



POLICY BRIEF

STARTING STRONG

Regular, quality screenings are a crucial first step in addressing developmental concerns in young children

INTRODUCTION

The early years of life are crucial for a child's health and development. In fact, 90 percent of a child's brain development occurs before kindergarten. The quality of care that children receive between birth and 5 years old impacts whether they will develop in healthy ways. Healthy development means that children of all abilities are able to grow up in a safe and loving home where their social, emotional and educational needs are met.ⁱ

From birth to 5 years old, children should reach certain milestones in how they play, learn, speak, behave, and move. Skills such as taking first steps, speaking words or phrases, and emotional self-regulation are considered developmental milestones. While each child is unique and will develop at his or her own pace, developmental milestones give a general idea of what typical development looks like and what is reasonable to expect as a child grows.

A child who consistently does not meet the guideposts of healthy development may have a developmental delay. Developmental delays can be a sign of one of two things – either an area where a child needs additional support in order to meet developmental milestones, or a sign of a potential lifelong issue that could significantly impact a child's long-term learning and well-being (developmental disability). The National Survey of Children's Health shows that certain populations of children are at higher risk for developmental delays, and a review of Census data shows that Arizona has high percentages of children in the at-risk populations.

Surveillance of a child's healthy development – including regular, quality developmental screening and referral for further assessment and follow-up services, as warranted – ensures that any potential learning and development issues are identified early enough for the child to get the maximum benefit of intervention services and supports. Early intervention treatments and therapies have the highest success rates when they are provided to children as early as possible in their development. And, children at risk for delays who are screened are more likely to receive early intervention services than unscreened peers.ⁱⁱ Without routine screening, only an estimated 30% of children with developmental issues are identified before they reach kindergarten.ⁱⁱⁱ

Quantitative and qualitative data point to a number of challenges faced by various sectors in Arizona's early childhood system in ensuring that timely, quality screening is occurring; and that appropriate referrals are being provided in cases where concerns may exist and further assessment is needed, including information with which families can actively support their child in reaching developmental milestones. These challenges include many children not being screened and, when they are screened, screenings being conducted by individuals who may not have had adequate training to appropriately conduct the assessment, score, interpret and share results with families. In addition, screenings may be conducted across a variety of settings such as at doctors' visits, in child care settings, or by home visitors with no clear linkages of information and services between those systems. When screening results do show concerns with a child's development and families are referred for follow-up assessment, the services may be complex, difficult to access, under-resourced, and in many cases not appropriate to meet the child's needs, particularly for children with mild to moderate developmental delays.

This brief focuses on the crucial first step in identifying concerns with children’s healthy development: timely and quality screenings. Subsequent briefs will examine the complexities of and gaps within the system of services and interventions that are intended to support children who have an identified developmental concern, delay or disability.

This brief also highlights collaborative efforts by First Things First and early childhood system partners to enhance the quality of developmental screening and offers recommendations on what families, providers and policymakers can do to ensure more children are getting the screenings they need to start strong and healthy in their development. The recommendations are not intended to be detailed or comprehensive; rather, they can serve as a vehicle to encourage further dialogue and collaborative action to ensure that all children are afforded the opportunity to start school ready to reach their fullest potential.

Background: Complexities of Arizona’s Early Intervention System

About 85% of a child’s brain growth happens between birth and 3 years old.^{iv} Although all children develop at their own pace, there are certain things that children typically learn to do at each age and stage of life. These are collectively known as developmental milestones. It is crucial that babies and toddlers be closely observed and supported in meeting those milestones. Monitoring a child’s development means paying attention to the child’s physical, mental, social, and emotional well-being, as well as noting developmental concerns. When children are not developing typically, effective and timely interventions – including regular, high-quality developmental screenings – offer them the opportunity to identify and receive the support necessary to put them on a trajectory for optimal success.

In Arizona, there are a variety of partners that comprise the early intervention system. A child’s growth and development are followed through a partnership between families, non-profit and public agencies, health care providers, early educators, and other professionals who may work with a family, such as home visitors. Each partner plays a key role in working with families to support a child’s healthy growth and development. Coordinating and aligning the work of these various collaborating partners is crucial in order to ensure that:

- Children receive timely and appropriate screenings and referrals;
- Appropriate prevention, early intervention and treatment services are available; and
- Children receive the support and services they need to achieve healthy development.

The early intervention system is complex and can be difficult for families to navigate with the many partners, various policies and numerous practices that drive the provision of services – including screening, assessment and evaluation, and services and therapies – and the delivery of services across the health care, education and social services sectors. Highlighted below are some key policies and practices specific to the front end of Arizona’s early intervention system – identifying young children with developmental delays and disabilities.



