

Linkage to Services and the Referral Process

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Prepared by:

Alexandra Parma, Cristina J. Peña and Krystal Green

In Los Angeles County, too many children ages 0–5 with or at risk for developmental and behavioral delays are not being referred and connected to the appropriate early intervention services. This includes linkages to follow-up assessments and preventative supports. Receiving timely intervention services for identified concerns or delays can improve a child's physical and socio-emotional health. This brief explores the various system-level challenges that may interfere with linkage to services and the referral process.

EXECUTIVE SUMMARY

Evidence indicates that when young children with or at risk for delays are successfully linked to appropriate prevention and intervention services before kindergarten, their developmental, behavioral and overall well-being are improved.¹ However, when developmental and behavioral delays go undetected and untreated, children have a greater risk of experiencing ongoing and more severe disabilities throughout their lives.²

Literature on early identification suggests 12–16 percent of children in the United States have at least one developmental delay.³ Early identification, which involves a combination of routine surveillance and screenings, greatly increases the likelihood that a young child with or at risk for delays will be spotted and referred to appropriate prevention and early intervention services. However, many children are still not getting linked to services, even when they are screened for delays.

The following challenges and system-level barriers interfere with successful linkage to timely early intervention services:

- 1. Even when children are screened and a delay is identified, providers may fail to make a timely referral.**
- 2. Fragmented services, complex eligibility and unclear referral processes in L.A. County make it difficult to match identified needs with appropriate referrals.**
- 3. There are limited available prevention and early intervention services in a community to address a child and family's unique needs.**
- 4. Parents and caregivers have diverse perceptions and understanding about the benefits of prevention and early intervention services.**



THE PROBLEM

In California, approximately 25 percent of young children are at risk for a developmental and behavioral delay. In Los Angeles County, it's estimated an even higher percentage of young children (30–40 percent) would benefit from prevention and early intervention services and supports.⁴ However, many children do not receive prevention and early intervention services until they reach kindergarten.^{5,6}

Approximately 15 percent of all young children experience developmental delays. In an ideal situation, close to 15 percent of all children would also receive public early intervention services. However, data from the Individuals with Disabilities Education Act (IDEA) suggests only 3 percent of all children receive early intervention under Part C by age 3.^{7,8,9} In addition to gaps in access to IDEA Part C services, children are also not connected to mental health services in a timely manner. Of the total number of children ages 0–5 receiving Medi-Cal and eligible for intervention services to address behavioral needs, only 2.6 percent accessed specialty mental health services.¹⁰

The importance of early intervention is clear. Evidence indicates that when young children with or at risk for developmental and behavioral delays are successfully linked to appropriate prevention and early intervention services before kindergarten, they are more likely to complete high school, maintain employment, live independently and avoid teen pregnancy. They are also less likely to engage in criminal behavior.¹¹

Furthermore, failing to intervene on delays and certain developmental skills, such as language, could further prevent the identification of other disabilities. This is because a child's communication abilities are a means to both observe and detect other physical, social and emotional challenges.¹²

It is important to note that early identification through a validated screening process does not provide a diagnosis, but rather indicates if a child is showcasing signs of delays or is at risk for developing future delays. At the sign of delay, children should be referred for a formal assessment and receive prevention and early intervention services based on their results.¹³

WHAT ARE PREVENTION AND EARLY INTERVENTION SERVICES AND WHO PROVIDES THEM?

Prevention and early intervention supports are important for ensuring that children reach their optimal development. Prevention approaches generally include activities, tools, and educational resources and trainings. These resources are meant to help parents, caregivers and families better support their child's development and recognize atypical behavior or potential challenges.¹⁴

When a delay or risk of a delay is identified, early intervention services are meant to enhance children's development and minimize the potential for special education and related services later in life. Early intervention services should also support and enhance a family's ability to meet the special developmental needs of their children.^{15,16}

Early intervention services may range in scope and are designed to improve a child's developmental functions and abilities in the following five areas:

- Physical — fine and gross motor, vision and hearing:
 - Reaching, rolling, crawling and walking
- Cognitive:
 - Thinking, learning and problem solving
- Communication:
 - Talking, listening and understanding
- Adaptive:
 - Independently eating, dressing and toileting
- Social or emotional:
 - Playing, feeling secure and happy^{17,18}

Early intervention services may include:

- Assistive technology
- Audiology or hearing services
- Family training, counseling and home visits
- Health services necessary for a child to benefit from other early intervention services
- Medical services for diagnosis and evaluation
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Care coordination and or case management
- Social work services
- Special instruction
- Speech and language services
- Transportation and related costs necessary for a child to receive services
- Vision Services

In L.A. County, prevention and early intervention services and supports are overseen and delivered by various state and county agencies, programs and community-based organizations, including but not limited to local Regional Centers, Local Educational Agencies including school districts, Early Start, Early Head Start, Head Start programs, Family Resource Centers, home visiting programs, Department of Mental Health, Department of Public Social Services, and community-based organizations.¹⁹

