

# Building a Developmental System of Care Puts All Children on Track for Success



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Since 2000 when *From Neurons to Neighborhoods*<sup>1</sup> was published, attention to the developmental and behavioral needs of young children and their families has grown. Even in light of the increased understanding of early brain development and the importance of relationships in early child development, an increasing number of young children arrive at kindergarten unprepared to learn. Although most children develop along a normal trajectory, more than a quarter of children in the U.S. need support and treatment to stay on track for healthy development and kindergarten readiness. Currently, limited services are available for a small percentage of children who face *severe* developmental or behavioral problems. It is important to understand that a child's developmental trajectory can also be derailed by *mild to moderate* concerns, yet very few services are available to address such challenges. Even with greater attention on improving the well-being of America's young children, too many children are not reaching their full potential because their developmental and behavioral needs are not being met.

When developmental and behavioral concerns are not addressed early, they can become more difficult and more costly to resolve when children are older.<sup>2</sup> Consider the potential outcomes for two toddlers described in the scenarios below.

**Julian:** At 20 months old, Julian was aggressive and threw tantrums frequently. Julian's child care center referred his parents, Tom and Joan, to a speech therapist who found that Julian had limited expressive language skills. However, his speech delay was not severe enough to make him eligible for services. His parents and child care teachers tried to teach him to "use his words," but his tantrums and aggressive behavior escalated. Because his behavior disrupted the class, the family was asked to withdraw from his child care program. Joan had to cut back her work hours to care for Julian since they could not afford the other child care programs nearby.

**Marcus:** Selma and David were concerned about Marcus, their 18-month-old. He was aggressive and threw tantrums frequently. Marcus' pediatrician referred the family to Healthy Development Services (HDS), a system of care that serves children with mild to moderate concerns. A developmental assessment found limited expressive language skills. Marcus participated in small group development classes. His parents consulted with a speech pathologist and received individualized behavior coaching sessions from a behavior specialist. Selma and David gained skills to support his use of language. Marcus' tantrums and aggression decreased and he made improvements in all areas of development. Selma and David felt confident about Marcus' future and their ability to support him.

*Creating the right conditions for early childhood development is likely to be more effective and less costly than addressing problems at a later age.*

—Center on the Developing Child at Harvard University<sup>3</sup>

The scenarios describing Julian and Marcus illustrate two potential paths for young children. Julian faces ongoing challenges because of his delayed communications development, but Marcus got help early to move past similar challenges. His parents were supported and learned to address the concerns. The kinds of help that Marcus benefited from are neither extensive nor expensive, but these services are not available to most children in the U.S. In San Diego County, California, First 5 San Diego made strides to address this critical gap. First 5 San Diego partnered with the American Academy of Pediatrics, CA Chapter 3 (AAP-CA3) to develop HDS, a system of care that provides a broad range of services to children with mild to moderate concerns and their families.

### Healthy Development Services—Bridging Service Gaps for Young Children

HDS was created to address service gaps for children with developmental concerns and behavioral issues. It is a comprehensive system of developmental and behavioral services for San Diego County's young children whose challenges are not severe enough to qualify them for existing early intervention services. HDS created new treatment services for children with mild to moderate needs, providing help for children who otherwise would not receive care.

There are several key features that contribute to the success of HDS. First, the developmental screening system was strengthened so that more children with concerns are identified and subsequently receive care. Second was an emphasis on the parent-child relationship, which is a hallmark of the program. The system focuses on helping parents learn new skills and gain knowledge to address their children's development and behavior needs. Last, attention is given to the workforce that directly provides services to the children helped by HDS. Services are provided by trained child development specialists and licensed clinical providers. The system has also supported efforts to increase the number of available providers qualified to work with young children, especially those that can address social-emotional development and its connection to behavioral issues.

HDS is shaped through a partnership between First 5 San Diego, AAP-CA3, and local service providers. Since 2006, HDS has complemented the county's existing services for children with severe developmental concerns, delivered services to children with mild to moderate delays, built a network of trained early childhood professionals, and developed relationships that have ensured that fewer children fall between the cracks.

### Fast Facts

- More than 1 in 4 California children from birth to 5 years old are at risk of developmental or behavioral delays of a moderate to severe level.<sup>4</sup>
- Young children living below the poverty level are at even greater risk of developmental or behavioral delays.<sup>5</sup>
- Nearly three quarters of California parents participating in a national survey reported that their pediatrician had not conducted a formal developmental screen during office visits.<sup>6</sup>
- In California, 31,858 children from birth to 3 years old (2% of the state's infants and toddlers) were enrolled in Early Start services in March 2015, including 2,489 children from San Diego County.<sup>7</sup>
- 1 in 5 children has a diagnosable mental disorder, and factors that predict mental health problems can be identified in the early years.<sup>8,9</sup>

## Individuals With Disabilities Education Act

Services are guided by the federal Individuals With Disabilities Education Act (IDEA) which mandates assessment and services for children demonstrating developmental delays and disabilities. Each state sets eligibility under IDEA. In California, children under 3 years old must demonstrate a moderate developmental delay in one area to be eligible for services through Early Start, the statewide program for young children with disabilities. Preschool-age children (3-5 years old) must demonstrate a significant delay in one area or moderate delays in two or more areas. While more than 30,000 California children from birth to 3 were served through Early Start services in 2014, and another 20,000 children between 3 and 5 years old received special education services,<sup>10</sup> many more young children with mild to moderate delays and concerns do not have access to services that support their development.

