Early Identification: Surveillance and Screening

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> In Los Angeles County, too many children ages 0-5 are not screened for developmental and behavioral delays. When children are not routinely screened, they miss out on opportunities to address developmental and behavioral concerns and receive early intervention services. Receiving intervention services when a delay is detected early can improve physical, mental and socioemotional health and overall well-being. This brief explores key challenges and system-level barriers that impact early identification in practice.

ISSUE BRIEF

MAY 2019



EXECUTIVE SUMMARY

Identifying young children with or at risk for developmental and behavioral delays is an essential first step toward ensuring that all children have the opportunity to reach their optimal physical, mental and socioemotional health and well-being. Early identification involves a combination of routine surveillance and screening throughout different stages of a child's life. Parents, caregivers and service providers (including community-based, health, and early care and education) share a role in early identification.

Approximately 12–16 percent of young children experience a developmental delay.¹ Therefore, the American Academy of Pediatrics recommends that all children receive developmental surveillance during every preventive care visit and screening with a validated, global screening tool at 9, 18 and 24–30 months of age and an autism-specific screening tool at 18 and 24 months.

However, despite the importance of developmental and behavioral screening and the prevalence of delays, only 21 percent of young children receive timely developmental and behavioral screenings in California.²

The key challenges and system-level barriers impacting early identification in practice include the following:

- 1. Providers have varying degrees of knowledge about developmental and behavioral delays and screening.
- 2. Competing priorities and limited support for providers make it difficult to successfully implement developmental screening in practice.
- **3.** Lack of financial incentives for providers affects the practice of surveillance and screening.
- Parents and caregivers have diverse perceptions and understanding about developmental and behavioral health, milestones and early identification.

THE PROBLEM

The American Academy of Pediatrics (AAP) recommends that children are screened for developmental and behavioral delays early and throughout their development.³ Despite this recommendation, **fewer than 1 in 3 children receive timely developmental and behavioral screenings in California.**⁴ Among states, California ranks 43rd in developmental screening rates for young children.⁵ The American Academy of Pediatrics (AAP) recommends that in addition to conducting developmental surveillance during every preventive care visit, service providers should also use a validated, global screening tool at 9, 18 and 24–30 months of age and an autismspecific screening tool at 18 and 24 months.

Approximately 1 in 4 children ages 0–6 are at risk for developmental and behavioral delays.^{6,7} Despite this prevalence, young children in California are not receiving routine screenings with a validated screening tool in accordance with AAP guidelines.^{8,9}

Timely screening is important. Children who are screened early and receive early intervention services show improved social and cognitive skills and have higher academic achievement than children who do not receive services.¹⁰ Identifying a delay and intervening early can also reduce the need for special education services later in a child's life.^{11,12} In a national study of over 3,000 infants and toddlers who received early intervention, one-third did not require additional intervention upon entering elementary school.¹³

Delays in screening result in the vast majority of children with or at risk of developmental or behavioral delays not being identified until they are 5 years old. Despite the fact that most children will show mild developmental delays by 2 years old, as many as one-half of American children with developmental delays will not be identified by the time they enter kindergarten.¹⁴

Furthermore, evidence indicates there are significant racial disparities in screening rates. Latino, African American and Asian children in California are screened at lower rates than their white peers, leading to delayed diagnosis. For example, compared to other children, African American and Latino children are less likely to be diagnosed early with an autism spectrum disorder (ASD), and are more likely to be diagnosed at older ages and with more severe symptoms. In addition, validated screening tools are not available in all languages and have not undergone validity testing for all racial/ethnic and language groups.¹⁵

California's early care and education (ECE) sector has elevated the importance of screening as well.

> Developmental screening practices are part of a set of standards that determines ECE site quality. The Quality Start Los Angeles quality rating and improvement system (QRIS) evaluates participating ECE sites on developmental screening and referral practices.¹⁶ Although developmental screening with a validated tool in ECE programs is increasing, it is not yet universal and only a small subset of ECE sites participate in QRIS. In a study of Los Angeles Universal Preschool (LAUP) sites, onethird of children were in classes where their teachers reported they did not screen at all for health or developmental problems.¹⁷ Even fewer children are screened at family child care home facilities.¹⁸

WHAT ARE DEVELOPMENTAL DELAYS AND BEHAVIORAL CONCERNS?

