

# HMG Affiliate Summary of Evaluations

<b>HMG Study 1</b>	
<b>Responder Information</b>	Name: Heather Little Affiliate: California
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<b>Study Focus</b> (select one)	HMG independent <b>HMG in combination with other initiative</b>
<b>Model Relevance</b> (Select one)	HMG Call Center Physician Outreach Family Engagement Community Outreach <b>Developmental Screening</b> Other (please specify):
<b>Study Framework</b> (Describe each)	Primary research question: How to help CA counties improve their Early Identification impact, specifically through developmental screenings. Target population: 0-5 Sample size (if applicable): Study design: County data review, interviews, base line evaluation
<b>Key Findings</b>	
<b>Other</b> <i>Please describe other relevant information such as budgets, consults, etc.</i>	

# EFFECTIVE SYSTEMS IN EARLY IDENTIFICATION OF DEVELOPMENTAL DELAYS

First 5 Association of California

May 2015

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# Effective Systems in Early Identification of Developmental Delays

## Executive Summary

The First 5 Association of California is interested in how to best find and serve children ages 0-5 with mild to severe developmental delays. Currently, developmental screenings happen inconsistently in California counties, with an average of 28.5 percent children being screened across the state. There is also a lack of data to show when developmental screenings happen, and whether or not the child has any follow up services after a delay is shown in a screening. More coordination is needed, and counties might benefit by considering the “Help Me Grow” model - a system that connects at-risk children with services. Coordinated systems with data collection may improve the consistency of these screenings (as well as assist in any enforcement of federal mandates) and connect children with special needs to services as early as possible.

## Background

A child’s brain has developed approximately 90 percent by the time the child is 5 years old. It is critical that a child with a developmental delay is served in that major developmental stage in order to better prepare that child for other types of learning. Developmental screenings are a very important first step in the process of identifying children who have a developmental delay and may be eligible for free services.

## Federal Mandates to Developmentally Screen Children

The Affordable Care Act requires that children ages 0-3 be screened for developmental delays. It is listed as a “Required Preventative Service for Children” and should be done at no cost to the family, but covered by the family’s insurance plan. The American Academy of Pediatrics recommended those mandated screenings be completed by a child’s pediatrician at 9, 18, and 30 months.

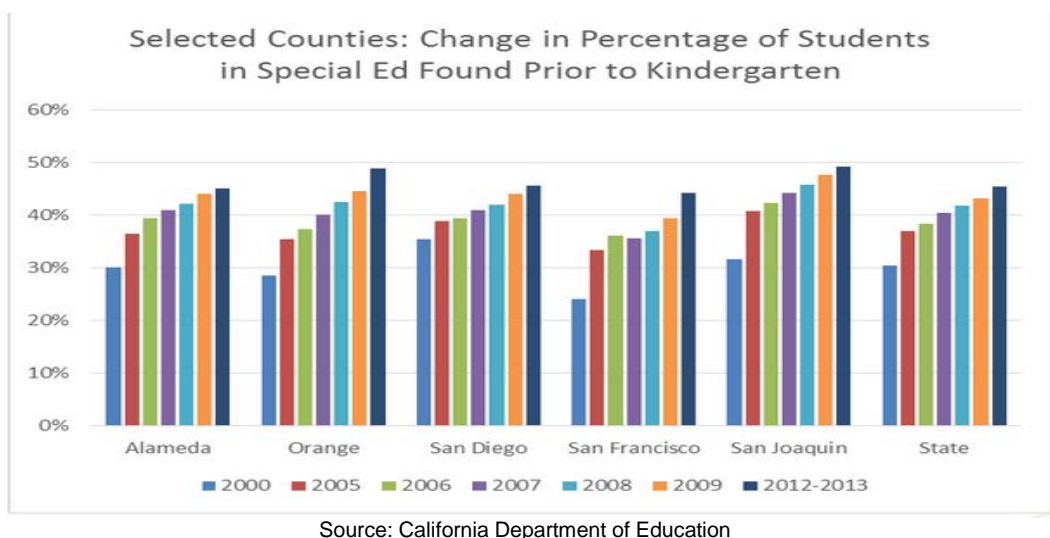
The Individuals with Disabilities Education Act also indirectly requires screening, as it mandates that schools “locate, identify, and evaluate” children with disabilities.