Health Care

The American Academy of Pediatrics has established recommendations and guidance to ensure that primary care providers are routinely monitoring children's development, conducting regular screenings, and referring families for further assessment when appropriate. The federal Medicaid program, known as the Arizona Health Care Cost Containment System (AHCCCS), and the federal-state Children's Health Insurance Program (SCHIP), known as KidsCare in Arizona, have similar requirements of medical providers working with children served by public health insurance programs through a benefit known as Early Periodic Screening, Diagnostic and Treatment (EPSDT). This is particularly significant, given that 50% of births in Arizona are paid for by Medicaid. All primary care providers are expected to partner with families to fulfill these requirements and provide families with information with which to support their child's healthy development (also known as anticipatory guidance).

AHCCCS' Children's Rehabilitative Services Program also works with the Arizona Long Term Care System in the Department of Economic Security's Division of Developmental Disabilities to serve children based on specific needs and conditions. The Arizona Department of Health Services' Office for Children with Special Health Care Needs works to improve systems of care, provide information and referral, training to families and professionals, family involvement and support, and telemedicine to provide services in remote areas of the state.



Education

The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. The IDEA governs how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children, and youth with disabilities. Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C. The Arizona Early Intervention Program (AzeIP) has primary responsibility for implementing Part C. Children and youth ages 3 through 21 receive special education and related services under IDEA Part B through the Arizona Department of Education and local school districts.

The IDEA requires states to have a comprehensive and continuous Child Find System that ensures all children birth to 21 in need of special education and related services are identified, located and evaluated. Child Find is a continuous process of public awareness activities, as well as screening and assessment processes designed to locate, identify and refer all young children with disabilities as early as possible. The Child Find process often involves creating informed referral networks consisting of physicians, Head Start programs, child care programs, parents, public health, schools, social services and others in the community that touch the life of a child.



Social Services to Strengthen Families

In Arizona, there are various services and programs through the nonprofit sector and public agencies dedicated to supporting families and their children with the full range of delays and disabilities by providing support, training, information and individual assistance. Evidence-based home visitation programs have been shown to be an effective way to improve outcomes for families and children experiencing various risk factors.⁹ While there are a number of evidence-based models available, the four most common in Arizona include Healthy Families, Nurse Family Partnership, Parents as Teachers and Early Head Start. Each program has its own unique curriculum and/or program implementation guidelines, but they all include a requirement that home visitors work with families to monitor children's development, conduct regular screenings and refer families, as appropriate, for further assessment. This also includes supporting families with anticipatory guidance as appropriate and warranted. To leverage funding and coordinate the delivery of home visitation in Arizona, the Strong Families Alliance – a consortium of agencies statewide whose work with families includes the funding and implementation of home visitation – was developed. The Alliance works to strengthen the home visiting system in Arizona and promote collaboration and the sharing of resources and best practices.

This high level overview of the system touches only on some key policies and practices that guide the early intervention system. Due to its complexity, it is critical that families have a comprehensive, integrated, coordinated and effective early intervention system of services for their children with developmental concerns, delays and disabilities no matter when, where or how they enter the system. The importance of this is further emphasized when understanding what developmental delays and disabilities are and how common they are among our young children.

What Are Developmental Delays And How Common Are They?

Developmental concerns can range from delays such as grunting instead of using words to ask for something, or not crawling or walking at a reasonable age, to a permanent disability that will remain with a person for life, such as blindness, severe autism or cerebral palsy.

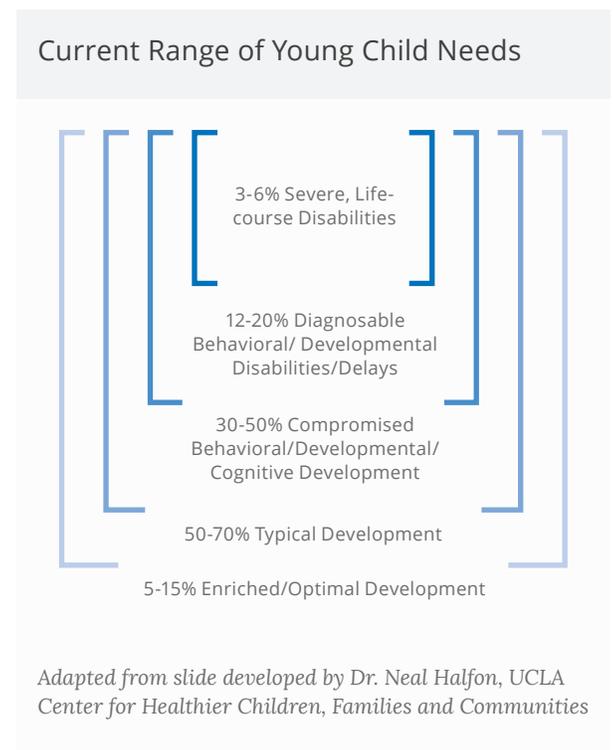
Delays can be ameliorated and even eliminated with early and appropriate intervention. Sometimes developmental delays can be precursors to or indications of developmental disabilities, which are “a diverse group of severe chronic conditions that are the result of mental and/or physical impairments. These impairments lead to challenges with everyday functioning such as language, mobility, learning, self-help, and independent living.” While disabilities can be supported and appropriate measures taken to improve the child’s development, there is no cure or fix for permanent disability. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime.^{vi}