A developmental delay means a child does not meet age-appropriate developmental milestones, functional or specific tasks that most children can do at a certain age. There are a range of milestones throughout early childhood and, therefore, delays impacting functions and abilities can emerge at different stages of development. Delays can occur in the following developmental areas:¹⁹

- Physical— fine and gross motor, vision and hearing:
 - Reaching, rolling, crawling and walking
- Cognitive:
- Thinking, learning and problem solvingCommunication:
- Talking, listening and understanding
- Adaptive:
- Independently eating, dressing and toileting
 Social or emotional:
 - Playing, feeling secure and happy

Literature on early identification suggests 12–16 percent of American children have at least one developmental delay.²⁰ In the 2011–2012 National Survey of Children's Health, 11 percent of children ages 4–5 had a high risk for developmental delays, 15 percent had moderate risk and 14 percent had low risk.²¹

WHY CHILDREN ARE NOT RECEIVING THE RECOMMENDED SCREENING

1 Providers have varying degrees of knowledge about developmental and behavioral delays and screening.

Primary care providers, pediatricians and specialists do not receive consistent training in child development and behavioral health, particularly as it relates to preventative care for young children.²² In addition, providers express varying levels of comfort and proficiency in talking to families about child developmental health and early intervention services, completing referrals and providing follow up.²³

Differing levels of health provider knowledge and understanding about early identification has resulted in inconsistent surveillance, screening and assessment practices in well-child visits. Research indicates there is a tendency among providers to misinterpret "surveillance" or clinical observation as a "screening" with a validated screening tool.²⁴

Child Adversity Impact on Child Development

TABLE 1

The following are the most commonly cited early childhood adversity risk factors contributing to developmental delays and socioemotional challenges in young children:

Experience of abuse or neglect Experience of homelessness Living in low-income households Living in neighborhoods deemed "unsafe" or "somewhat" safe to play Prenatal exposure to alcohol and drugs Having parent(s) with a mental health condition Being a child of a teenage

mother

The 2015 L.A. Care Gap Analysis Report, commissioned by First 5 LA, captures the identification and intervention practices of a sample 21 physicians in L.A. County and illustrates the confusion between surveillance and screening. Two-thirds of the physicians said they relied on clinical observation solely. One-third utilized at least one validated screening tool, and very few reported adhering to AAP's recommendation to use both a comprehensive screening and an autismspecific tool.24

a mental Unfortunately, surveillance alone is insufficient. A study published in the Journal of Developmental & Behavioral Pediatrics found that clinical observation alone missed 45 percent of children eligible for early intervention.²⁵

Provider knowledge about screening tools is also a barrier to successful screening. There are a number of different screening and assessment tools available to detect developmental and behavioral delays. No one tool is universally accepted, and there is limited evidence for providers to draw upon as they select the tool that is most appropriate for their patient populations. In addition, not all tools are validated instruments where reliability has been measured and documented. Furthermore, there remains a lack of available validated tools in other languages aside from English and Spanish, leaving providers who work in diverse communities such as Los Angeles poorly equipped. These nuances related to the screening and assessment tools can create additional misunderstanding among service providers.²⁶

Frequently Used Validated Screening Tools

Screenings are typically completed by the primary caregiver and scored and interpreted by a trained provider.

Ages and Stages Questionnaire (ASQ): Assess a child's communication, gross motor, fine motor, problem solving and personal-social abilities.

- **ASQ-3:** Assess developmental progress
- ASQ:SE: Assess socialemotional progress

Parent's Evaluation of Developmental Status (PEDS): Assess a child's language, motor, self-help, early academic skills, behavior and socialemotional/mental health.

Modified Checklist for Autism in Toddlers – Revised (CHAT/M-CHAT-R): Screens for early signs of autism spectrum disorder (ASD) or developmental delays.

In the ECE sector there is a lack of research on screening practices and provider knowledge. However, recent research commissioned by the Connecticut Office of Early Childhood and Connecticut United Way gives us some insight with findings from eight focus groups and a survey of 329 ECE providers. Among sites, surveillance and screening services provided to families and children varied widely. In general, small, privately owned facilities receiving few or no public funds and family child care providers were less likely to be aware of or use formal screening tools, or to have specific protocols in place to identify and address behavioral needs and challenges. In addition, similar to health care sector providers, ECE providers from both center-based and family-based facilities expressed challenges discussing behavior and development with parents.²⁷

2 Competing priorities and limited support for providers make it difficult to successfully implement developmental screening in practice.