## Benefits of Screening

*Developmental screening* is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder (speech, language, cognitive, motor, and personal-social). While children develop at different paces, developmental screening tools highlight potential areas where the child is behind his or her peers. Recommended tools, such as the Ages and Stages Questionnaire (ASQ) or the Parents' Evaluation of Developmental Status (PEDS), have a much higher detection rates than surveillance alone (~85 percent vs ~30 percent).

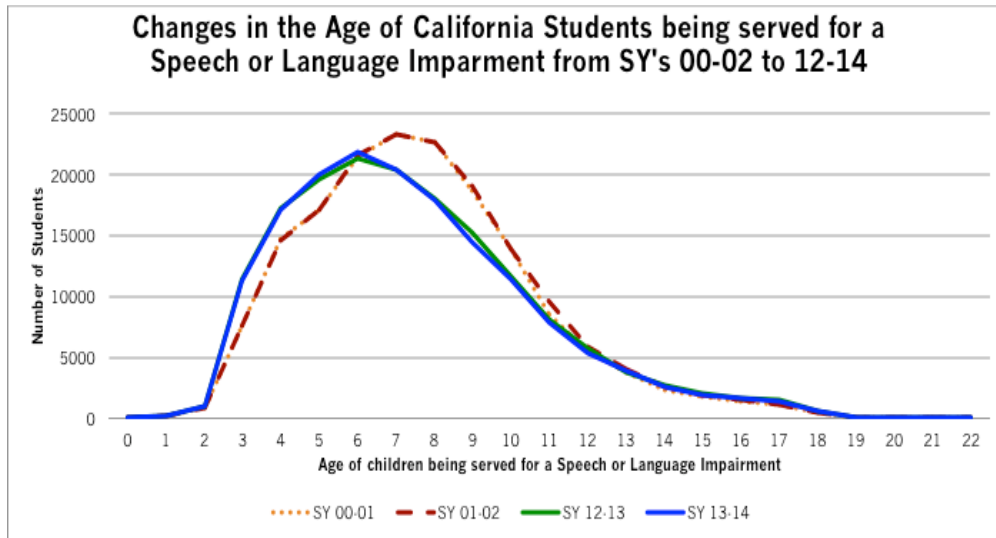
## California

California has made large strides in finding and serving children earlier. While still under 50 percent of children with special needs are found prior to kindergarten, that number used to be closer to 30 percent as of the year 2000, an improvement of over 65 percent.



## Focus: Speech and Language Impairments

While it is beneficial to find and treat all kids with special needs early, children being treated for speech and language impairments have potentially the most to gain from early intervention. This is also an important area for intervention as low-income children are three times more likely to be at risk for a developmental delay. Studies have shown that the “30 million word gap” (the gap between the number of words that low-income children hear by the age of 3 versus their middle to high income counterparts) could be a large contributor to speech and language delays. Developmental screening can find these children earlier which can lead to earlier services. California has made progress in this area, as from 2000 to 2010, the state successfully shifted the modal age of which a child is being served for a speech or language impairment from age 7 to age 6. There are more students ages 3-6 being served, and less 7-11 year olds, which might be due to efforts of First 5 and similar organizations pushing for earlier interventions.



### How does screening lead to services?

Once a child is screened, if a concern is raised, the child will be formally assessed, generally either by the local school district or by the state-funded Regional Center. If the assessment shows that the child is eligible for services, they will receive them. The process is difficult to navigate, as children are assessed and served by different entities if they are ages 0-3 or ages 3-5. There are 3 million children ages 0-5, 4,700 pediatricians, over 20,000 child care providers, 21 regional centers, over 1000 school districts, and numerous nonprofits or community based organizations working on early child care and education. While many organizations are working well individually, there is room to coordinate to find and serve children who need special services.