Research shows that a very small percentage of young children (3 to 6%) have profound health issues and concerns that are likely to require ongoing care and attention throughout their lives (See Figure 1). Some of these issues are congenital and others may be the result of severe illnesses or injuries. Some require institutionalization or constant in-home care and management, and may be subject to repeated hospitalizations for complications resulting from their conditions.^{vii}

A much larger number of young children (12 to 20% of the overall population) have developmental or mental health conditions or needs which require attention. In terms of developmental delays and disabilities, research indicates that about 1 in 8 very young children (12% of children 6 months to 3 years old) could be diagnosed with a developmental delay or disability. About 1 in 6 (18%) of children 2 to 5 years old could be diagnosed with a mental health disorder, including attention deficit/hyperactivity disorder, depression, and a variety of other mental disorders.^{viii}

An even larger proportion of the young child population may have developmental concerns without necessarily manifesting a specific condition or having a specific diagnosis. Between 30-50 percent of children fall into this category of development. A child’s home environment may make them vulnerable to developmental concerns that – if not addressed in the early years – are likely to affect future development and functioning.^{ix} For example, by age 3, there are

Figure 1





profound differences in vocabulary acquisition among children from under-resourced families (less than 550 words) compared to their more affluent peers (about 1,100 words).^x

The aforementioned categories of developmental concerns to disabilities are shown in Figure 1. In total, as many as half of all children birth to 5 years old are in need of some level of support in order to achieve their optimal development. Without that support, the child's specific challenges may only worsen, compromising their long-term learning and well-being.

Furthermore, the 2016 National Survey of Children's Health shows that certain populations of children are at higher risk for developmental delays, and a review of Census data shows that Arizona has high percentages of children in the at-risk populations. According to the survey:

- Children at/below the Federal Poverty Line (\$24,600 for a family of four) are more than 2X as likely to have high risk for developmental delays compared to their peers living at 200% FPL. More than 1 in 4 young children in Arizona (29%) live in poverty.^{xii}
- Hispanic and African American children are 2X more likely to have a high risk of delays than white children. Half of Arizona's children birth to 5 years old are Hispanic or African American (45% and 4%, respectively).^{xiii}
- Children with parents who lack a high school diploma are 2X more likely to have high risk of delays compared to children with parents with a diploma and 3X as likely as children whose parents have education beyond high school. Of all Arizona births in 2015, almost 1 in 5 were to mothers with less than a high school diploma (18%).^{xiv}

Given these factors, it is crucial that Arizona ensures that all children are afforded the opportunity to have any and all developmental concerns identified and supported as early as possible.

Identifying Developmental Concerns

Developmental screenings play a vital role in giving families information about their child's development across all developmental domains, including cognitive, physical and social-emotional development. The screenings help identify areas in which children are developing typically, as well as areas in which additional assessment is needed to determine if a delay exists and the best course of treatment for the delay.^{xv} A screening is not a diagnostic assessment. There are a variety of best practices when it comes to developmental screening, depending on the setting where the screening occurs.

Ideally, quality screening includes the use of valid and reliable screening tools; trained screeners who know how to use and score the tool, interpret the results and share information with families; engaged families, who are best positioned to provide accurate and reliable information about their child's abilities and behaviors; and referrals for follow-up assessment when concerns are noted, including providing families with information about what they can do to support their child in meeting developmental milestones, also known as anticipatory guidance.

There are a variety of evidence-based, high-quality tools available for children's developmental screening. Examples of some of the most commonly used tools are: the Ages and Stages Questionnaire (ASQ) and the Ages and Stages Questionnaire – Social Emotional (ASQ-SE); the Parents' Evaluation of Developmental Status (PEDS), favored by many pediatricians and primary care physicians; and the Modified Checklist for Autism in Toddlers (MCHAT).

As previously noted, screening can be provided through a child's primary care provider, but can also be done by other professionals in health care, social service, or early education (child care) settings. Regardless of where a child is provided a screening, it should be conducted in a timely manner and include risk-appropriate referrals in order to be most effective.

