorado has taken advantage of existing EPSDT Outreach Coordinators to assist families and providers. These coordinators connect families to available low or no-cost community-based services such as food banks, housing agencies, Head Start, and Women, Infants, and Children (WIC) services.<sup>47</sup>

Oregon used lessons from its ABCD III project to inform the development of standards for its Patient-Centered Primary Care Homes (PCPCH). One of the core attributes of a PCPCH in Oregon is coordination and integration, which includes data management, care coordination and care planning.<sup>48</sup> Oregon also leveraged its ability to require that Managed Care Organizations (MCOs) undertake PIPs to promote care coordination by making the ABCD III project an option for the two required PIPs the MCOs must implement. Eight of fifteen MCOs in Oregon chose to implement this PIP, serving nearly 1 in 3 children in the state. The state contracted with the Oregon Pediatric Improvement Partnership (OPIP) to facilitate a Learning Collaborative of these eight MCOs focused on how to engage providers, parents, and EI agencies at the community level to implement activities aimed at improving care coordination for children.<sup>49</sup> Like Oregon, Minnesota’s ABCD III team

## Arkansas

“ABCD III is one of the reasons why we have been so successful in working on our broader care coordination initiatives.”

*Angela Littrell, Infrastructure Development and Implementation Manager, Division of Medical Services, Health Care Innovation Unit, Arkansas Department of Human Services. Quote Provided for NASHP State Health Policy E-News, “[Success in ABCD: Spotlight on Arkansas](#),” December 11, 2012.*

## Iowa

“[The] second phase of the ABCD II Initiative in Iowa is now called the 1<sup>st</sup> Five Healthy Mental Development Initiative and continues to receive state appropriations.... What’s been most rewarding about working on 1<sup>st</sup> Five is to see the impressive strides in practice change for both private and public partners as they work together in this model...These relationships are the cornerstone to creating a more effective support system to responding to the needs of young children.”

*Sonni Vierling, Iowa 1<sup>st</sup> Five Healthy Mental Development State Coordinator, “[7 Years Since ABCD II](#),” National Academy for State Health Policy, ABCD Electronic Resource Center: [Iowa Page](#), January 2013.*

aligned its work with its state health care home standards and the team built upon the standards when establishing protocols.<sup>50</sup> Many practices then considered ABCD III as a step to be taken towards achieving health care home certification.<sup>51</sup>

The ABCD III states also tested and implemented policies to pay for care coordination. Oregon, for example, added the 99366 Current Procedural Terminology (CPT) code, which covers multidisciplinary team conferences, to its Prioritized List of Health Services to allow for reimbursement from Medicaid.<sup>52</sup> Oregon is considering adding the codes 99367 and 99368, also accounting for multidisciplinary team conferences, to the Prioritized List as well.<sup>53</sup> Some states have tied payment for care coordination to medical home standards, and offer a per-member per-month (PMPM) payment for these services.<sup>54</sup>



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## BUILDING BLOCKS OF SUCCESS

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The ABCD experience has demonstrated that Medicaid and other state agencies can play an important role in promoting policy- and practice-level change to improve identification, care, and coordination of services for children with developmental delay. The ABCD collaborative experience highlights critical factors to success that are described below.

### **MEDICAID IS AN IMPORTANT DRIVER OF SYSTEMS CHANGE**

Medicaid agencies played a critical role in leading the development of ABCD projects. From the beginning of ABCD, state Medicaid programs were critical stakeholders because they provide opportunities to improve coordination between a state's health care and child development systems to better support children at risk or with developmental delays.<sup>55</sup> Because Medicaid is a payer of services, the program can significantly influence provider behavior, particularly as it relates to identifying children at risk for developmental delay. Across states, the median rate of children between the ages of 12-24 months covered by Medicaid and CHIP who saw a primary care provider in FY 2011 for at least one primary care visit was 97 percent.<sup>56</sup> Participating Medicaid agencies experimented with various approaches for improving screening rates among primary care providers, coordinating and communicating follow-up care between medical and non-medical providers, and collecting and measuring data to improve policy and procedures.

