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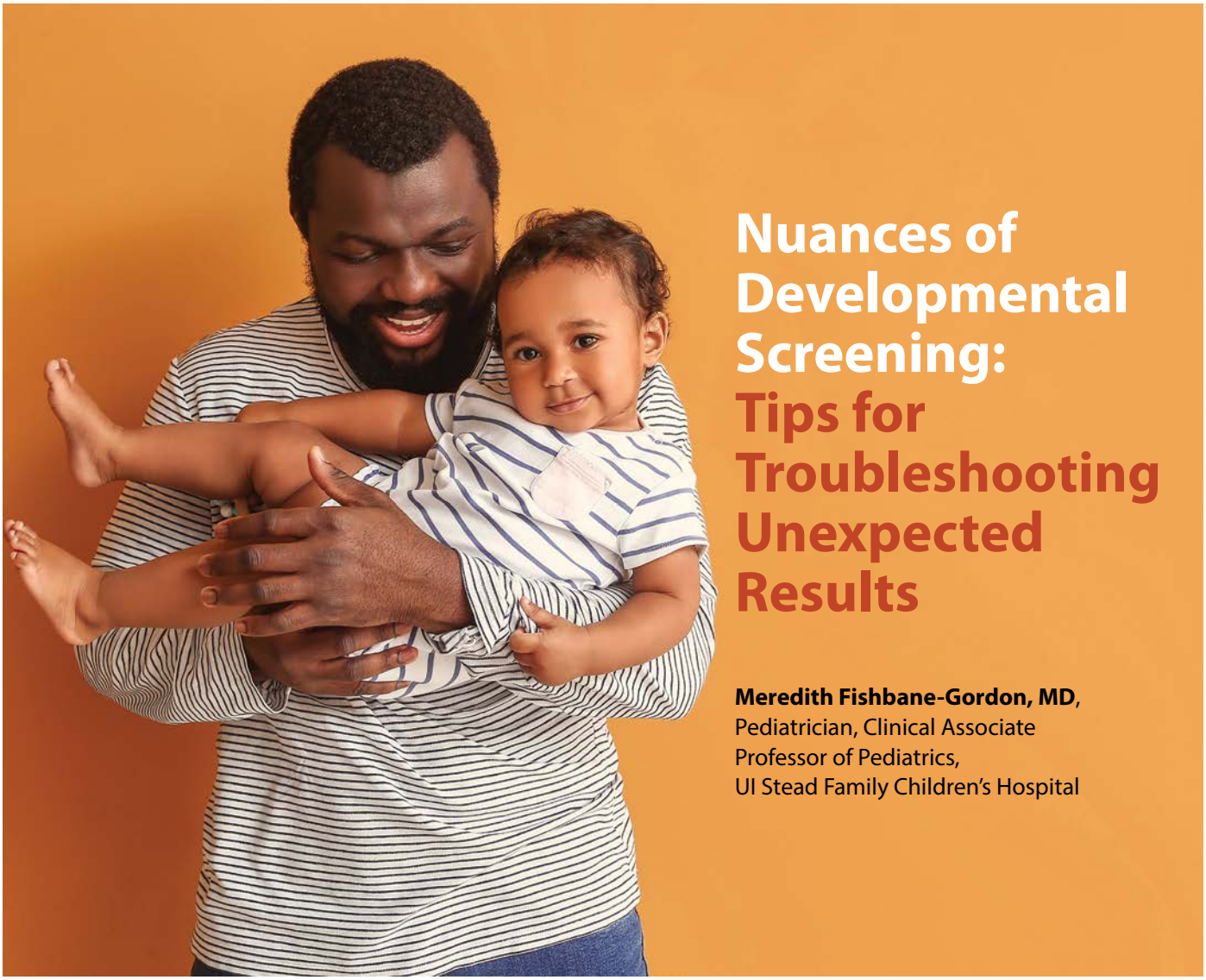

