# THE IMPORTANCE OF CHILDHOOD SCREENINGS:

IMPROVING ACCESS TO EARLY IDENTIFICATION, REFERRALS, AND LINKAGES TO SERVICES











### August 2017

Arkansas Advocates for Children and Families

Central Arkansas Office: Union Station 1400 W. Markham St., Suite 306 Little Rock, AR 72201 (501) 371-9678

Northwest Arkansas Office: 614 E. Emma Avenue, Suite 235 Springdale, AR 72764 (479) 927-9800

### **IMPROVING ACCESS**

# TO EARLY IDENTIFICATION, REFERRALS, AND LINKAGES TO SERVICES

Contributors: Marquita Little, AACF Health Policy Director; Angela Duran, Campaign Director, Arkansas Campaign for Grade-Level Reading; Ann Rosewater, Senior Consultant, Campaign for Grade-Level Reading

#### INTRODUCTION

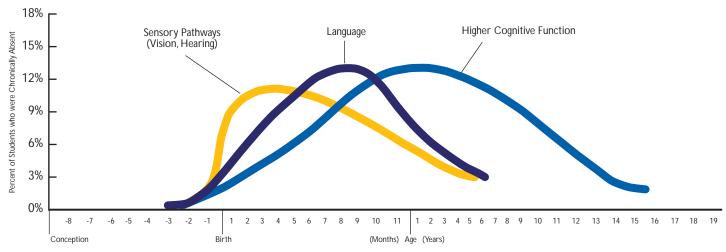
The health care system has improved dramatically over the past 20 years in Arkansas. Today, 95 percent of children have health coverage, and we've lessened the coverage gap resulting from differences in household income. Also, the state has made strides in recent years to reward the provision of high-quality preventive care through the patient-centered medical home model. Yet, children in Arkansas lag behind on several important health indicators, because many kids still lack access to the treatment and key developmental screenings they need. According to the 2017 Kids Count data released by the Annie E. Casey Foundation, when compared to other states, Arkansas ranks 46th in overall child health. Also, 18 percent of children are not in excellent or good health.

Early investments in the health and well-being of young children are especially important to ensure they are ready to learn and thrive in school. Research shows that children perform better in school and are more economically stable as adults when they have a healthy start.<sup>3</sup> In addition, children have better health outcomes, and it is more cost-effective to detect and treat illnesses early.

Developmental screenings are an effective way to ensure children are hitting important milestones in their growth and development. But Arkansas is behind the rest of the nation in ensuring that children get these important screens and checkups.

The most important period in a child's life is the first three years due to the rapid brain development that occurs. During this critical period, a child develops 85 percent of his or her core brain structure.<sup>4</sup> This early rapid brain development creates the foundation for more complex brain function later, like language, memory, and visual skills.<sup>5</sup> It is also is the best time to influence children's long-term health and well-being. If developmental delays can be identified early, children can receive services to help them catch up so we can achieve our goal of all children reading on grade level by third grade. However, many children who would benefit from early interventions are not identified until they start pre-K or kindergarten. Access to screenings and the services those screenings indicate as necessary are both areas that are ripe for improvement in Arkansas. Improving these screenings and services is an important step toward ensuring children, especially low-income children, are healthy and successful in school.

### HUMAN BRAIN DEVELOPMENT Synapse Formation Dependent on Early Experiences



Source: Harvard University, Center on the Developing Child. (2007). "The Science of Early Childhood Development": http://developingchild.harvard.edu/resources/inbrief-science-of-ecd

#### **EARLY INTERVENTION PRINCIPLES**

To improve well-being, health, and educational outcomes for children in Arkansas, the state must have an effective early intervention system that promotes the importance of young children's early development, screens all children, makes appropriate referrals, and assures that children receive the services they need to thrive. Based on research and best practices, an effective system should be built on the following principles:

- Build parents' capacity to help their children grow and learn;
- Provide services in inclusive and natural settings;
- Use family-centered practices;
- Use evidence-based screening tools;
- Focus on both physical and social-emotional health:
- Ensure "warm hand-offs" to services to make sure children receive the services they need; and
- Create mechanisms that encourage cross-sector coordination.