### **IMPROVING CHILD DEVELOPMENT REQUIRES PARTNERING ACROSS SYSTEMS, PROVIDERS, AND SUPPORT SERVICES**

Often, the services required to address children's developmental needs are segmented across different systems (e.g. the health care, early care and education, and mental health systems) and across different health care providers, including physicians, nurses and therapists; yet the facets of a child's development are all interconnected. An early lesson from ABCD I, carried forward to subsequent years, underscored the importance of interagency/program coordination and partnerships, resulting in improved developmental services.<sup>57</sup> Despite the challenges of coordinating agencies, programs and providers with different perspectives, requirements, service delivery models and funding streams, Medicaid staff recognized the importance of bringing these different entities together to improve policy and outcomes.

ABCD state teams worked together to successfully chip away at systemic barriers that made it difficult for all parties involved to navigate the multiple systems and programs that provide care and support for children identified at risk or with a developmental delay. Throughout the course of the initiative, participating Medicaid programs developed more productive partnerships with other agencies, programs, and providers through stakeholder groups, memoranda of understanding and contracts. State and local partners included other agencies and programs, such as Title V, childcare and Early Intervention; providers, including pediatricians, family doctors, allied health professionals; and community-based nonmedical service providers. The impact of care coordination improvements crosses programs and services. For example, care coordination protocols including screening and referral guidelines that were created by the Illinois ABCD team are being incorporated into protocols for both home visitors and childcare workers.

### **PHYSICIAN ENGAGEMENT AND LEADERSHIP IS CRITICAL FROM THE ONSET**

Early in this initiative, ABCD states recognized that pediatric health care providers play a central role in identifying, referring, and coordinating care for children with or at risk for developmental delay since



nearly all children under the age of five are seen by a pediatric primary care provider.<sup>58</sup> Many participating state agencies strengthened relationships with the American Academy of Pediatrics' state chapters. Providers began to see Medicaid agencies as partners rather than simply payers of services. In many of the ABCD states, Medicaid agencies solicited input from providers through surveys and community meetings to inform interventions. They also shared best practices and provided workshops, training sessions, and manuals to providers. State Medicaid agencies also facilitated primary care practice support and quality improvement techniques that helped providers standardize processes, provide evidence-based care, and improve quality in primary care practice settings.

- In Vermont, the partnership between the Medicaid agency and the Vermont Child Health Improvement Program, a network of pediatric providers, unlocked the flow of communication resulting in the sharing ideas and feedback to improve trainings offered by the state. In addition, many physicians served on advisory committees and were instrumental in communicating policy changes to their peers.<sup>59</sup> Other states, including Minnesota and Oregon, use child health improvement partnerships to ensure public/private sector synergy.

States that participated in ABCD III identified other types of incentives for providers to continue participating in their ABCD programs. For instance, to remain certified by the American Board of Pediatrics, physicians must implement and participate in practice improvement for four components of Maintenance of Certification (MOC). The fourth component (part 4) requires quality improvement activities.<sup>60</sup> The ABCD III states were able to qualify some ABCD quality improvement efforts to receive credit, which created an incentive for practices to implement these activities.

- In Illinois and Minnesota, pediatricians have received credit towards their maintenance of board certification for participating in ABCD initiatives designed to improve developmental screening rates or care coordination.

### **FAMILIES MUST BE ACTIVELY ENGAGED AS PARTNERS**

Recognizing the importance of engaging families as partners in effective identification, follow up services, and care coordination, many of the ABCD states made efforts to reach out to the parents and families of children with or at risk for developmental delay. Because children's health and development is so contingent on the environment in which they are raised as well as the day to day choices that families make, educating and engaging families to build skills for managing a child's care is essential for the health of the child.<sup>61</sup> Developmental screening depends on parent involvement. Tools such as the *Ages and Stages Questionnaire* and the *Parents' Evaluation of Developmental Status* are completed by parents as a mechanism to elicit concerns and recognize parents as experts on their children.

In addition to engaging parents in care for their own child, states that participated in ABCD recognized the need to engage parents in the services and programs they receive, and the larger systems and policies that govern those services.<sup>62</sup> Some of the ABCD states also proactively sought out and engaged parents to serve on leadership teams, get their feedback on materials and services, and provide input on training curriculum.<sup>63</sup>

- Arkansas and Oregon held community cafés to get information on the challenges parents face and ways that care coordination could better assist them in ensuring appropriate services for their children.\*

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\* A community café is a series of guided conversations designed to bring parents together to discuss important issues relevant to them. Cafés provide an opportunity for parents to explore these issues and think about them as a group and to build relationships over time. For more on community cafés see [http://www.ctfalliance.org/initiative\\_parents-2.htm](http://www.ctfalliance.org/initiative_parents-2.htm).