## Solutions Implemented by HDS and Recommendations

**Challenge:** *There are not adequate developmental and behavioral treatment services to address the needs of young children with mild to moderate concerns.*

Funding for services is available for children with the most severe delays (see **Individuals With Disabilities Education Act**), but funding to provide services to children with mild to moderate concerns is limited. In addition, there is a shortage of knowledgeable service professionals to meet the needs of children from birth to 5 with developmental delays and behavioral concerns, especially for children and families with mental health or complex needs (e.g., maternal depression).

Prior to developing the framework for HDS, First 5 San Diego combined community and expert input with the current literature.<sup>11</sup> Clear service gaps were noted in speech and language services and behavioral services.

**Solution:** A comprehensive system of care for children from birth to 5 with mild to moderate developmental and behavioral concerns was envisioned as the most effective way to address the gap in kindergarten readiness and lifelong learning.

The comprehensive system of services addresses concerns in:

- Global development
- Specific developmental domains such as speech and language, physical therapy, and occupational therapy
- Vision and hearing
- Behavior and early childhood mental health

Services also include:

- Parent education, support, and empowerment through classes and coaching
- Care coordination to ensure that families follow through on referrals and receive all the services they need



Photo by Debbie Rappaport

HDS focuses on the whole child. The system recognizes that a child's social, emotional, and cognitive development are tightly intertwined, dependent on the quality of their early relationships, and influential in their long-term health and learning. HDS also recognizes the importance of the parent-child relationship. Services are provided in the context of the entire family, acknowledging that services for young children are most effective when services engage the parents along with the child to strengthen social-emotional development.<sup>12</sup>

HDS has supported professional development programs to respond to the gap in the workforce that is qualified to serve young children's developmental and behavioral needs. For example, the system worked with local colleges to increase the number of available, qualified, early childhood professionals in San Diego County, especially those with expertise in social-emotional development.

### **Recommendations:**

- Provide funding for coordinated services for children with mild to moderate developmental and behavioral concerns.
- Expand services to include children at risk of moderate to severe future delays and challenges.
- Fully fund IDEA and Early Start and create services that are standardized across all states to meet the demand for early intervention services for children with severe concerns.
- Provide professional development opportunities to increase the availability of early childhood professionals working with developmental and behavioral concerns of young children.

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**Challenge:** Even with clear goals for routine screening from the American Academy of Pediatrics<sup>13</sup> and Healthy People 2020,<sup>14</sup> *mild to moderate concerns go undetected early in life*. Often pediatricians and other service professionals are hesitant to provide developmental screening if supportive services are not available.<sup>15</sup> In its role as the countywide coordinator for HDS, AAP-CA3 met with member pediatricians to understand the barriers to developmental and behavioral screening. The main finding was that unless services for children with mild to moderate concerns were in place, pediatricians were reluctant to conduct developmental screenings because there was no place to direct families for help.

**Solution:** The HDS framework includes developmental and behavioral treatment services and care coordination for children identified with concerns. Making treatment services and care coordination available addresses pediatricians' most significant barriers to completing developmental screenings. Once pediatricians knew that the children they identified with concerns were receiving appropriate and quality services, developmental screenings and referrals increased.

HDS also promotes the completion of developmental screenings in community locations where children are served. Training on standardized screening tools was provided by HDS for community partners such as early care and education providers, public health nurses, and staff from community-based organizations. HDS training efforts have increased the capacity among the workforce that serves young children to be able to identify developmental and behavioral concerns.

The system also places attention on regular and effective communication strategies around screening and referral processes with pediatricians and other community referral sources. Such focus has resulted in confidence that there is a seamless system of care for children and families to have their developmental and behavioral needs addressed.

## **Recommendations:**

- Connect screening efforts to treatment services.
- Use standardized tools for developmental and behavioral screening.
- Make screening available through a wide range of providers, such as pediatricians, their staff, and community partners.
- Reimburse service providers for conducting developmental screening.

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## **Challenge: Families often face challenges in finding needed services.**

Due to the complexity in the system of care, families may have difficulty finding the right services for their child even when services are available. Service providers themselves may not be familiar with all the options available in their community, especially those outside their own field. Such barriers occur in the absence of a well-coordinated system of care.