Nuances of Developmental Screening: Tips for Troubleshooting Unexpected Results

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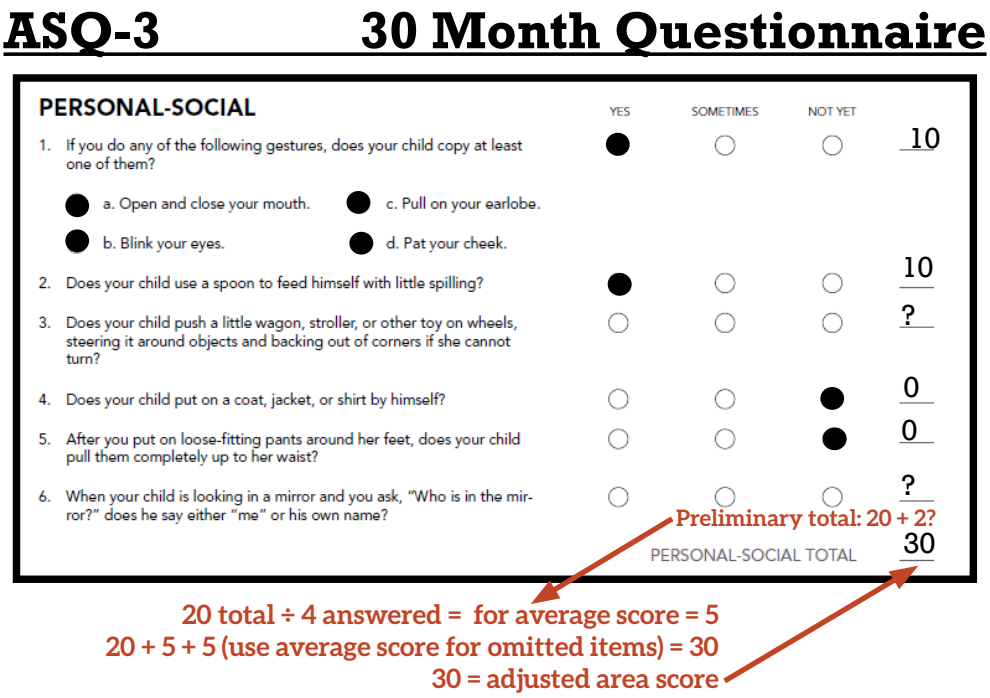
The American Academy of Pediatrics (AAP) and Bright Futures promote universal screening for both general development (at 9, 18, and 30 months) and autism (at 18 and 24 months). While many of us are regularly utilizing developmental screening in our practices, it can be challenging to know what to do with some results when they don't fall in the clearly "normal" or "refer" categories. The Ages and Stages Questionnaires (ASQ-3) and the Modified Checklist for Autism in Toddlers Revised with Follow-up (M-CHAT-R/F) are

(continues on page 2)

efficient and reliable assessments of child development and autism spectrum disorder (ASD) in the general pediatrics practice. While the ASQ-3 offers different questionnaires to cover early childhood (ages 1 month through 66 months), the M-CHAT-R/F is only valid if used between 16 and 30 months of age. Although they both have great reliability when completed accurately, there are often instances when scoring or interpretation can be confusing. There are often simple solutions that can help clarify the results to ensure maximum reliability.



ASQ-3 variances: scoring an incomplete screen

If you've ever read the questions on an ASQ-3, it is not surprising that some parents do not know the answers to some of the questions, especially as a child gets older as the skills are very specific. In an ideal world, a parent will be provided these questionnaires ahead of the visit and have sufficient time to be able to practice the skills with their child in their home to ensure the most accurate answers possible. Unfortunately, this is not practical for many reasons. To compensate for this reality, the ASQ-3 scoring system allows families the ability to skip up to two questions in each domain and still determine valid scores.

If a parent has only skipped one or two questions in a domain, it's important to make sure that an *adjusted area score* is completed or the child may falsely appear to be behind compared to peers. For example, if a parent knows that their child is doing two items in the domain, cannot do two items in the domain, and a child has not tried two items in the domain, if we do not calculate an *adjusted area score* to compensate for those items we should skip, the child's raw score would be 20 (10+10 for "yes" skills, 0 points for "no" skills), which is often considered *at risk for developmental delay* in most of the Ages and Stages Questionnaire scoring cards.

However, using the adjusted score, we can apply our understanding of the child's current skills to extrapolate what their score would likely be *if* the child had been given sufficient time to practice these novel skills prior to the appointment time. In the example noted above, the *raw total score* is 20; however, only four items were answered. This means that the *average score is five* (20÷4). By taking *five* and substituting that number as the new credit for those skipped items, we can create a *new adjusted area score* for the domain: 20+5+5 = 30. This new adjusted area score is then used to determine where the child falls on the scoring sheet. This adjustment of the score allows the provider and the parent to make a more accurate assessment of the child's skills while utilizing the validated screening tool, albeit in less-than-ideal scenarios. The above graphic illustrates adjusted area scoring as described in this paragraph.