Many states engaged parent groups.

- In Oklahoma, the Oklahoma Family Network has been part of the state and local teams responsible for ensuring that children are referred to appropriate resources.
- In Maryland, the Developmental Screening Advisory Group held quarterly meetings through the Parents Place of Maryland.<sup>64</sup>

Several states incorporated indicators of family satisfaction into their measurement strategies. Studies of families of children with special health care needs (CSHCN) have repeatedly found the value that families place on care coordination and the benefits they receive.<sup>65</sup>

### **IMPROVEMENTS AT MULTIPLE LEVELS (PRIMARY CARE PRACTICE, COMMUNITY & STATE POLICY) SUPPORT AND REINFORCE EACH OTHER**

ABCD states served as “testing grounds” for many policy and practice innovations that have not only improved child development services but have also been leveraged to improve the care of other populations. Testing models at the local level has helped to build effective policies and spread innovations.

Many of the state innovations supported by the ABCD initiative began as small locally-based pilot projects at the primary care or community level and led to improved state services and policies.

- Colorado participated in NASHP’s Screening Academy to learn promising practices to improve the use of standardized developmental screening tools among pediatric primary care providers during routine well-child visits. Colorado’s ABCD project, led by a partnership of pediatric primary health care providers, parents, leaders from state agencies, and major health care systems, as well as other stakeholders, began as a pilot project in one county in 2005 and was expanded statewide two years later due to its success.<sup>66</sup> Most recently, ABCD Colorado became institutionalized as its own state entity and other state screening initiatives are turning to the ABCD project for assistance.

### **DATA THAT DEMONSTRATES RESULTS BUILDS A CASE FOR SUSTAINABILITY**

Collecting, analyzing, and evaluating data helps make the case for improving policy and procedures. Measurement also brings attention to issues. The ABCD II, Screening Academy, and ABCD III programs required participating states to collect data and measure results to make the case for sustaining and spreading their efforts once the grant funding for their projects ended. Each ABCD state was required to identify, measure and evaluate indicators that would be most useful to its state, as well as a mutually agreed-upon indicator across states. The ABCD II states collectively decided to evaluate the percentage of children who were screened using a standardized screening tool. Although each state used different indicators, they all were able to demonstrate that the pilot practices increased the rate of developmental screening through the course of the initiative. For Iowa, this measure provided sufficient evidence to result in the Legislature funding the initiative after the grant ended. Through ABCD III, all of the participating states measured how often a primary care provider who refers a child for follow-up services is aware of the results of the referral. Improved measurement and monitoring systems are critical to support the significant number of children who receive a positive screen and a referral, but who do not make it to the referral source and fall through the cracks in programs.

- The use of standardized screening tools among pediatricians in Colorado increased significantly from 5 percent at the beginning of the project to 60 percent.<sup>67</sup>

- Oklahoma found through its ABCD III project that of 364 children referred for services, the PCP received information about the result of that referral for 288 of them, a completion rate of 79 percent. Previously the state had no way of tracking this information.<sup>68</sup>

### **COLLABORATIVES PROVIDE A FORUM FOR SHARING AND LEARNING ACROSS PARTICIPATING STATES**

Through the ABCD Initiative, NASHP established a learning collaborative model that has since been replicated in other projects. The learning collaborative model provides a forum for participating states to work together over time and share their successes and challenges with their peers. Participating states have been able to test, modify and evaluate their policy and process innovations. In addition, NASHP staff has intensively supported states through the provision of technical assistance, bringing both internal and external experts to support states' efforts to improve child developmental services. An external evaluation of ABCD I found that due to the learning collaborative model "all states implemented programs that addressed their stated goals and made changes in Medicaid policies, regulations, or reimbursement mechanisms."<sup>69</sup> The study concluded that, "even a modest level of external support and technical assistance can stimulate significant programmatic change and inter-organizational linkages within public agencies to enhance provision of child development services."<sup>70</sup>

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## COMPLEMENTARY NATIONAL AND STATE EFFORTS FACILITATE IMPROVEMENT AND IDENTIFY NEXT STEPS

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**T**hroughout the course of ABCD, states and federal partners have shared strategies, successes, and challenges, resulting in improvements at both the state and federal level. States leveraged national policies to succeed and, in turn, influenced those policies. The following sections describe some of these influences, and remaining areas in which a coordinated state and federal approach can improve early child development initiatives.