Building the capacity of parents or caregivers is an essential part of ensuring children have what they need to thrive, because parents and caregivers have the greatest impact on a child's development. When parents are engaged and supported, they have a better understanding of the role they play in shaping their child's development.<sup>6</sup> Parent involvement helps open the line of communication between the family and primary care providers. This increased understanding of their child's needs also helps parents understand the need for regular well-child visits and the importance of childhood screenings. It is vital that families be recognized and engaged when identifying a child's needs, referring to follow-up services, and providing care coordination.<sup>7</sup> Families should also be engaged and involved in program and policy changes that improve access to early identification and service delivery. Arkansas has even conducted community cafés in the past to understand the unique challenges that parents face and how care coordination could be used to assist them in connecting with appropriate services for their child.8 Some of this feedback regarding the need for care coordination and improved communication was a key driver for the state designing the patient-centered medical home (PCMH) model.

This report will examine the early childhood development and intervention system in the state, as well as progress and barriers toward designing a system that reflects these guiding principles.



### BARRIERS AND OPPORTUNITIES IN ARKANSAS

In July 2016, stakeholders from multiple sectors convened to discuss the current state of child health and education and strategies to improve access to and delivery of early childhood screenings, referrals, and services. National and state experts presented research on child development, promising practices for building comprehensive screening and referral systems, and successful models being implemented nationally and locally. Stakeholders then collaborated to examine state-level data and discuss barriers and opportunities to improve the developmental promotion, screening, referral, and follow-up processes and services in Arkansas. Key findings related to each step in this comprehensive system, as well as new and developing opportunities on which to build, are presented below.

#### **SCREENINGS**

Meeting participants considered two types of screenings: physical/developmental and social-emotional. The American Academy of Pediatrics (AAP) defines a developmental screening as the administration of a brief tool to identify possible development delays. Developmental screenings, usually conducted during pediatric well-child visits, are an effective way to ensure children are hitting important milestones in their growth and development, showing their progress and allowing problems to be recognized early and addressed. However, less than half (45 percent) of children enrolled in Arkansas Medicaid receive a well-child visit, compared to a national average of 58 percent.

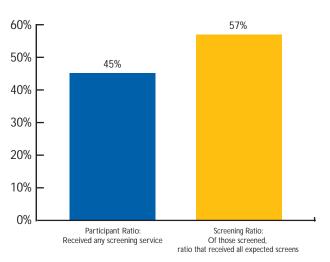
Key sources of data on this subject are program reports for early periodic screening, diagnosis, and treatment (EPSDT), an essential benefit for children. Every state Medicaid program reports EPSDT screening data to the federal Centers for Medicare and Medicaid Services (CMS) to determine whether children enrolled in the Medicaid program receive required health screening services and referrals for treatment. Because of the differences in children's needs, the specific screen or treatment services are not defined by federal or state law, and EPSDT is broadly defined; the treating physician decides what each child needs.

The data below show the number of Medicaid-enrolled children in Arkansas who receive EPSDT screens during well-child visits and whether they receive all recommended screenings for their age group (also known as the periodicity schedule). While they help paint a picture of the extent to which developmental screenings

may be occurring, EPSDT metrics are not a proxy for the specific incidence of developmental screenings with a standardized screening tool, as recommended by AAP. States have the option to report developmental screening data for Medicaid through CMS's child core set of health measures, called "Developmental Screening in the First Three Years of Life." To date, Arkansas has not elected to report these data, but doing so would provide a more accurate picture of children receiving developmental screenings.