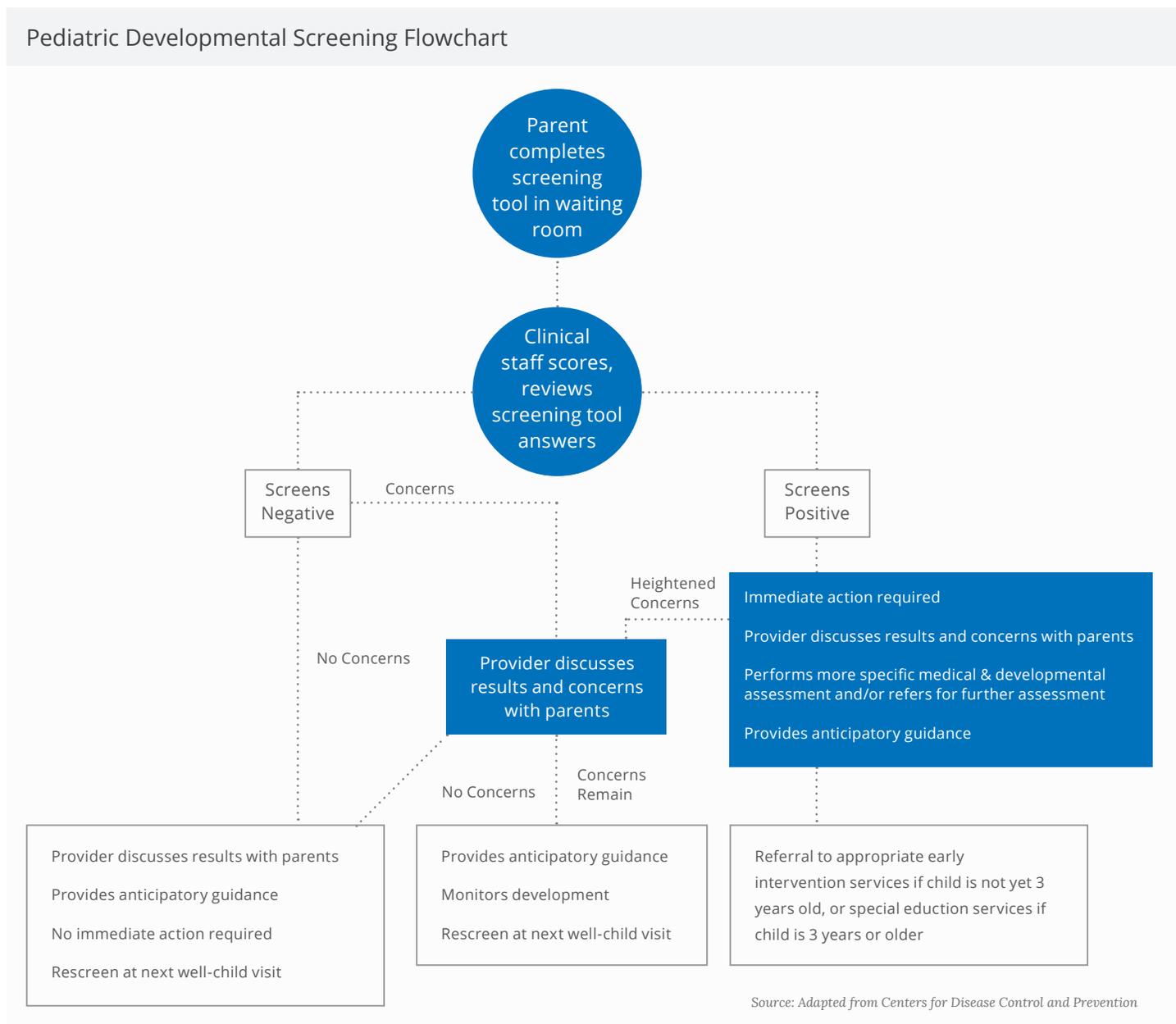


The American Academy of Pediatrics (AAP) recommends that developmental surveillance be part of every well child visit – which typically occur every 2-6 months between a child’s birth and 3 years old.^{xvi} Developmental surveillance includes asking parents about any concerns they have regarding their child’s development, taking a developmental history, observing the child, noting any factors that place the child at risk for a developmental delay and documenting their observations. If a primary care provider does have a concern, the visit would include doing a timely developmental screening.

Regardless of whether a concern is noted or not, the AAP recommends routine standardized screenings at well-child visits at 9, 18 and 30 (or 24) months of age.^{xvii} In addition, children who have health care coverage through publicly-funded programs are supposed to have their development monitored regularly as part of their Early Periodic Screening Diagnostic Treatment (EPSDT) benefit.^{xviii}

Figure 2 describes how this process ideally would look in a primary care provider’s office.

Figure 2



HOW ARIZONA'S YOUNG CHILDREN ARE FARING

Despite the importance of developmental screening as a core component of the early intervention system, there are several quantitative and qualitative measures that suggest a fragmented system of screening for Arizona's young children. Highlighted below are key challenges to providing quality screening for our young children across health, early education and social services sectors.