However, if the family does not answer three or more items in a specific developmental domain, then the domain cannot be scored. In this uncommon scenario, the provider and family need to decide next steps together through shared decision-making; often the options include in-office follow-up or referral for further evaluation. To support families, providers can provide copies of free resources available on the ASQ website[1] that contain age-appropriate activities to promote development. The CDC has a **Milestones in Action** website that houses a free photo and video collection of developmental milestones and suggestions to encourage development throughout early childhood.[2]

M-CHAT-R/F in need of follow-up questions

The M-CHAT-R/F is typically straightforward to score.[3] If the score is two or less then the child is "low risk" for autism; if the child has a score of eight or above, they are considered "high risk" for autism. Providers should refer all "high risk" children right away for further evaluation by both a developmental specialist as well as early intervention services (called Early ACCESS in Iowa).

If a child has a score of three to seven, they fall into the "medium risk" category and additional work is needed to determine if further evaluation is warranted. The M-CHAT-R/F provides the follow-up questions in the free packet that is available to download for primary care providers (**https://mchatscreen.com/**). Having these questions pre-printed in the office for easy access can save time when a child flags in the medium risk category. When this happens, a provider or other trained support staff should go through each of the follow-up questions only for the missed items to arrive at either a "PASS" or "FAIL." Once these follow-up questions are done, if the child fails two or more follow-up questions, they should be treated as "high risk" for autism and referred for further evaluation and support as noted above. The follow-up questions improve the detection of ASD and increase the likelihood that a positive result is accurate.

Taking the next step

A good rule of thumb is to refer a child for further evaluation if you, a caregiver, or a screening tool note concerns about the child's developmental skills or developmental progress. The referral process is straightforward if the child is under 3 years of age as a single referral to Early ACCESS (or 1st Five) will help facilitate further evaluation of the child's development in all domains.

When a child is 3 years or older, the next steps vary by the number and type of concerns. While the Area Education Agencies (AEAs) can help with the evaluation and creation of an Individual Education Plan (IEP) if the child qualifies for developmental therapies, this process can be a bit tricky for families to navigate. Often, referral to individual, local private therapies (ex: speech, PT, OT) can be a straightforward complement to connect families to the services their child needs while awaiting the AEA evaluation.

When to refer a child to a developmental pediatrician

While primary care providers are welcome to refer a child with a developmental delay to a developmental pediatrician, scarcity of these specialists require us to be thoughtful with our connections. Significant delays in one domain, delays in two or more areas, developmental regression, neurological concerns, atypical development, and/or concerns for possible autism are all definite reasons to connect your patient with a developmental pediatrician. As the wait times for these visits can be more than nine months, it's very important to also connect patients with appropriate local services to begin therapies right away.

Online Resources

1. **https://agesandstages.com/free-resources/resources/**
2. **https://www.cdc.gov/ncbddd/actearly/milestones/milestones-in-action.html**
3. **https://mchatscreen.com/mchat-rf/**

Early ACCESS to Interventions with Iowa Area Education Agencies

Jess Burger, MSEd, Early Education Administrator, Grant Wood Area Education Agency

Early ACCESS is Iowa's early intervention system for infants and toddlers under 3 years old who are not developing as expected or who have a medical condition that can delay typical development. Iowa Area Education Agencies (AEAs) are responsible for administration of Early ACCESS across the state to ensure that no matter where a family lives in Iowa, services are available.

The focus of Early ACCESS is to support parents to help their children learn, grow, and develop through their everyday activities and routines. Families and Early ACCESS staff and service providers work together to identify, coordinate, and provide needed services and resources. This team approach ensures a child has positive early experiences that are essential prerequisites for later success in school, the workplace, and the community. Services to young children who have or are at risk for developmental delays can promote health and prevent disease, not just prepare children to succeed in school.[1]

Early ACCESS services are available to infants and toddlers from birth to age 3 to support children who:

- Have a health or physical condition that may affect his or her growth and development.
- Have developmental delays in his or her ability to play, think, talk, or move.

The first three years of a child's life are the most important for setting the foundation for ongoing development. Starting supports and services early improves a child's ability to develop and learn.

Anyone can refer children under the age of 3 to Early ACCESS, including parents, family members, medical providers, and childcare providers, although nonparent referrals do require parental consent. Upon receiving a referral, trained Early ACCESS staff will work with the family to coordinate a child assessment to learn more about the child's interests and abilities, and a family

assessment to learn about a family's routines, what goals a family has for their child, and learn how a family may be interested in helping their child develop and grow.