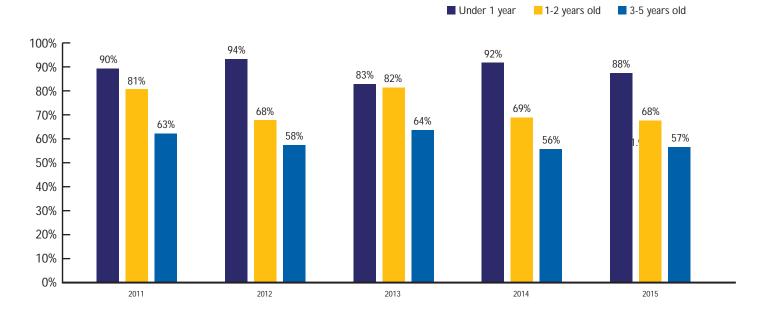
The charts below show two measures that are reported to assess the state's EPSDT screening performance for both developmental and physical screens. The participation ratio indicates the number of children in Medicaid who received any initial or periodic screening services during the year. In Arkansas, less than half (45 percent) of children received any screenings services in a year. The screening ratio shows the proportion of the recommended screenings children received. In Arkansas, less than two-thirds (57 percent) of children receive all recommended screens. This suggests that even when children in Arkansas are screened during the year, most are not likely to receive all screenings recommended for their age group. Arkansas also falls below the national average on both EPSDT performance measures.

# CHILDREN RECEIVING SCREENING SERVICE (2015)



Data in Arkansas also shows that the percentage of children receiving recommended screens decreases with age. Therefore, if a delay is not identified in the first year of life, the chances of it being identified in future years goes down.

### CHILDREN RECEIVING A SCREEN BY AGE



Further, national research shows that historically, 70 percent of health care professionals rely solely on their clinical judgment rather than using formal, evidence-based developmental screening tools. While efforts have been made to improve this over time, particularly through training child care and health providers on certain tools, Arkansas still lacks policies that require and incentivize the use of standardized screening tools across the system. As a result, doctors may be missing delays that would be detected by such tools.

Developmental screenings also occur in other settings: child care centers, Head Start, home visiting, pre-K programs, and by the organizations that provide services to children who have delays. However, there are often no formal mechanisms for communicating the results of these screens to a child's primary care physician (PCP) and few records to determine if appropriate referrals and services are provided when delays are identified.

Social-emotional screenings are not required as part of EPSDT; however, there is evidence that the need is great. Children's development of social and emotional capacities contributes significantly to their health and learning. <sup>12</sup> In a study of 1,448 children enrolled in Arkansas Head Start and Arkansas Better Chance pre-K programs, 16 percent had clinically elevated behavioral screening results. <sup>13</sup> Recognizing the under-identification of children's mental health issues and the limited capacity of most doctors to screen and make referrals, the AAP has provided guidance on how to implement such processes within medical practices and identified potential screenings tools. <sup>14</sup>

However, given the lack of a service array specifically for young children requiring behavioral health services in Medicaid, it is unlikely that these tools are being used widely. Additionally, providers would have a greater incentive to provide social-emotional screening services if there were billable codes in the Medicaid system for both social-emotional and developmental screens.

According to local experts and stakeholders, some additional factors in Arkansas that may be contributing to low developmental and social-emotional screening rates include the following:

- Some families do not understand the importance of well-child visits and therefore visit the doctor (or an emergency room) only when their child is sick or their school or child care provider requires immunizations or other documentation.
- Families may also face difficulty finding transportation to the doctor or taking time off from work for a well-child visit, especially if the clinic's hours are the same as their work day.
- Many children see a family physician instead of a pediatrician. Family physicians see patients of all ages and may not have the depth of knowledge necessary to conduct developmental screens.
- Many pediatricians and family physicians do not feel equipped to conduct behavioral health/socialemotional screenings.
- Since parents are more likely to bring their children to see the doctor when they are sick, some pediatricians may conduct a screen during a sick child visit, but they have run into challenges

billing for EPSDT during such times. That means there is usually no record of the screen in claims data for Medicaid or the insurance provider.