Screening Rates

- The 2016 National Survey of Children's Health found that only 1 in 4 Arizona parents (26%) surveyed said that they were asked by a health-care provider to complete a developmental screening tool concerning their child's development in the past year. The prevalence of physician-ordered, parent-completed developmental screening was low regardless of demographic, health-care, or risk indicators. The Arizona rate was on par with national results (26% and 27% respectively).^{xxix}
- The state's Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), reports that in 2016, only 1 in 5 (21%) of 1, 2 and 3 year-olds served by the program for the preceding year had received a developmental screening.^{xx} The data were collected to establish a baseline for the agency's Performance Improvement Project (PIP), referenced later in this brief.
- In addition to the data cited above, from 2014-2016, as part of the federal Early Childhood Comprehensive Systems (ECCS) grant, Raising Special Kids, with the support of First Things First, conducted ten Family Forums around the state. One of the chief concerns noted by parents was that they did not feel their medical provider listened to their concerns regarding their child's development, in particular when they suspected something was not right.^{xxi}

Building Capacity of Professionals to Provide Quality Screening

While policies are in place that promote timely and appropriate screenings of children that occur in various settings, utilization of valid and reliable screening tools and trained screeners who know how to use and score the tool, interpret the results and share information with families is highly variable within and across sectors. For example, research suggests that barriers to screening for the health sector may include clinicians' and clinical staff's lack of knowledge and inadequate training on screening. In addition, managing workload in pediatric practices to ensure adequate time to conduct screenings has been raised as a concern.^{xxii}

Furthermore, access to and availability of training for home visitors and other social service providers has also been identified as a barrier to providing quality screening. Based on system partner dialogue and family experiences, training provided on these important screening tools can range from watching a 20-minute video to in-depth seminars.

In addition, early care and education programs in Arizona are comprised of center based and family child care home providers. This includes for-profit and nonprofit providers, school districts, and Head Start programs serving infants, toddlers and preschoolers. While early care and education programs should include screening and assessment as a core component of their programs, this varies considerably across programs due to knowledge and use of screening tools, lack of or limited program policies on screening and assessment, availability of staff to conduct screenings while meeting ratio and group sizes, and variance in staff qualifications of the early childhood workforce.

Family Engagement

Families may perceive developmental screening as a way to find something “wrong” with children, which is something that can make parents reluctant to have their children screened. One way to approach the screening discussion is to view screening as a partnership opportunity for parents/caregivers and providers to support children’s healthy development and open up communication about how to keep children developing in the best ways possible. It is important for families to understand the purpose behind the screening, as well as the partnership with providers, so that the most appropriate steps are taken by all parties to promote the best possible outcomes for the child’s development.

A key component of the screening process involves the post-screening discussion of results with families. If a child demonstrates mild concerns or delays but not sufficient delay for a referral for further assessment, and in the discussion a provider communicates that there is not sufficient delay to warrant a referral for further assessment, the family could assume that everything is fine. In reality, however, the child may need some extra support in a key developmental domain, and without that support, the mild delay could progress to a more significant concern down the road, requiring a greater investment of resources and time to support the child’s development. If, on the other hand, a child demonstrates significant delays or concerns and the provider communicates that further assessment is required, without considering the family’s preparedness for next steps or acceptance that their child may not be typically developing, the family may feel anxious and disconnected and decline to proceed with an assessment and potential services that could support their child. It is essential that these conversations take into consideration a variety of factors that could influence a family’s capacity or readiness to take action on behalf of their children, and that they are conducted in a sensitive and thoughtful way so that children and families benefit. Often these conversations are where the process stops.^{xxiii,xxiv}

It is important to acknowledge that many parents are doing their best with what is available to them to navigate a complex system of early childhood development, and are eager to do more. According to Zero to Three’s National Parent Survey, nearly 9 in 10 parents regardless of race, ethnicity, income, and education levels are passionate about their roles and share an even greater desire to do more to help their children. Almost 70% of parents say that if they knew more effective parenting strategies, they would use them to improve their child’s health and development. It is important for the early childhood system to give families the support and resources they need and streamline a complicated system.^{xxv}



Coordination and Risk Appropriate Referrals

There is no central repository of screenings conducted, who is being screened, and the results or the follow-up that occurs/does not occur after the screening. The result is that children may be getting screened multiple times by different providers, inappropriately screened or not screened at all. Families may then receive conflicting or insufficient information on their child's development. This can lead to confusion, frustration and families becoming overwhelmed, which could then lead to children not receiving needed and timely assessments or services.^{xxvi}

Across system partners, knowledge and understanding of available resources and services and the ability to help families navigate the system when it has been determined that children need further assessment have been raised as significant challenges. Services and resources by community also can vary greatly, including waiting lists for services as well as workforce shortages, particularly in rural and tribal communities. These challenges leave partners overwhelmed with the task of connecting families to appropriate, timely and available interventions.