In addition, some early intervention services such as occupational therapy, speech therapy and mental health services are also considered a health benefit under California's Medi-Cal fee-for-services (FFS) and Medi-Cal Managed Care, and within some private health insurance plans.^{20,21}



WHY THE REFERRAL PROCESS AND LINKAGE TO SERVICES IS SO CHALLENGING

1 Even when children are screened and a delay is identified, providers may fail to make a timely referral.

As with early identification, there remains varying levels of understanding among service providers (including community-based, health, and early care and education) regarding the importance of intervening at the earliest sign of delay. Several studies show there are inconsistent referral patterns among physicians, with some providers not referring when a developmental or behavioral screening identifies a delay.^{22,23} Some providers adopt a “wait-and-see” or “they-will-grow-out-of-it” approach when a delay is detected or a parent expresses concern with the result.²⁴

Providers may wait to refer because they are concerned they will incorrectly identify a child with a developmental and behavioral challenge and make an inappropriate referral. Providers express worry that making an inappropriate referral will cause undue stress or stigma to families and burden local service systems.²⁵ Popular validated screening tools such as the Ages and Stages Questionnaire (ASQ) and Parents’ Evaluation of Developmental Status (PEDS) are fairly sensitive in detecting delays, and most children are correctly identified. However, a non-nominal proportion of children who identify with a delay in their screening will find they do not have a delay after further evaluation.²⁶

In the early care and education (ECE) setting, providers have noted lack of private space to hold sensitive conversations with families is a barrier to complete a timely referral in their practice.²⁷ Further research is needed to determine all the causes leading to excess time between completing a validated screening and making a referral in the ECE setting.

2 Fragmented services, complex eligibility and unclear referral processes in L.A. County make it difficult to match identified needs with appropriate referrals.

Providers experience difficulty navigating the service landscape comprised of changing federal and state

laws, varying eligibility criteria and complicated referral pathways. Providers also need to navigate multiple service systems while making an allowance for a child and family’s specific situation to determine the most appropriate prevention and early intervention services. In addition to weighing the screening results, delay type and severity of need, providers must also consider the child’s health care coverage, geographic service area and family’s preferences, including language and cultural needs.^{28,29,30}

Furthermore, ongoing policy changes at the federal and state levels have raised important questions about which entities are responsible for delivering developmental and behavioral care and services. For example, in 2014 federal law transferred the responsibility of delivering behavioral health treatment from Regional Centers to Medicaid Managed Care Health Plans. Behavior health treatment can include occupational therapy, speech therapy, and applied behavioral analysis services for individuals under 21 with autism spectrum disorder.³¹ Policy changes may unintentionally contribute to ambiguity related to referrals.

Amid these federal and state policy changes, providers indicate a lack of accurate and easily accessible information related to eligibility criteria for certain programs and services. For young children over the age of 3, eligibility criteria for prevention and early intervention services and programs can vary greatly based on the severity of the delay or condition.³²

In addition to eligibility criteria, determining the appropriate payer(s) for early intervention services, including navigating “payer of last resort,” “proof of denial” and “pre-authorization,” may cause further delays and interruptions in accessing services when families are bounced between payers. Intervention services and supports may be covered by public or private insurance, purchased by a public agency as an entitlement service or paid for out of pocket. In some instances, costs are based on an income sliding scale.^{33,34,35} The age of a child may also affect which entity is responsible for paying for early intervention services and supports.^{36,37}

Finally, there is no clear referral process and criteria for children with or at risk for delay, and families may be sent to multiple wrong entities before reaching an appropriate support. Health providers may also be unaware they can refer a child to a specialist within the managed care plans’ network when an early intervention service is a covered health benefit under Medi-Cal. Often times they refer a child to their local Regional Center solely. The Regional Center may then be required to refer the family back to the plan, creating confusion and frustration for a family.³⁸



3 There are limited available prevention and early intervention services in a community to address a child and family's unique needs.

Across the country there is a documented shortage of developmental and behavioral pediatric providers. The workforce is aging, reducing the number providers in the field, while the demand for services increases.³⁹ For example, there is a shortage of speech-language pathologists for young children with speech delays, and California has one of the greatest unmet needs.⁴⁰ In 2016 there were 145,100 speech language pathologists in the U.S. However, the Bureau of Labor Statistics projects an additional 25,400 speech language pathologists will be needed to fill the national demand between 2016 and 2026, representing an 18% increase in job openings.⁴¹

Low Medi-Cal reimbursement rates are also cited by both experts and providers as a disincentive for providers to accept Medi-Cal beneficiaries.^{42,43} This exasperates the shortage of available in-network prevention and early intervention service providers and specialists for children covered by Medi-Cal.⁴⁴

The Individuals with Disabilities Education Act (IDEA) requires states to provide intervention services to children diagnosed with developmental disabilities. However, children who fall below the severity threshold are not eligible for these services and, therefore, may have fewer available options for prevention and early intervention supports.^{45,46}