While statewide screening rates are relatively low, there is anecdotal evidence that in some parts of the state, particularly in rural areas, significant numbers of preschool age children have been screened, and unusually high rates of delays have been identified among those children. These screenings often are being conducted by the entities that ultimately provide the services to the children. Of course, this raises some concern that children may be over-identified for unnecessary treatment and supportive services if providers can "self-refer" for their services.

### REFERRALS AND LINKAGE

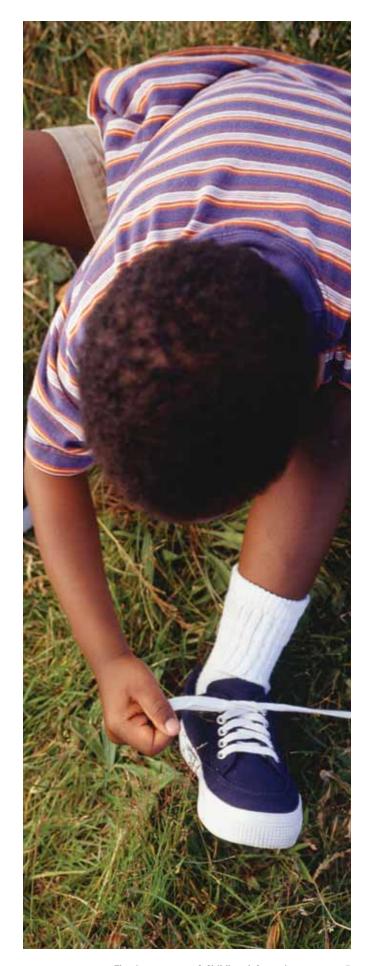
Once a developmental or social-emotional screen is completed and a potential delay has been identified, the doctor or provider conducting the screen often refers the child's family to another entity for further evaluation and/ or provision of services.

The Early Intervention Part C program is a key next step for many children identified with significant delays. Early Intervention Part C, called First Connections in Arkansas, is a federally funded program that helps infants and toddlers with serious delays and disabilities. Two overarching goals of First Connections are to build the capacity of the families to facilitate their children's development and to provide services in natural settings. First Connections works with families to conduct additional assessments and evaluations, if necessary; helps families understand their rights and the array of potential services available to them; develops an Individualized Family Service Plan with the family; and connects the families to those services.

The Part B program provides similar services for preschool-aged children ages 3 to 5. In Arkansas, Part B services are overseen by the Arkansas Department of Education, through educational service cooperatives and individual school districts.

The doctor or organization conducting the initial screen may also refer a family directly to a provider of services such as a developmental day treatment center or another private provider. These organizations may also provide screenings and refer families to their own services.

The following challenges have been identified with the ways that referrals occur, especially for children with low to moderate developmental needs:



- Pediatricians and family doctors are often unaware
  of the array of appropriate service options in
  their communities. In rural areas, options may be
  limited. Even in urban communities, a doctor may
  make a referral to a particular provider not because
  it's the best option but because that is what he has
  always done.
- If a doctor identifies a social-emotional issue, she currently has limited referral options because Arkansas has not had the necessary services in place in Medicaid for young children. The limited Medicaid-reimbursable services are often inadequate or inappropriate for young children.
- Early childhood education providers such as Head Start, child care centers, and pre-K programs have similar challenges in making referrals, for both developmental and social-emotional services.
- Without support and guidance from their physicians or early childhood education providers, families have difficulty learning about and navigating through the service options available to them.
- The ability of developmental day treatment centers and other providers to self-refer may be leading to over-provision of services, or provision of the wrong kinds of services, for some children.
- There are multiple ways that children can be referred for services, and there is no statewide system for tracking those referrals and whether families access the services.

### **SERVICES**

In Arkansas, key providers of services for young children with developmental delays are the developmental day treatment centers. Core services include 1) diagnosis and evaluation, and 2) habilitation (instruction in areas of self-help, socialization, communication, etc.). Services are primarily provided in clinical or early childhood education facilities and should be provided to both the child and the parent. The centers also offer occupational, physical, and speech therapy. They often offer child care or pre-K classes in addition to the core services and therapies, which make them convenient for and attractive to working parents.