Early ACCESS service providers get to know the family's daily activities, priorities, and hopes for their child. Together, service providers and caregivers plan and practice interventions that can be used throughout the day within the family's established routines and activities. Service providers support families by coaching them to help their child grow and learn. Everyday routines and activities are teaching and learning opportunities. The more children are able to practice skills, the more their development is being supported. Referrals can be found at **https://achieve.iowa.gov/early-access-referral**.

Reference

1. Center on the Developing Child at Harvard University (2010) The National Scientific Council on the Developing Child: The Foundations of Lifelong Health are Built in Early Childhood.

CART services help support challenging day care behaviors

Grant Wood AEA's Childcare Alliance Response Team (CART) provides behavioral support for children ages birth to 5 who are experiencing challenging behaviors in a childcare setting. The children serviced through CART are not identified as having special education needs. CART services are provided at no cost to the family or the childcare program.

Grant Wood AEA receives funding from Early Childhood Iowa to provide CART services in Benton, Cedar, Linn, Johnson, Jones, and Tama counties. Referrals to this program are available to children in home day care or day care centers that are located in those counties. The child's county of residence is not a factor in determining eligibility for services.

A childcare provider is a critical partner for families in caring for their children. When a child's behavior, even behaviors that are a normal part of growth and development, become challenging or overwhelming in a day care setting, some families and day care providers may benefit from an external consultant who can assist in helping the family and providers who support the child.

CART service providers are typically called in to a day care setting, in-home or center-based, to help provide support for challenging behaviors in children. Often these are situations when a family is in danger of losing the childcare setting for a child because of challenging behaviors. The services provided by AEA CART staff are

customized to the needs of the day care and the child, but generally a CART service provider will first observe the child in the childcare setting and may:

- Suggest general education interventions/ strategies.
- Develop collaborative, individual plans to support the needs of the child.
- Make a referral to other resources as necessary.

It's important to note that either parents or day care staff can request CART support. The support will always take place in the childcare setting, not the home, but either party can initiate a conversation to help support a child. CART can support school-based preschool programs, in addition to the Grant Wood AEA staff assigned to the school building

Learn more about CART services by emailing referrals@gwaea.org, or use the website referral form at **https://www.gwaea.org/cart/**.

1st Five Supports EPSDT Through Community Service Referrals

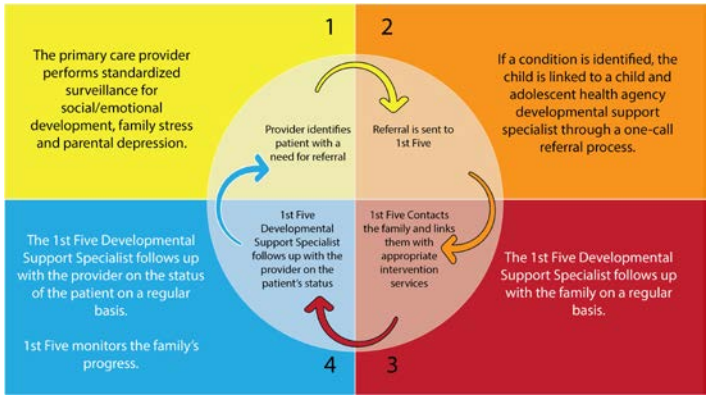
Michelle Holst, MPA, Iowa HHS, State Coordinator, 1st Five Healthy Mental Development Initiative

Researchers and those working in child health and development are clear that the sooner a child with emotional and developmental concerns receives early intervention services, the better the outcome. Consistent developmental screenings beginning soon after birth are critical for identification of developmental and/or social-emotional issues that can impact a child's healthy development. However, as discussed in the **EPSDT Fall 2022 issue**, screening without the ability to provide resources is less helpful.

According to the **American Academy of Pediatrics** (January 2020), "Early identification and intervention for developmental disorders are critical to the well-being of children and are the responsibility of pediatric professionals as an integral function of the medical home." Nearly all Iowa children under the age of 5 are seen in primary care, making this a nearly universal access point. Parents and caregivers respect and value the guidance offered by their children's providers. With the prevalence of developmental delay ranging from 17.4% of the population in urban areas to 19.8% in rural areas, (**Centers for Disease Control and Prevention**, 2020,) it's clear that many children can benefit from intervention. Yet, nationally, only 63% of pediatricians are screening children at recommended time frames (AAP, 2020), meaning many children are not being served in the early years while their brains are most plastic and adaptable to intervention.

