Identifying Young Children for Early Intervention in California

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Only about 10 percent of eligible infants and toddlers with developmental delays nationwide receive early intervention services, which are widely agreed to reduce delays and lessen the adverse effects of risk factors and disabilities on learning and development. California serves fewer children than the national average. Challenges arise from spotty screening; tenuous linkages to referral and evaluation; and the intricacies of crossing multiple agencies—sometimes without knowledge of English—for families. In Massachusetts, a unified early childhood data system and robust interagency linkages resulted in a far greater percentage of their infant and toddler population served. Taking steps towards a unified early childhood data system alongside mandates for interagency streamlining and cooperation would likely increase the number of children and families served in California.

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Introduction

Of the 454,920 babies born in California in 2018, the vast majority are developing as anticipated. A small percentage, though, have Down syndrome or hearing loss; some are not communicating, learning, or behaving as expected; and some are at risk for developing learning and behavioral problems because of factors like very low birth weight or abuse and neglect.

What can we do for these young children so that they can be the best that they can be and someday have the opportunity to achieve in school and contribute to the state economy? Fortunately, the federal government mandates—and California provides—a set of services tailored to the needs of the child known as early intervention. It is well established that early intervention can lessen the impact of developmental delay and disability as well as provide needed supports to the child and family. Early intervention might consist of visits to the home to assist the family, in addition to individual therapies that the child needs.

But how do we find and identify children in need so that they can access these services as early as possible? That is the topic of this brief.

Federal and State Mandates Regarding Early Intervention

Mandated Components of Early Intervention from Federal Law

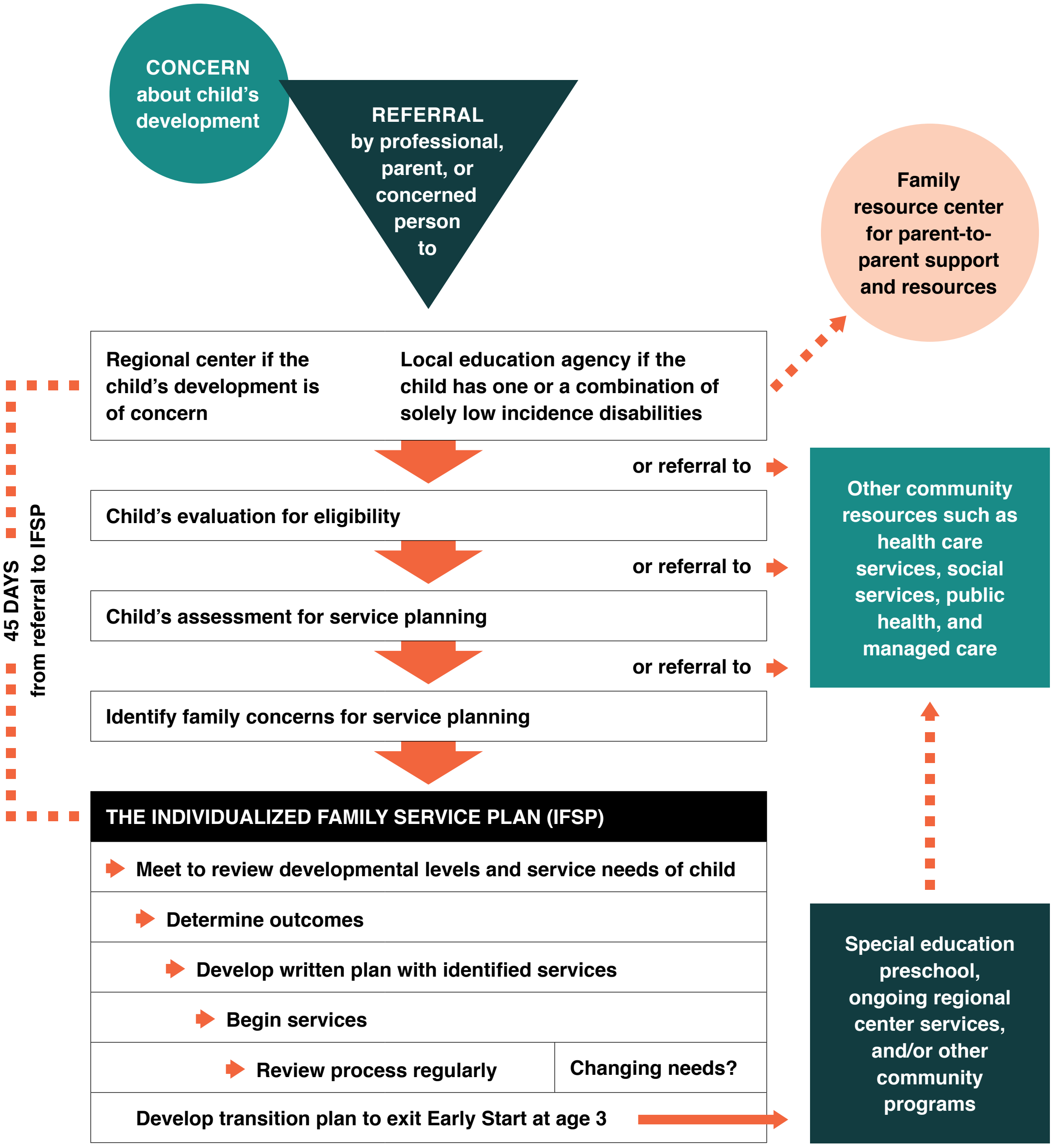
Among the required components of Part C of the Individuals with Disabilities Education Act (IDEA), which governs services for infants and toddlers from birth to age 3, are the following:

1. Appropriate early intervention services based on scientific research, to the extent practicable, are available to all infants and toddlers with disabilities and their families, including Native American infants and toddlers as well as those experiencing homelessness.
2. Timely and comprehensive multidisciplinary evaluation of needs of children and family-directed identification of the needs of each family.
3. An Individualized Family Service Plan (IFSP) and service coordination.
4. A comprehensive Child Find and referral system.
5. A public awareness program focusing on early identification of infants and toddlers with disabilities, and providing information to parents of infants and toddlers through primary referral sources.[1]

California Statutes and Regulations

California's program for implementation of Part C of IDEA is known as Early Start. Regulations were approved in 1998.[2] Early Start is administered by the Department of Developmental Services, although some programs are provided by school districts. Figure 1 shows how California Early Start is designed to operate.

Figure 1. The California Early Start System



Note. Figure from ceitan-earlystart.org/central-directory/early-start/referral-to-es/referral-process

The rationale for federal and state emphasis on public awareness programs, a comprehensive Child Find and referral system, and timely and comprehensive multidisciplinary evaluations comes from decades of research culminating in these conclusions:

- Intervention can reduce developmental delays and lessen the adverse developmental effects of risk factors and disabilities.
- Intervention is more effective when begun early.
- Effective early screening and assessment systems can result in earlier provision of intervention services.[3]

Expenditures in early intervention and programs for infants, toddlers, and their families in the first three years of life are widely seen as providing a robust return on investment—in fact more so than those made at any other point in a child's life. Economist James Heckman's analysis indicates that programs providing health, early learning, and care from birth produce a 13 percent return on investment per child per year.[4] A large body of research has demonstrated that high-quality early intervention for infants and toddlers with developmental delay and disability has had long-term cost savings in terms of decreased grade repetition, reduced special education spending, enhanced productivity, lower welfare costs, increased tax revenues, and lower juvenile justice costs.

Eligible Children Are Not Receiving Early Intervention

Despite the now-longstanding emphasis on early identification and referral of infants and toddlers at risk, far fewer children than are eligible are receiving early intervention services. Rosenberg and colleagues looked at a birth cohort from the national Early Childhood Longitudinal Study. Their analysis found that about 13 percent of children in the sample had developmental delays that would make them eligible for Part C early intervention, but only 10 percent of children with delays were receiving them. Notably, African American children were less likely to receive services than children in other ethnic groups.[5]

The most recent data from the U.S. Department of Education indicate that 3.1 percent of the total population of children from birth to age 3 receives early intervention services; in California the percentage is 2.9.[6] Clearly, many children who could benefit from early intervention are not being served—a projected 3,025 young Californians.

Furthermore, numbers of older children with developmental delays are increasing. The recent National Health Information Survey documented increases over time in the number of children identified with developmental disabilities aged 3 to 17 and found that the prevalence of developmental disabilities increased from 12.84 percent of the population in 1997–99 to 17.76 percent in 2015–17. Growth was led by increases in children with any developmental disability, attention deficits, autism, and intellectual disabilities.[7] This growth will place an added burden on education budgets that are already bursting at the seams.

The primary issue is that the number of children receiving early intervention in the U.S.—and even more so in California—is likely significantly lower than the number who are eligible. In fact, the majority of those children are not being served at all.

Why Are We Missing So Many Children?