First Connections works with families of children ages birth to 36 months to connect them to service providers, which include developmental day treatment centers and other private providers. To be eligible for services, a child must have a delay of 25 percent of chronological age or greater in one or more areas of development or a documented medical diagnosis that is likely to result in a developmental delay.

Once a child reaches age three, he or she must access services through the Part B program, which is offered through educational service cooperatives and some school districts. To be eligible for services, a child must have a condition that falls into one of the following categories: autism spectrum disorder, deaf-blindness, hearing impairment, multiple disabilities, orthopedic impairment, other health impairment, speech or language impairment, traumatic brain injury, or visual impairment. For preschool-age children, services can be provided at pre-K programs or child care centers.

Stakeholders have identified the following challenges regarding the way services are provided in Arkansas:

- Some children are prescribed the full allowable amount of a particular service, even when they do not need it.
- At the same time, many children do not receive services they need.
- Children with mild and moderate issues often fall through the cracks.
- PCPs who make referrals often do not receive follow-up information from the providers about the provision of services and outcomes achieved.
- When the referral is made by an entity other than the PCP, the physician often does not receive information about the screening results, referral, or the provision of services and outcomes.
- The capacity of First Connections staff varies across the state, resulting in uneven provision of services to families.
- First Connections has limited funding, all of which comes from federal dollars. Unlike other states, Arkansas provides no funding to support the service
- Services are primarily provided in clinical or early childhood education facilities, which is different from the prevailing trend across the country to provide services in more natural and inclusive settings.
- Mental health services for infants and toddlers and their families are almost nonexistent in Arkansas, since Arkansas Medicaid has not reimbursed for them in most cases. This has forced many behavioral health providers and doctors to provide what limited services they can under the current system.

#### OPPORTUNITIES ON WHICH TO BUILD

Arkansas has been an innovator in both early childhood education and health care. Several recent efforts, and new efforts in development, provide opportunities on which to build a child health promotion, screening, referral and service system that meets the principles outlined above.

Patient-Centered Medical Homes. Because of the state's patient-centered medical home initiative and the ability to reward health professionals for innovative practices, care coordination has improved significantly. This primary care model focuses on providing comprehensive, team-based, coordinated, and high-quality care. <sup>17</sup> Health care providers have several specific activities that they engage in to improve care coordination, including identifying a care coordination lead, implementing specific care coordination strategies, and addressing care coordination barriers. For example, more health professionals provide parent education and tools like text reminders for appointments and follow-up. Many clinics also try to make care convenient with flexible clinic hours.

Home Visiting. The Arkansas Home Visiting Network, which administers developmental screens for children in the families they serve, is developing a partnership with First Connections. The network includes several different home visiting programs. All programs use the Ages and Stages Questionnaire, and most use the Ages and Stages

Questionnaire: Social Emotional, which screens for mental health. The Home Visiting Network will link families identified by the screeners as needing follow-up to First Connections.

Behavioral Health Transformation. Current efforts to transform the state's behavioral health system will create a service array for children ages birth to 3. These new services will include treatment that allows the mother or caregiver to receive services as well. After over a decade of work to transform the children's behavioral health system in the state, this proposal received legislative approval in 2016, and implementation began in July 2017.

### Early Childhood Education and Mental Health.

Through the University of Arkansas for Medical Sciences' Project Play, licensed mental health professionals build the capacity of early childhood education programs to promote social and emotional health in children. Services include observation; coaching on strategies to promote pro-social behavior; training on behavior management, child development, and mental health; promoting team building and communication between staff; and supporting individual children and families with screening, behavior management plans, and referrals. The Division of Child Care and Early Childhood Education at the Arkansas Department of Human Services (DHS) has also recently released regulations that prevent suspensions and expulsions of pre-K students.