The **1st Five Healthy Mental Development Initiative (1st Five)** engages with primary care providers to promote their use of developmental screening tools during well-child visits. It operates to support the voluntary participation of primary care practices in 88 counties across Iowa.

1st Five is a public-private partnership between participating practices and local community agencies. It is administered by the Iowa Department of Health and Human Services. 1st Five assures that, if needs become apparent during a developmental screen, providers have a pathway to refer the child to services through a one-step avenue.



1st Five is in all counties except Cherokee, Clinton, Ida, Iowa, Jackson, Johnson, Lyon, Plymouth, Scott, Sioux, and Woodbury. 1st Five is free and voluntary.

How do I refer to 1st Five?

Local 1st Five Site Coordinators are available to provide information, education, and support for practices to begin or enhance developmental screening protocols. Primary care practices may refer to 1st Five after engaging with a local site coordinator to establish a referral relationship. A list of local 1st Five Site Coordinators is available at **https://hhs.iowa.gov/1stfive/contact-information**, or by calling 800-383-3826 for assistance.

Referrals are typically sent via fax. There are no income or resource guidelines. A child does not need to be covered by Medicaid in order to be referred.

What happens after referral?

Through 1st Five, a Developmental Support Specialist (DSS) will work with a child's caregiver to connect the child to interventions that address concerns identified during a developmental screening. A DSS may also refer families to additional resources for concerns that impact the child's development and well-being, such as inadequate housing, food insecurity, and parent support/education needs. Once the child is connected to services, 1st Five reports back to the primary care provider to inform them of the services that are in place for the child and the outcome of the 1st Five referral. The 1st Five Four-Part Model is illustrated above.

1st Five Four-Part Model of Implementation

In the state's fiscal year that ended June 30, 2022, 1st Five identified 5,374 specific needs among referred children and families (**Iowa Department of Health and Human Services, 2022**). The highest percentage of needs were related to growth and development concerns such as physical therapy, occupational therapy, feeding disorders, and speech therapy. This was followed by resource needs, including services such as childcare assistance, food banks, housing support and transportation, and family support needs.

What services can families receive through 1st Five?

One of the most common referral resources accessed through 1st Five is Early ACCESS, which provides additional evaluation after a screening indicates developmental concerns. Early ACCESS is Iowa's early intervention system (IDEA Part C) for infants and toddlers under 3 years old who are not developing as expected or who have a medical condition that can delay typical development. Early intervention focuses on helping parents and other caregivers support growth and development during everyday routines and activities (**Iowa Family Support Network, 2023**).

Referrals for resource needs span a variety of programs and services for everything from formalized energy assistance or childcare programs to local clothing closets and food banks. The presence of a safe, stable, and loving caregiving environment is crucial to a young child's brain development. Stress within the home and family puts a strain on healthy development. Family support is a group of voluntary programs for expectant parents and parents of children in the period of life from birth through age 5, providing educational family support experiences designed to assist parents in learning about the physical, mental, and emotional development of their children (**Iowa Family Support Network, 2023**). The service often happens through visits to the child's home, sometimes known as "home visiting." Data included in 1st Five's family support category also encompasses domestic/family violence intervention, Head Start and Early Head Start, and a variety of educational testing and therapy.

Additional programs and services accessed through 1st Five include infant and early childhood mental health services, perinatal/postpartum depression counseling, Medicaid and Social Security applications, and dental care.

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What's in this issue

If you have questions about **billing** related to EPSDT Care for Kids services, please call Provider Services: **1- 800-338-7909**. If you have questions about **clinical issues** and EPSDT Care for Kids services, please call **1- 800-383-3826.** Please note: Due to budget restraints, the *EPSDT Care for Kids Newsletter* is sent to offices and organizations, rather than to individuals. **The newsletter is also available online at www.iowaepsdt.org**. Readers are welcome to photocopy or download material from the newsletter to share with others. If you wish to reproduce material from the newsletter in another publication, whether print or electronic, please obtain permission prior to publication by contacting Michelle Johnston at **michelle-johnston@uiowa.edu**. Please include the following acknowledgment with reprinted material: Reprinted by permission of the Iowa *EPSDT Care for Kids Newsletter.*

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