Much of the attention paid to answering this question has focused on screening: "The first step to connecting children with the supports they need for healthy development."[8] Screening is a first-line check of a child's development using developmental and behavioral screening tools. A screening tool is a formal research-based instrument that asks questions about a child's development, including language, motor, cognitive, social, and emotional development. A screening does not provide a diagnosis; rather, it indicates whether a child is on track developmentally and whether a closer look by a specialist is needed.[9]

All children should be screened, and the natural screeners are those who see children often: pediatricians, first and foremost. The American Academy of Pediatrics (AAP) recommends regular screenings during well-baby visits in early life, and they are covered under most insurance programs and Medi-Cal. Despite this, fewer than 1 in 3 California children receive developmental screenings, and California ranks 43rd in developmental screening rates for young children.[10, 11]

Of course, screening has limitations. For one, it appears that brief screenings may not consistently identify children with social-emotional needs;[12] their caregivers may be less accurate in identifying these issues than they are with physical or cognitive delay. The tools themselves also have limitations in this respect, which is disturbing in the context of current concerns, particularly related to young children with behavioral challenges who will later be more likely to be suspended or expelled from preschool and might benefit from linkage to early childhood mental health services. While screening increases referral and access, therefore, it is not by itself sufficient to ensure access. It is simply the first step in the process of getting services to children and families.

California AB 1004, passed in late 2019, requires doctors to screen children enrolled in Medi-Cal for developmental delays—using AAP-approved screening tools—at ages 9 months, 18 months, and 30 months. Governor Newsom's 2019–20 budget provided additional financial incentives for physicians who conduct screenings of the approximately

42 percent of California children who are insured through Medi-Cal. Through these measures, there is hope for improved early identification of children at risk, those who experience trauma, and those with disabilities and delays. Let us hope that the remaining 58 percent of California children are also screened regularly.

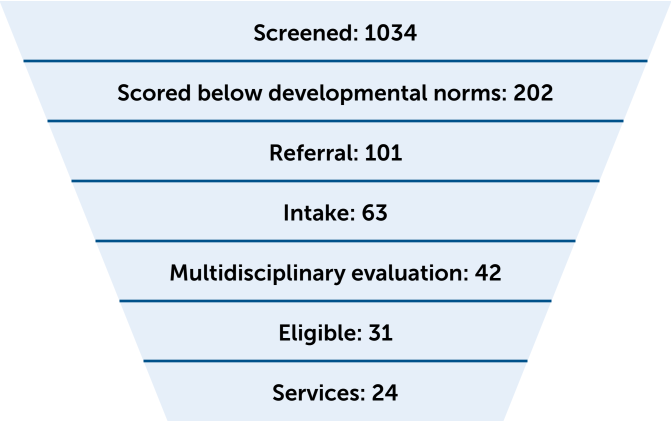
Early Start Child Find Has Room for Improvement

The California Legislative Analyst's Office report from 2018 and follow-up in 2019 identified several weaknesses within the current California early intervention system.[13, 14] The follow-up in particular, which was a response to Governor Newsom's budget initiatives, examined reasons why California does not serve all eligible children. Here is a brief excerpt from the report:

> *In conversations with stakeholders and experts, we were made aware of at least five major reasons why some eligible children do not receive early intervention services.*
>
> - *First, some children do not receive regular physician checkups.*
> - *Second, some physicians do not consistently screen children for developmental challenges.*
> - *Third, some physicians do not refer all potentially eligible children for formal evaluations (in some instances because these physicians are unfamiliar with the state's early intervention system or misunderstand its eligibility criteria).*
> - *Fourth, some parents do not follow through on physicians' referrals (in some instances because they hope their children will grow out of their developmental challenges).*
> - *Fifth, some parents who try to follow through on referrals become discouraged before their children receive services. In some instances, this is because the evaluation process itself is time consuming or difficult to understand. In other instances, parents may become discouraged even after their children are deemed eligible for services because they are unable to find providers who accept their insurance (including Medi-Cal), who are willing to provide services in the families' homes (as encouraged by federal law), or whose clinics are within reasonable travel distances.*[15]

The path from screening to receiving services can be seen as a funnel, with number of children screened at the top and number receiving services at the bottom.[16]

Table 1. Results from the Translating Evidence-Based Developmental Screening Study [17]



In this study, conducted in Pennsylvania, 11 percent of those who did not meet developmental norms on the screening ultimately received services and many children dropped out of the process for unknown reasons. It would be interesting to see results like this in California, but the data are largely unavailable. Analyses in Florida, Mississippi, and Connecticut indicated a similar winnowing down, with Connecticut serving 4.7 percent of their birth–3 population and Mississippi 1.7 percent. [18]

The bottom line: non-normative performance on a screening is not a diagnosis, but even when screening occurs many children miss out on connecting to services along the way.