## IMPROVING THE SYSTEM: RECOMMENDATIONS FOR ARKANSAS

Overall, one of the stakeholders' most obvious findings was the major differences across each part of the system regarding access to screenings, referrals and linkage, and follow-up treatment. Recently there have been greater investments directed toward improving care coordination and access to supports and resources related for primary care and medical conditions. Despite some progress as the state transitioned to a patient-centered medical home (PCMH), services focused on early intervention and on children with disabilities remain difficult to navigate and are fragmented across the health and education sectors. Lastly, the need to identify and connect families to resources and treatment for social-emotional health is urgent because of the sheer lack of services for the early childhood population. However, several important policies have improved services to children, and a major effort is underway to begin to allow Medicaid to cover behavioral health services for the early childhood population.

Based on the barriers and opportunities identified above, and the current policy environment in the state, Arkansas should implement the following measures to improve supports for young children, especially as health reform efforts move forward:

- 1) The state should prioritize and incentivize providing early identification and prevention services.

  Initiatives to improve care, like the PCMH model
- Initiatives to improve care, like the PCMH model, should include specific strategies and metrics focused on young children and the early identification and treatment of health conditions. State systems, like the Medicaid and early childhood divisions at DHS, should continue to work together to increase accountability and create financial incentives for providers to support early intervention and prevention activities. For example, in the PCMH program, providers should be encouraged to provide care coordination focused on parent and caregiver education about their child's health and include metrics that track these types of activities. Also, simply allowing providers to bill for both a developmental screen and social-emotional screen by adding a code for both in Medicaid would likely increasing screening rates and provide better data.
- 2) Screening tools should be comprehensive and standardized across the systems. Implementing a standardized developmental and behavioral screening tool is one of the most reliable ways to ensure at-risk children are identified. The Ages and Stages Questionnaires

are currently being used in many settings in Arkansas, including most home visiting programs, many early childhood education programs, and some pediatric clinics. This would be a good place to begin building on the current investment.

- 3) The state should strengthen system-wide care coordination and access to patient data. Assessment findings should be shared rapidly across systems, and families must be linked to services after receiving a screening, even when that screening occurred in a different setting. If a need is identified during a primary care visit or in an early childhood program, the family should be referred and connected to services appropriately. This coordination also requires an improved data system to track early identification and intervention services. A more robust data system will improve access to data on screenings, referrals, and health outcomes, as well as address known communication challenges between families, primary and specialty providers, and professionals in early education settings.
- 4) The state should improve support for the entire family and reward family engagement. Consistently, parents and caregivers were identified as key drivers to ensuring young children receive screenings and needed services. Providers should be given incentives for offering ongoing education and engagement with parents.
- 5) The state should create a continuum of high-quality care, and treatment should be delivered in the least-restrictive setting. 19 As strategies to increase screenings and assessment of young children, a continuum of care must be established simultaneously to meet the needs of all families. This should include:
  - Prevention-based interventions such as parent training for all families and quality early childhood education, especially for disadvantaged children;
  - Targeted services for children and families in need of support;
  - Intensive and individualized early intervention programs for children with higher levels of need;
  - Care provided across each level in the least restrictive setting, which is a best practice.

Screening all children early and focusing on prevention and early intervention will require the development of multi-sector strategies and dedicated resources across both the health and education systems. These important investments in young children are vital to ensuring every child in Arkansas has the resources he or she needs to be ready for school and become healthy, productive adults.