### **SETTING BENCHMARKS AND MEASURING PROGRESS**

ABCD helped inform quality indicators for children's health. The Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 required that quality measures be established to measure child health. The efforts of the ABCD states to measure developmental screening was an impetus for the selection of developmental screening for inclusion in the CHIPRA Core Measurement set with specifications based on learning from the ABCD effort and on collective input received from the ABCD community.<sup>71</sup> Released in early 2011, the core set of quality measures includes the percentage of children screened for risk of developmental, behavioral, and social delays using a standardized screening tool in the 12 months preceding their first, second, or third birthday. According to a federal report, seven states have begun to collect this data over the past year.<sup>72</sup> Inclusion of this measure in the CHIPRA core measure specifications has increased a national and state-level focus on developmental screening. Experts believe that having this measure may increase the use of standardized screenings.<sup>73</sup>

### **Next steps**

Despite success in establishing developmental screening as a core measure for CHIPRA, implementation of the measure remains problematic. Anecdotally, some ABCD states are noticing a decrease in the rate of developmental screening that coincides with the use of Electronic Health Records, because some EHRs have templates for screening that do not conform to standardized objective developmental screening instruments. The EHRs also may not have a format that allows providers to attach the results of the screening process. Efforts to address this challenge include:

- The Agency for Healthcare Research and Quality (AHRQ), as part of the CHIPRA Centers for Excellence initiative, is sponsoring the Pediatric Measure Center of Excellence Developmental Screening and Follow up Work Group, which is responsible for recommending measures and measurement strategies for developmental screening in state Medicaid/CHIP programs. This Work Group includes members who have been leaders in state ABCD initiatives.
- AHRQ has developed the Children's EHR Format, designed to bridge the gap between the functionality present in most current EHRs and the functionality necessary for an EHR to be able to address the specific needs of children – particularly those enrolled in Medicaid or CHIP.<sup>74</sup>
- Federal agencies and stakeholder groups are examining mechanisms to validate a public domain developmental screening tool to enhance the likelihood of incorporating standardized screening tools into EHRs.

### **PROMOTING AND ALIGNING SCREENING EFFORTS**

The experience of ABCD states in promoting developmental screening has both informed, and been supported by, federal policy. In late 2011, the Centers for Medicare and Medicaid Services (CMS) issued

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the 2012 RBRVS Final Rule that would make CPT (Current Procedural Terminology) code 96110 ineligible for Medicare payment. Primary care providers use CPT code 96110 to receive reimbursement from the federal Medicaid program for developmental screening services. The rule caused confusion and concern among states and providers about the impact since Medicaid and private payers often depend on Medicare payment rules. ABCD states were instrumental in providing valuable feedback to CMS on the potential negative repercussions of this change for children and families. CMS' decision to provide further guidance on the 96110 code was a very important improvement in the policy, clarifying that the Final Rule has no impact on Medicaid payment for code 96110.

### **Next steps**

Despite increasing recognition of the value for developmental screening, there is a risk of diluting its effect through duplicate and uncoordinated screening among various health and education programs. If children are repeatedly screened within a variety of programs and the results are not communicated or coordinated, families may perceive a lack of benefit. A partnership of federal agencies within HHS, spearheaded by the Administration for Children and Families, is examining ways to integrate developmental screening into systems of care for children under the age of five. The results of this partnership could help states ensure that all kids are screened appropriately (i.e. screened at appropriate intervals without redundant screening by various programs, with results used to inform care delivery).

### **IMPROVING REFERRAL AND INFORMATION SHARING**

The ABCD states have identified the EHR Incentive Program, particularly Meaningful Use objectives, as a strategy for promoting referral and information sharing. Participants who wish to receive incentive payments to improve care coordination must report on a subset of clinical quality measures provided by the federal government.<sup>75</sup> Among these measures is “closing the referral loop: receipt of specialist report,” which seeks to measure the “percentage of patients with referrals...for which the referring provider receives a report from the provider to whom the patient was referred.”<sup>76</sup> This measure aligns with the common outcome among the ABCD III states, which now have experience testing such a measure.