Both service providers and health plans experience difficulty incorporating developmental screenings into the already overburdened well-child visit workflows. Other mandatory health screenings and competing procedures often take priority. Physicians express that sufficient time is required for early identification, not only to assess a child but also to discuss the child's development with parents and caregivers when a potential delay is detected.²⁸

Children who miss well-child appointments or lack continuity with one primary health care provider have a higher likelihood of not receiving recommended screening.²⁹ Evidence indicates there is limited or no coordination among different service providers. As a result, service providers may be unaware of the screening a child received, the screening result, or the type of intervention services provided.^{30,31,32}

In the ECE sector, research reveals that many providers also experience infrastructure and workflow challenges to monitoring the development and behavior of young children in their programs. These challenges include staffing and time limitations to complete screening, limited ability to store or use data from surveillance and screening, and lack of regulation or information about early identification to guide practice.³³



3 Lack of financial incentives for providers affects the practice of surveillance and screening.

Developmental screenings for children ages 0-3 and autism screenings for children at 18 and 24 months are covered under all public and most private health insurance plans without additional cost to families as Essential Health Benefits through the Affordable Care Act (ACA).³⁴ However, there are different levels of oversight and regulation across health plans and locations.

States take different approaches in promoting early identification, including setting reimbursement rates for screening, recommending or requiring certain screening tools, specifying when developmental screenings can be administered and leveraging Medicaid-managed care contracts.³⁵ In California, all health plans, including Medi-Cal Managed Care and Medi-Cal fee-for-service, are encouraged but not mandated to provide well-child health assessments in accordance with the AAP/Bright Futures Periodicity Schedule.³⁶

Because of the way billing occurs in managed care plans, it can be difficult to track screening activities that happen during a well-child visit. Physicians often do not separately code for developmental screening activities.³⁶ Furthermore, many health providers are compensated within a permember, per-month system in a capitated health insurance model. As a result, there is little financial incentive to either report or report accurately the use of the proper developmental and behavioral service codes. Physicians may conduct surveillance and or ask the caregiver a few questions about the child's development and behavior, rather than use a validated developmental screening tool, and report it as a screening.³⁷ Another important system barrier that impacts both ECE and health providers is the cost of completing screenings.³⁸ For health providers in particular, this can include the cost to license developmental screening tools and the cost to imbed screening tools into electronic health records for efficient workflow.^{39,40}

4 Parents and caregivers have diverse perceptions and understanding about developmental and behavioral health, milestones and early identification.

Parents and caregivers are often the first to notice if their child is showing atypical development or behavior. However, limited parental knowledge may inhibit "parent-to-provider" communication about a perceived developmental delay or behavioral concern. Furthermore, many parents are not prompted to start this conversation during well-child visits. The 2016 National Survey of Children's Health indicates 70 percent of parents of children ages 0–5 in California surveyed were not asked by their child's doctor or other health care provider if they have concerns about the child's learning, development or behavior.⁴¹

Equipping parents, caregivers and family members with appropriate information to better monitor their child's developmental and socioemotional progress is an important element of early identification. It is also important to employ culturally sensitive parent engagement as evidence indicates that perceptions of normal child development differ between cultural backgrounds.⁴²



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ISSUE BRIEF 1 • MAY 2019

LOOKING AHEAD:

Identifying young children with or at risk for developmental and behavioral delays is a crucial first step toward ensuring optimal health, school readiness and overall well-being. First 5 LA has been committed to strengthening early identification and intervention systems in the county through multiple strategies for over ten years. One of these strategies is Help Me Grow (HMG), which First 5 LA is currently planning and implementing in partnership with L.A. County Department of Public Health.

HMG is a national model that promotes local cross-sector collaboration to bolster early screening and surveillance of developmental and behavioral delays for all young children.

HMG strives to coordinate existing systems (i.e.: health, ECE, mental health, developmental disabilities, child welfare, school districts, and community-based organizations) that serve children with or at risk for delays and their families to ensure they receive appropriate intervention services and supports. The HMG model operates through four core components. Each component will contribute to increased screening rates in L.A. County.

Addressing the barriers to timely developmental and behavioral screening requires a systems and policy change approach. Together with county partners and stakeholders, First 5 LA seeks to help transform local systems to better serve children and families.

Centralized Access Point:

of a telephone or web-based hub to link children and their families to early intervention services and supports.

Community and Family Engagement:

promotes HMG and provides networking events for service providers across diverse sectors and families to bolster knowledge about healthy child development and local services.

HMG Four Core Components

Child Health Care Provider Outreach:

provides training and support to child health providers to promote and integrate early identification into practice.

Data Collection and Analysis:

identifies gaps and barriers in early identification to continuously improve systems and access to screenings.

Acknowledgments:

The authors would like to thank Dr. Marian Williams, Whitcomb Hayslip, Therese Delgadillo as well as former and current First 5 LA colleagues Reena John, Mercedes Perezchica, Ruel Nolledo, Andrew Olenick, Zully Jauregui and Tina Chinakarn for their contributions to research, review and copyedits.

To learn more about this effort please visit:

- First5LA.org/Help-Me-Grow/
- helpmegrowca.org
- helpmegrownational.org

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