Empirical Research on Child Find Procedures Is Scant

Traditional empirical research on Child Find—with random assignment to experimental and control groups—is virtually nonexistent. When services are mandated for all, experimental conditions are not possible. In addition, with each state having its own eligibility criteria, definitions of developmental delay, and lead agency administering the program, comparisons between states lose meaning. Two systematic reviews, though, examine studies that describe processes leading up to services for infants and toddlers.

Twardzik and colleagues started by looking at peer-reviewed papers related to program administration factors that might influence enrollment in early intervention. They ended up with ten that met the rigorous requirements for inclusion in their systematic review. Among these there was very little commonality of results, since state differences in lead agency, eligibility criteria, and degree of risk did not allow for meaningful comparisons. They concluded that poor interagency coordination had posed barriers for implementation of Part C services since its inception and argued that "a collaborative approach" was likely to lead to better implementation of the law.[19]

Barger and colleagues' review identified 43 papers that met their criteria of documenting at least two of the required steps towards connecting children with early intervention services. They described the literature on the topic as "sparse and fragmented" and wrote that almost no studies documented the entire Child Find process ranging from screening to services.[20] There is no data required by the federal government to document the breadth or effectiveness of the elements of Child Find (public awareness, screening, referral, evaluation), while a great deal is required on the other end (transition to special education, outcomes of early intervention).

Barger et al. identified two model programs. One is a Nebraska program (NE-TIPS) that tracks the path of a specialized population (Neonatal Intensive Care Unit graduates) to early intervention. The second, the Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System, is a population model involving the Massachusetts lead agency (Department of Public Health), the Boston University Department of Public Health, and the Centers for Disease Control and Prevention. Barger et al. describe PELL as "the primary population model for successfully linking existing systems for developmental monitoring and Child Find purposes."[21] PELL is a data model that links systems in order to better track and identify young children in need of early intervention, and it appears to be relatively successful. Massachusetts served 9.4 percent of their age 0–3 population in 2016.[22]

Each summary of research findings points to the complexity of the screening, referral, and identification processes as well as to the challenges of coordinating these processes across multiple agencies. While the number of infants and toddlers receiving early intervention services has grown consistently over more than 30 years of implementation, cracks in the system nationally and in California have allowed many children and families to slip through, so that only an estimated 10 percent of eligible children receive services. Despite ongoing pleas from research and practice for improved interagency coordination, we are left with problems that can seem intractable. But are they? What is the motivation to act?

Steps Can Be Taken to Improve Things

Rather than make cross-state comparisons, we must look at what is occurring within our state, where 2.9 percent of the population of infants and toddlers is served. Is this good enough for the children of California?

Clearly, the glitches in the efficient implementation of Part C in California described in the Legislative Analyst's Office reports must be addressed on a system or statewide level. These are some of the steps that might be taken:

1. California should unify and expand its system of collecting data on our children. Starting with a central screening registry and moving to improved documentation of screening links to referral and evaluation; then to the links between multidisciplinary assessment and the IFSP; then to initiation of services; and finally to the link between children leaving Part C and entering (and progressing) in preschool, coordinated data would allow us to follow the progress of children in the system and follow up if they do not continue to move through it. As Elliot Regenstein put it:

   > *And here's the cold reality I confronted many years ago that you need to face right now if you haven't already: if your state doesn't have a unified early childhood data system, the ceiling of what you're likely to accomplish … is far lower than you need it to be.*[23]