### **Next steps**

As mentioned previously, privacy and confidentiality requirements of HIPAA and FERPA regulations continue to create difficulties in sharing of information needed to coordinate care between medical and non-medical providers. There have been several efforts to facilitate information sharing, including the following:

- CMS has authorized a forthcoming report on HIPAA and FERPA issues to identify barriers and make recommendations.
- The Uninterrupted Scholars Act of 2013 amends FERPA and expands exceptions under which an educational agency may release a student's education records absent parental consent and generally allows schools to release a student's education records to a caseworker, or other party that has the right to access the student's case plan.<sup>77</sup> The expansion of FERPA exceptions will assist in the sharing of information between EI and providers.
- The Office of Special Education Programs (OSEP) is promoting states' development and use of coordinated early childhood data systems that link data on infants, toddlers, and young children with disabilities with data in other early childhood data systems and have longitudinal linkages to data systems for older children. OSEP has funded the Center for IDEA Early Childhood Data Systems

(DaSy), a technical assistance center, to assist state agencies with the development or enhancement of data systems for early intervention and early childhood special education programs supported through the Individuals with Disabilities Education Act (IDEA).<sup>78</sup> These data systems will improve state capacity to collect, analyze, and report high-quality data that are required under IDEA.

## COORDINATING CARE

The efforts of the ABCD III states in improving care coordination and linkages to services have presaged a growing national effort to improve care coordination. Many current Federal initiatives promote the development of delivery systems that rely on increased care coordination.

- The Center for Medicare and Medicaid Innovation’s (CMMI’s) State Innovation Models (SIM) initiative supports states in reforming their delivery systems and payment models.<sup>79</sup> Many of the states that received a SIM Testing Award to implement a State Health Care Innovation plan included strategies in their plans to improve care coordination.<sup>80</sup> Among the testing states are two ABCD III states, Arkansas and Oregon, both of which have included strategies to improve care coordination statewide.<sup>81</sup>
- CMMI’s Comprehensive Primary Care Initiative (CPCI) is a multi-payer initiative designed to foster collaboration between public and private payers to strengthen primary care. Through this initiative, Medicare works with commercial and state health insurance plans to provide bonus payments to PCPs who are better able to coordinate care for their patients. Additionally, participating practices receive resources that assist in providing better care coordination.<sup>82</sup> All of the four states participating in CPCI statewide have participated in ABCD (Arkansas, Colorado, New Jersey, and Oregon).
- In regard to children, the EPSDT Integrated Care Subgroup of the National EPSDT Workgroup has identified care coordination as one of its core priorities for children. The Subgroup is developing a document for states that describes CMS policies related to care coordination under current authorities as well as a guide detailing effective state strategies for promoting care coordination that will be informed by the success of the ABCD states.

### Next steps

As much as care coordination has become a focus of health delivery reform initiatives, a gap remains in coordination between health care delivery, public health, and other social determinants that impact child development. Participants at the ABCD February 2013 meeting emphasized the need for greater recognition of the impact of family stressors and adverse childhood experiences to child health and development. Screening and interventions for perinatal depression, family stress, violence, trauma, and mental health issues are crucial for addressing long-term health and mental health of children and families. The business case for investment in early child development through the identification and amelioration of these factors needs to be amplified.

### Oregon

“What’s made the ABCD project so rewarding is... the knowledge that behind the measureable success are children who now have a lifetime of well-being as the result of this collaborative effort.”

*Charles Gallia, Senior Policy Advisor, Oregon Health Authority. Quote Provided for NASHP State Health Policy E-News, “Success in ABCD: Spotlight on Oregon,” April 23, 2013.*

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## CONCLUSION

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**T**he legacy of the ABCD initiative lies in the successes of the participating states in making practice, community, and policy level improvements to promote healthy child development; the improvements that have occurred at the federal level; and lessons about policy and practice-level quality improvement that transfer to other health care delivery system and early childhood initiatives.

As states continue to address issues related to early childhood development, the implications of the ABCD initiative and the examples from participating states offer lessons, strategies, and policies that can make a difference in the health and development of young children.

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