### **FOOTNOTES**

- 1 Little, M. (2016). "Clearing the hurdles to coverage: Kids' health coverage in 2016." Arkansas Advocate for Children and Families. Retrieved from: http://www.aradvocates.org/wp-content/uploads/AACF-finish-line.webfinal.2.-11.17.16.pdf.
- 2 Kids Count Data Center. Retrieved from: http://datacenter.kidscount.org.
- 3 Chester, A. (2015). "New study documents positive long-term effects of Medicaid coverage." Georgetown University Health Policy Institute. Retrieved from: http://ccf.georgetown.edu/2015/04/09/new-study-documents-positive-long-term-effects-medicaid-coverage.
- 4 Shore, R. (1997). "Rethinking the brain: New insights into brain development." Families and Work Institute.
- 5 Center on the Developing Child. (2007). "The Science of Early Childhood Development" (InBrief). Retrieved from http://www.developingchild.harvard.edu.
- 6 Cole, P., & Lerner, C. (2015). "Comments on Family Engaged before the Interagency Policy Board." Zero to Three.
- 7 National Academy for State Health Policy. (2013). "The Enduring Influence of the Assuring Better Child Health and Development (ABCD) Initiative."
- As part of a National Academy for State Health Policy (NASHP) grant-funded project in 2012, an Arkansas team designed a protocol for raising awareness and collecting information about early screening and intervention services from families and other stakeholders. The portal was used to gather information about child health services and ways to improve the delivery system and is available on the NASHP website: http://nashp.org/sites/default/files/abcd/ABCDresources.org/abcd.ar\_.communitycafe.812012.pdf.
- 9 American Academy of Pediatrics. (2009). "A summary report: Developmental screenings in early childhood systems." Retrieved from: http://www.healthychildcare.org/pdf/DSECSreport.pdf.
- 10 Early and Periodic Screening, Diagnostic, and Treatment. Centers for Medicare & Medicaid Services. Retrieved from: https://www.medicaid.gov/medicaid/benefits/epsdt/index.html.
- 11 Glascoe, F.P. (2000). "Early detection of developmental and behavioral problems." Pediatrics in Review, 21(8), 272–280.
- 12 Rosewater, A., & Meyers, J.C. (2016). "Connecting Social and Emotional Health and Literacy: Critical for Early School Success." Child Health and Development Institute of Connecticut.
- 13 Conners-Burrow, N.A.; Whiteside-Mansell, L.; McKelvey, L.; Amini-Vermani, E.; & Sockwell, L. (2012). "Improved Classroom Quality and Child Behavior in an Arkansas Early Childhood Mental Health Consultation Pilot Project." *Infant Mental Health Journal*, 33(3), 256–264. DOI: 10.1002/imhj.21335.
- 14 Weitzman, C., & Wegner, L. (2015). "Promoting Optimal Development: Screening for Behavioral and Emotional Problems." The American Academy of Pediatrics. Retrieved from: http://pediatrics.aappublications.org/content/pediatrics/135/2/384.full.pdf
- 15 Arkansas First Connections. (2015). "Family Guide to Transition at Age 3." Retrieved from: http://www.arkleg.state. ar.us/bureau/research/Publications/Task%20Forces/Legislative%20Task%20Force%20on%20Autism/DDTCS--Developmental%20Day%20Treatment%20Clinic%20Services.pdf
- 16 Arkansas DHS: https://dhs.arkansas.gov/dds/firstconnectionsweb/PDFs/families/FC2015FamilyTransitionGuide\_REV.pdf
- 17 Arkansas Center for Health Improvement. (2015). Retrieved from: http://www.achi.net/Content/Documents/ResourceRenderer.ashx?ID=276.
- 18 Zero to Three. (2013). Arkansas ECMH consultation project. Retrieved from: https://www.zerotothree.org/resources/733-arkansas-ecmh-consultation-project.
- 19 Mark, K., & Varges-Baron, E. (2016). "Let's create a national policy framework for healthy child development." The Hill Blog. Retrieved from: http://thehill.com/blogs/congress-blog/healthcare/290944-lets-create-a-national-policy-framework-for-healthy-child.

Arkansas Advocates for Children and Families 1400 West Markham, Suite 306 Little Rock, AR 72201 (501) 371-9678

Northwest Arkansas Office 614 East Emma Avenue, Suite 235 Springdale, AR 72764 (479) 927-9800



### **LEARN MORE AT WWW.ARADVOCATES.ORG**