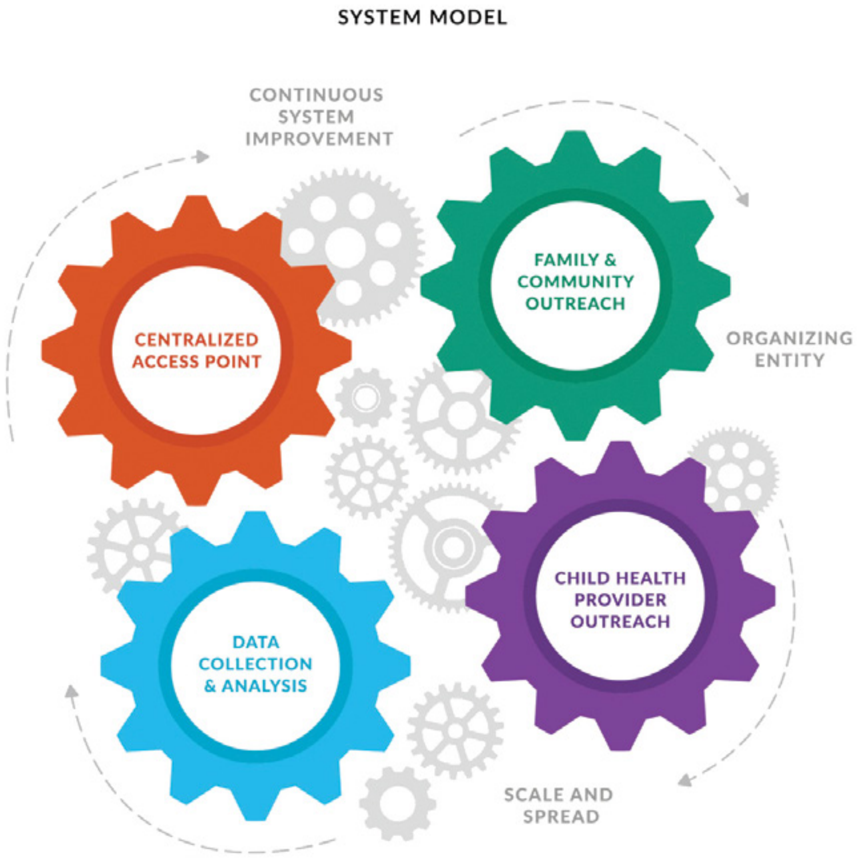
2. Agencies that serve children should create or strengthen their interagency agreements and develop explicit procedures for serving children when their needs overlap. A more unified system would lessen the drop-off in follow-up that occurs when children move across systems. See PACE brief "Realizing One Integrated System of Care for Children" for more on interagency collaboration.

3. California should deepen incentives for regional centers, local representatives of the Department of Developmental Services, to evaluate children and refer them to high-quality early intervention programs.

4. Parents frequently need support in following through on referrals. Programs that send referral documentation directly to the appropriate agency or have office staff help parents fill out and send forms have more successful transitions from screening to evaluation. These supports should be routinely provided to families in their preferred language.

In fact, there currently exists a national model—the Help Me Grow program, which has been adopted by First 5 California and First 5LA—that incorporates these suggestions. Help Me Grow's overall goal is to coordinate existing systems that serve young children and their families so that they receive intervention services and supports (see Figure 2). Putting the heft of the State of California behind this effort—or one like it—would increase the likelihood of success.

Figure 2. Four Cooperative and Interdependent Core Components Characterize the Help Me Grow System Model



Note. Figure from helpmegrownational.org/hmg-system-model

In Conclusion

Perhaps we should shift from a glass-half-empty approach to the opposite. Hebbeler and colleagues, for example, remind us that because of the passage of Part C:

> *The biggest victory, and one that is easy to lose sight of amid the struggles to work out implementation details, is that there are programs all across this country for young children with delays and disabilities. Because of the federal law, upward of a million young children each year receive some kind of intervention to address their developmental needs. This is an accomplishment for which our nation can be truly proud.*[24]

And indeed, there is much to be proud of. But California can do much better.

Endnotes

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[14] Petek, G. (2019, February). *The 2019–20 Budget: Governor's proposals for infants and toddlers with special needs.* Legislative Analyst's Office. lao.ca.gov/reports/2019/3954/infants-toddlers-022819.pdf

[15] Petek, 2019, p. 6.

[16] Kavanagh, J., Gerdes, M., Sell, K., Jimenez, M., & Guevara, J. (2012, Summer). *SERIES: An integrated approach to supporting child development.* The Children's Hospital of Philadelphia Research Institute, Policy Lab. policylab.chop.edu/sites/default/files/pdf/publications/PolicyLab_EtoA_SERIES_Developmental_Screening_Summer_2012.pdf

[17] Kavanagh et al., 2012, p. 3: "Of the 1,424 well-child visits that fell within the AAP-recommended screening schedule, an ASQ (screening tool) was administered to 1,034 (72.6 percent) of them. Overall, 19.5 percent of the children who were screened performed significantly below the average for their age, and a provider referred 50 percent of those children. Only 66.7 percent of children referred completed the first step in early intervention intake involving the assignment of a service coordinator; subsequently, only 66.7 percent of children assigned a service coordinator ever completed a multidisciplinary evaluation (MDE) to determine their developmental needs and eligibility for services. Ultimately, only 11 percent of those who performed significantly below the average for their age on a standardized developmental screening measure ever received services."

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