These challenges have unintended consequences for partners in the early intervention system. For example, as detailed in Figure 3, depending on the referring source, as many as 2 out of 3 children referred to AzEIP ultimately are not eligible for AzEIP services.

To qualify for AzEIP services, a child must have a 50% delay in at least one developmental domain, which is considered a narrow eligibility criteria when compared to other states. While infants and toddlers may not meet the eligibility criteria for AzEIP, these young children may have mild to moderate delays that require some level of intervention. System partners may be erring on the side of caution and over referring children to AzEIP for further assessment. This puts significant strain on this part of the system because AzEIP is required to assess all children referred to them. Additionally, the earlier concern noted about the difficulty in sharing screening information among partners means that often AzEIP does not have earlier screening results to include in its follow-up assessments.^{xxvii}

While it should be expected that some children referred to the program will not be eligible for services (particularly given the narrow eligibility criteria previously mentioned), the levels outlined in Figure 3 have elevated the issue of risk-appropriate referrals among system partners.



Lastly, when children are determined not eligible for AzEIP, families must go through another process to find appropriate services, which often takes considerable time and effort, thus delaying further assessments and interventions. The challenges faced by system partners who are following up on concerns identified through initial screenings, and the gaps in services for children who do and those who do not qualify for publicly funded programs will be discussed in subsequent briefs.

What is obvious from the aforementioned challenges is that Arizona’s current early intervention system lacks the definition, coordination and integration necessary to ensure that children are receiving the timely and quality screenings necessary in order to put them on the trajectory for optimal development.

Figure 3

Many Children Referred for Follow-Up Assessment Not Eligible for Services

Referral Sources	Eligible	Not Eligible	N/A (child's case closed before eligibility determination-could be loss of contact, voluntary withdrawal etc.)	Grand Total	% Eligible by Referral Source
Domestic Violence Shelter or Program.	1	3	2	6	17%
Department of Child Safety	289	345	747	1,354	21%
Physician's Office	1,799	1,458	2,758	5,889	31%
Public Health Facility	274	209	402	881	31%
Public Health or Social Service Agency	509	352	673	1,518	34%
Hospital	556	215	782	1,542	36%
Child Care/Early Learning Program	503	389	509	1,384	36%
School	36	27	35	98	37%
Homeless Shelter or Program	3		4	7	43%
Foster Care or Adoption Agency	37	20	23	79	47%
Parents/Family	1,318	878	637	2,775	47%
Audiologist	70	3	14	85	82%
Grand Total	5,401	3,854	6,463	14,964	36%
Percentage totals	36%	26%	43%	N/A	N/A

Source: Arizona Early Intervention Program (AzEIP), State Fiscal Year 2017 (July 1, 2016 - June 30, 2017)



What First Things First and Its Partners are Doing

In 2013, First Things First was awarded a three-year federal HRSA Early Childhood Comprehensive Systems (ECCS) grant focused on enhancing screening rates, improving existing services, and strengthening families' abilities to support their children's optimal development.

Stakeholders from state agencies, nonprofits, the Arizona Chapter of the Academy of Pediatrics, funding agencies, parent advocacy organizations, parents and others were convened to assess the early intervention system, to align collective goals on the recommendations of evidence-based screening tools and screening intervals, and to seek common areas of focus for collective work to improve the system.

This ongoing collaboration is building momentum, with all of the key system partners committed to understanding the complexity of the system and how each partner interfaces with the others in order to be able to focus in on system improvements. While this may seem an obvious goal, in reality it is difficult to achieve, given that each system partner has its own laws, policies and programmatic priorities; multiple funding streams; and families involved with multiple systems that have no formal communication or data sharing among them. To inform this collective work, several projects were undertaken to better understand the statewide context, concerns, gaps and barriers to families getting needed services and resources. The projects/studies included:

- **Family forums** conducted to hear directly from families about their experiences.
- **Interviews with early childhood comprehensive system professionals** on the screening, referral and treatment options, as well as system gaps for identifying and treating, children with developmental concerns.
- **An evaluation study** of an innovative effort to conduct developmental screenings online in three regions of the state.
- A Learning Collaborative conducted with a group of pediatric providers to increase understanding of the early intervention system and improve screening, risk appropriate referrals and knowledge about how to help families navigate the complex system of resources.