**Solution:** Coordination must occur at several levels. Coordination is needed between families and providers so that children are able to obtain services and to ensure the right services are matched to each child's unique needs. HDS' coordination among systems of care, such as early intervention, preschools, and other early care and education settings, is critical to avoid duplication of services. Service coordination at all of these levels increases the effectiveness of treatment for children receiving care.

AAP-CA3 provides countywide coordination and support for HDS. This countywide leadership led to the creation of a shared vision, built a continuum of care, facilitated service delivery, and promoted best practices. These translate into a better experience for families receiving services. To build a countywide system of care, AAP-CA3 and service partners continually work to:

- Create detailed referral and service pathways and provide feedback to referral sources.
- Develop intake processes and other practices that ensure integrated, high-quality services for prevention and treatment across the county.
- Create extensive partnerships that support uniform practices, measurement, and evaluation.
- Identify and remove barriers to service.
- Provide training that increases community capacity to conduct developmental and behavioral screening and assessment using standardized tools.

## **Recommendations:**

- Co-locate services to support families as well as to encourage cross-sector understanding and collaboration.
- Create opportunities to bring together representatives of the various disciplines serving young children (health, mental health, early education, etc.) to share knowledge, build awareness of services, and problem solve on case, community, and/or practice issues.
- Promote interdisciplinary work through case studies and shared decision-making.
- Cover the cost for service providers to engage in care coordination through insurance reimbursement or other sources.



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**Challenge:** *Services for mild to moderate developmental and behavior concerns are not currently covered by families' medical insurance. Families are not able to pay for services. Services paid through insurance may have limits and cover only the most severe needs.*

There is limited funding for early childhood services. Early intervention services traditionally have been underfunded or understaffed. The lack of funds makes it challenging for organizations to deliver mandated services, let alone to offer preventive interventions designed to reduce the risk of future problems. A recent survey of San Diego County families found that lack of insurance coverage, lack of eligibility for services, and cost of services were top barriers for families seeking help for their children.<sup>16</sup> Children who have mild to moderate developmental and behavioral concerns often do not qualify for coverage by insurance and families are forced to pay for services out of pocket.



Photo by Andrea Booher

In San Diego County, First 5 San Diego assessed the gaps in services for children from birth to 5 years old. Through this process, it became widely understood that there may be disruptions during children's critical developmental periods, necessitating additional support to keep the children's development on track. If the opportunity to address these concerns in a timely manner is missed, intervention will require more time, money, and resources later. Most troublesome is that these children may never reach their full potential.

**Solution:** First 5 San Diego provided multiyear, consistent funding to develop a comprehensive system of care, which included an investment in countywide coordination and technical assistance. This investment in HDS has the potential for a lasting positive economic impact by helping children reach their fullest potential.

### **Recommendations:**

- Include payment for services for children with mild to moderate developmental and behavioral concerns, such as speech therapy, occupational therapy, physical therapy, and behavioral health, in insurance plans included under the Affordable Care Act and public insurance programs.
- Increase funding to support a continuum of coordinated and integrated services for children at risk for developmental and behavioral challenges.
- Provide funding for care coordination to help families navigate the system.
- Provide a long-term funding source to stabilize programs.

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## Put All Children on Track For Success!

Every child should have the opportunity to live to their fullest potential. Developmental and behavioral screenings to identify concerns early in a child's life are an essential component of maximizing a child's well-being. Intervention to prevent these risks from becoming lifelong challenges is possible. Yet preventive interventions designed to reduce the risk of future problems are rarely funded. **Funding is needed to expand services to more children with a broader range of concerns and to support access to those services.**

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HDS is an example of how, through First 5 San Diego funding, San Diego County improves opportunities for its children by increasing the availability and access to developmental and behavioral services for young children with mild to moderate concerns. Lessons gleaned over a 10-year period have resulted in the implementation of services within a coordinated system that can prevent developmental and behavioral risks from becoming lifelong challenges. More than 25,000 children annually have been served by HDS, and there is potential for many more children to benefit from similar services. The time has come to ensure that children throughout California and the U.S. have similar opportunities to be supported so that they may grow, thrive, and reach their fullest potential. Investing in our children's early development is the path to our best future.

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## About Us

The American Academy of Pediatrics, CA Chapter 3 (AAP-CA3) is the San Diego and Imperial Counties chapter of the American Academy of Pediatrics, a national organization of pediatricians who dedicate their efforts and resources to the health, safety, and well-being of infants, children, adolescents, and young adults. For more information visit [www.aapca3.org](http://www.aapca3.org).

Headquartered in Washington, DC, with a regional Western Office in California, ZERO TO THREE is a national, nonprofit organization that informs, trains, and supports professionals, policymakers, and parents in their efforts to improve and to promote the health and development of infants and toddlers. For more information visit [www.zerotothree.org/western-office](http://www.zerotothree.org/western-office).

Healthy Development Services is funded through First 5 San Diego. For more information visit [www.first5sandiego.org](http://www.first5sandiego.org).

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