Even when children are not eligible for services under IDEA Part B and C, they can still benefit from developmental and behavioral intervention supports. A national study carried out by UCLA Department of Pediatrics from 2006 to 2008 estimated that one-quarter of all 2-year-old children who were deemed ineligible for early intervention services (Part C) under current guidelines, demonstrated inadequate school readiness, including poor cognitive and behavioral outcomes when they entered kindergarten and could have benefited from early preventative and intervention services and supports.⁴⁷

Furthermore, there are geographic service gaps that limit the supports that a family can access. Several L.A. County communities and areas, such as residents of Antelope Valley and South L.A., have expressed limitations to local resources to support children's health.⁴⁸ ECE providers have also indicated that language and cultural preferences, as well as transportation options, may further limit their ability to make a successful and local referral.⁴⁹

4 Parents and caregivers have diverse perceptions and understanding about the benefits of prevention and early intervention services.

Evidence indicates parents and families may experience a range of emotions, from relief knowing a potential delay has been identified to denial and shame associated with receiving a diagnosis. Early care and education providers in particular have noted family reluctance to accept their child's challenges and parental fear of the referral process as common barriers to referral.⁵⁰

Parents and families play a key role in early screening and are central to ensuring children at risk for or with developmental and behavioral challenges receive early prevention and intervention services and supports. However, many variables may decrease a family's receptivity to prevention and early intervention, including wariness of home visits or unwillingness to acknowledge potential developmental delays. Some families also have varying levels of understanding about how services may be improving their child's development.⁵¹

In order to understand parental beliefs and expectations regarding child development and early intervention supports, providers must acknowledge the influence of the family's unique situation. Parents may hold beliefs such as "children are different and develop on their own time," or trust their social networks more than physicians regarding child development. In a study of African American and Hispanic mothers of children ages 0-36 months with developmental delays, mothers reported feeling pressured into using services. The end result was a process from which mothers were further disengaged. Providers need to elicit parents' expectations and any concerns early when children are screened for delays and continue to engage them as equal partners throughout the decision-making process as it relates to prevention and early intervention.⁵²

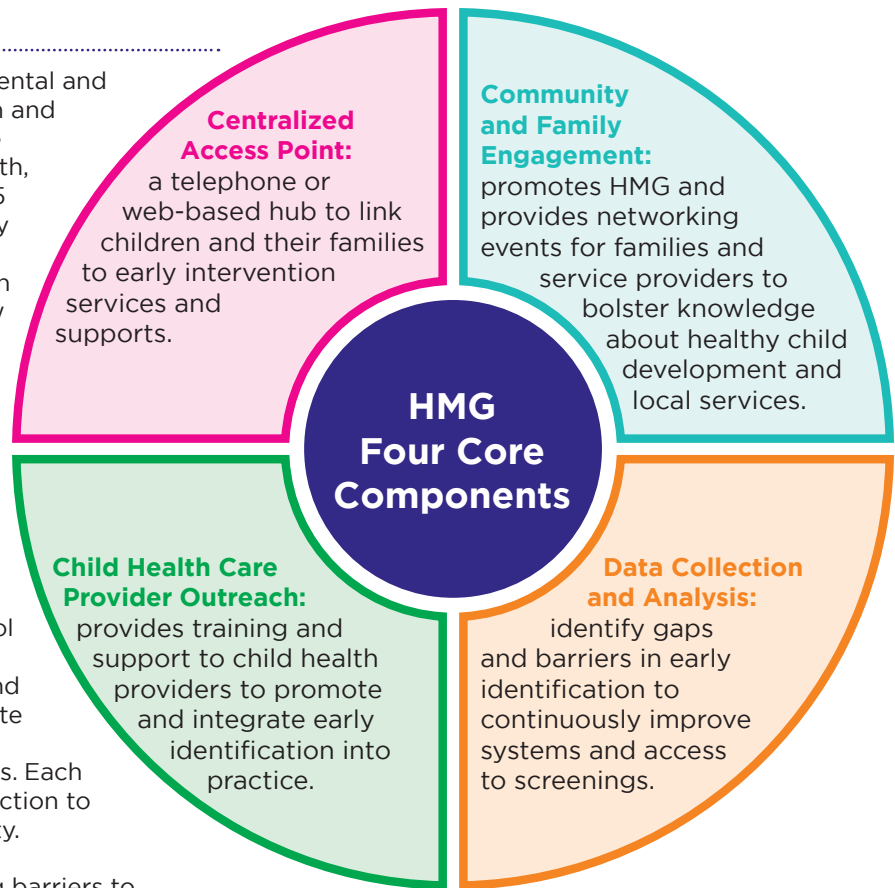


LOOKING AHEAD

Ensuring children with or at risk for developmental and behavioral delays are connected to prevention and early intervention services as soon as possible increases their chances to obtain 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 improved connection to services for children and families in L.A. County.

Streamlining the referral process and reducing barriers to accessing services 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.



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To learn more about this effort please visit:

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

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