As a result of this work, the partners developed a Developmental Pathways Project to support the early childhood community in understanding the screening, referral and intervention pathways available when there is a concern with a young child's development. The aim is to ensure that all agencies and stakeholders conducting screening are providing high quality screening and risk-appropriate referrals for families of children with developmental concerns, along with simultaneous work on the part of state agency

policymakers to streamline the referral and service pathways. In addition, the project aims to increase the coordination and support to families in navigating a complex system of supports and services. The Pathways Project has resulted in common goals, to which system partners can align or leverage their efforts in order to achieve collective impact. Some notable examples include:



Training

In September 2016, First Things First and the Department of Economic Security/Arizona Early Intervention Program (AzEIP) partnered in hosting a three-day ASQ Training of Trainers workshop for 46 program administrators, AzEIP contractors, program managers, Child Care Health Consultants (CCHCs) and FTF staff to learn how to effectively use two Ages and Stages Questionnaires (the ASQ-3 and the ASQ:SE-2), which are among the most valid and reliable developmental screening tools available and widely used in Arizona programs.

The training included an in-depth exploration of the importance of screening and how to use the screening tools, how to engage families in the screening process, how to talk with families about the screening results and, most importantly, how to partner with families and caregivers in setting the stage for their child's healthy development. Each of the workshop participants agreed to train 10 more people over the course of the year in the same information shared with them.

One of the goals of providing a Training of Trainers workshop was to ensure that as system partners we are working to build capacity throughout the state, not just training a finite set of providers in a system challenged by rapid turnover. This investment allowed for a reach of close to (and likely more than) 500 professionals who conduct screening and referrals with families – supporting quality screenings, risk appropriate referrals and appropriate routing of children and families to the services and supports they need.



Leveraging Efforts to Integrate Screening In the Medical Home

A number of system partners are leveraging their collective efforts to ensure that children have a medical home and that the services provided to children include regular screening. As a result of the following efforts, more pediatricians and primary care offices are being supported in enhancing their screening practices through their professional associations, the major sources of reimbursement for their services (public health insurance programs and their contracted health plans), and community-based system partners working with the same families. For example:

Arizona's Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS) is also working to increase developmental screenings among children who have Medicaid coverage. For example, AHCCCS is working on a three year performance improvement project (PIP) from 2016-2019 focused on increasing developmental screening rates among children 0-3 using standardized screening tools. Although not formally tied to the PIP measurement, AHCCCS will be evaluating whether or not follow-up appointments are scheduled and maintained and services provided for any concerns identified through the screening process. Of note, AHCCCS's Targeted Investments (TI) initiative is incentivizing the health system to integrate physical and behavioral health care. The TI program will make almost \$300 million available for eligible providers. One of the prioritized populations in the TI program includes children with behavioral health needs, which includes performance measures on developmental screening for providers.

At the Arizona Chapter of the American Academy of Pediatrics, a workgroup of pediatricians are examining how to increase, improve, and sustain developmental screening in the clinical practices serving children enrolled in AHCCCS. Developmental screenings and autism screenings have also been a key topic at the statewide Governor's Autism Spectrum Disorder Task Force.

State agency partners are focused on strengthening the home visitation system to increase coordination of screening by home visitors with primary care providers. This includes identifying professional development opportunities to increase capacity and skills of the home visitation workforce as well as researching consultation models to integrate with the home visitation programs so that children with mild to moderate delays have access to supports and services as needed.

The Developmental Pathways Project continues to inform and aid in defining next steps in this collective work. Specific strategies are being identified with an emphasis on how to improve policies and coordination, where screening practices and evaluation/assessment processes need improvements, where professional development and capacity building is needed to strengthen the workforce, and how to identify, improve upon and increase existing resources and supports for families. This work is also focused on the inclusion of abused or neglected children, a high risk population that needs coordinated and streamlined services and supports.

As mentioned previously, monitoring children’s development and ensuring that families have the information and support they need in order to support their child’s healthy development is a responsibility we all share. As state agencies and other system partners work to improve screening rates, tools and resources, there are actions that families, providers, communities and policymakers can take to help more Arizona children get a strong start in their health and learning.

What Can Families Do?

Ensuring healthy development requires working with families and strengthening their capacity to respond effectively to their child’s development. Any family of a child with a physical, developmental, or behavioral concern or impairment may require outside help, and often professional guidance and support, to respond to that condition or challenge and manage the stress that it can place upon the whole family.^{xxviii}

And at the same time, families also need support – through individuals who can coach and teach, but also through peers. Parenting is not an easy task, in the best of situations, and when faced with developmental or behavioral challenges of a child, families face another layer of challenge. Support groups for parents, especially for parents of children with developmental concerns who often report feeling extra isolated and alone, can serve as a lifeline, offering community, solidarity, helpful information and a sense of belonging.

- For information about how to support your child, visit sites with credible parenting information like firstthingsfirst.org.
- In preparing for provider appointments, keep notes about and document issues that you are concerned about; take pictures of your child doing a specific task; record audios or videos on your phone of behaviors that concern you; write down your questions and take them with you so you remember what to ask and tell your child’s primary care provider or specialist during your appointment. Time is often limited, so writing it down helps to keep you and the provider focused where you need to be.
- Ask for a developmental screening for your child if you have concerns.
- If a doctor tells you there is nothing to be concerned about, ask what you can do at home to support your child’s development.
- Contact Raising Special Kids (info@raisingspecialkids.org) or Child Find (at your local school district) if you have a developmental concern you want addressed, or believe your child needs screening and potentially further assessment.
- Contact the Birth to 5 Helpline (birthtofivehelpline.org or 877-705-KIDS (5437)) for information or help in a particular aspect of parenting.

- If a doctor or other professional tells you that there are concerns about your child, follow up and act right away. If you're not sure how to move forward, ask for help in how to do it. The earlier you get help, the more actively you engage to help your child, the better the chances that your child will get the supports needed.
- Ask questions; be your child's first teacher and best advocate; speak up for your child to get what he or she needs.

What Can Providers Do?

Providers come in a range of shapes and sizes, educational backgrounds and experiences. They can range from primary care providers (PCPs) and developmental/medical specialists to home visitors (HVs) to school teachers and parent educators.

Some key areas that providers can focus on include:

- Engage families; listen to their concerns and ideas; involve them early and always in the process of helping their child.
- Empower the parent as the child's first teacher and ensure that they are given concrete, specific steps to help their children. The ASQ Learning Activities include simple and useful tools to help families practice developmental skills with their children.
- Make sure you are using appropriate screening tools and conducting high quality screening to ensure that resources are well used. When providing results, remember that it can be challenging to receive information about one's child that is concerning. It can also be frustrating to feel that something is wrong and not know the pathway to get help for a child. Partner with parents in supporting the child's optimal development by helping provide a warm handoff to other services so that they can access the support they need.
- Participate in professional development opportunities around quality screening, interventions, and Adverse Childhood Experiences (ACEs), to always be growing as you help families grow. The more you can learn about risk appropriate referrals, the more families will be routed appropriately to the services they need without having to travel multiple pathways and lose precious time in getting a diagnosis or help.
- Know your local resources; know the people who provide them; make a warm handoff to ensure the family gets the needed services.
- Follow up with families at their next appointment to know if they got the services they were referred for.
- Participate in system-building conversations locally and statewide to help clear away the obstacles that keep families from accessing needed supports for their children.

What Can Communities Do?

Communities can support families in a variety of ways. The importance of developing community-based responses that build upon local strengths and local innovations that enlist or develop local champions can be essential to supporting families and children in their healthy development. Key actions that communities can take include:

- Use the power of numbers: organize to support families and to advocate for screening and services for families of children with special needs or concerns.
- Practice inclusion so that families of children with developmental concerns or special needs can feel integrated and part of their local community.
- Organize support groups for parents.
- Participate in system-building conversations locally and statewide to help support clearing away the systemic obstacles that keep families from accessing needed supports for their children.

What Can Policymakers Do?

- Fund research to identify opportunities for coordination, collaboration, resource maximization, duplication avoidance, and facilitating seamless movement through the pathways.
- Then invest in system coordination and improvements to help service and data systems talk to each other. Help Me Grow is an example of a program that works in many states to help coordinate programs, providers, systems and data around children's development and has shown excellent results in improvements in care, appropriate routing of children and families to appropriate services, and identification of gaps so that they can be addressed. Such high functioning programs require investments and have high returns, saving costly future investments.
- Take a look at Adverse Childhood Experiences (ACEs) and support the development of trauma-informed organizations and communities. Trauma affects early and later health and development – promoting resiliency and stability in children, families and communities also supports healthy child development.
- Support professional development of existing professionals and those currently in training to improve the quality of supports for families. Track where screenings are occurring, to what extent they are occurring and how effectively children are being referred. Where there are issues with families not getting appropriately routed, address them with targeted training and capacity building.
- Support work to ensure Arizona has adequate providers in the specialty areas required to serve the population in need.
- Invest in innovative service delivery such as telemedicine for families in more remote and difficult to reach areas.

Each child develops in his or her own way, but there are developmental milestones that, when not met, can signal the need for further assessment. Arizona stakeholders need to work together to build awareness of typical development and the importance of regular, quality screenings to ensure any potential concerns are identified and addressed early on. This brief identified the concerns that exist regarding screening rates in Arizona, and steps many system partners are taking to ensure families and children have access to regular, quality screenings.

Subsequent briefs will address related issues – including challenges that exist in the current publicly funded programs to support children with developmental concerns, and the lack of supportive services and interventions for families whose children don’t qualify for those programs. In the meantime, stakeholders can use the information in this brief to begin (or continue) the dialogue in their communities and spheres of influence to ensure that young children in Arizona get a strong start on a path toward lifelong learning.

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