There also needs to be data collection so that future studies could be completed on the effectiveness of the systems put into place.

### Help Me Grow System

“Help Me Grow” is an early care coordination system designed to identify children at risk for developmental or behavioral problems and to connect these children to existing community resources. The system contains four components:

1. Child Health Care Provider Outreach
2. Community Outreach
3. Centralized Telephone Access Point
4. Data Collection

In 2005, Orange County became the first site to replicate the Help Me Grow model. Since then, the model has been implemented in 8 other counties in California, and in 23 states nationwide.



## **Policy Options to Increase Developmental Screenings in California**

First 5 Association of California and its partners have several policy options to consider in order to increase the rate of developmental screenings in California.

1. *Introduce a Legislative Resolution that encourages early developmental services*
  - a. First 5 Association and other stakeholders have drafted a resolution and have support from members of the legislature.
  - b. The effectiveness of this option is limited, but may increase awareness of the issue, which could lead to more interest.
2. *Push to include developmental screenings in regulatory evaluations of health plans.*
  - a. First 5 Association is pursuing this by writing letters to DMHC and other insurance regulators in the state.
  - b. Developmental screenings could be a measurement included in DMHC's triannual report on routine medical survey of health plans.
  - c. Developmental screening will be on a list of competing priorities, and may not be as well audited without complaints from parents or pediatricians.
3. *First 5 Commissions pay for universal screenings through health care providers for ages 0-3 and/or through school districts for ages 3-5.*
  - a. First 5 Commissions could ensure that children are screened at pediatrician offices by offering reimbursements, and or by paying for screenings at school districts.
  - b. This option would divert funds from other programs in counties that are not currently paying for screenings; the feasibility of this option is lower.
4. *Push for coordinated models that emphasize screening and increased data collection.*
  - a. Help Me Grow is a great example of a model that is known to be effective in coordination of systems.
  - b. The ease and cost of implementation of Help Me Grow should be a factor of consideration, and further research is needed in this area.
  - c. Further data collection is needed to show that the model has improved outcomes for children.

## **Looking Forward**

First 5 Association could increase the effectiveness of any of these options by working with other organizations to maximize awareness of the issue. The Association should also work with Help Me Grow on how to best message its purpose to counties, as well as develop implementation plans for counties not yet involved. Finally, the Association should consider all policy options to increase screening with the understanding that providing services to children earlier is the ultimate goal.

# Effective Systems in Early Identification of Developmental Delays

## Introduction

California's early care and education system is like many systems in California: wide-ranging in quantity and quality of services by geographical region and demographics, and ultimately a very different system in the 58 different counties. Multiple governmental and nongovernmental organizations work to provide subsidized early care and education programs.

In 1998, California voters passed the "Children and Families Act of 1998," also known as Proposition 10, which levies a 50-cent tax on cigarettes and other tobacco products and uses the funds for early childhood development programs. Revenues generated by Prop 10 are distributed 80 percent to 58 First 5 county commissions, and 20 percent to First 5 California. No state tobacco tax revenues go directly to the First 5 Association of California (the Association).

Instead, the First 5 Association of California is a nonprofit membership organization serving the 58 First 5 county commissions, funded by membership dues paid by the county commissions (based on birthrates, with a cap). The Association "connects commissions to other public and nonprofit partners, including county departments, foundations, and child advocacy organizations to ensure collaboration and a common statewide agenda to ensure the best future for our children."<sup>1</sup> While there are 58 counties, they divide into 6 regions: Northeast, Northwest, Sacramento, Bay Area, Central, and Southern. Counties in the same region often work together to provide uniform practices, and may even share some funding for grants.

First 5 Association of California works with all 58 First 5 county commissions to coordinate best practice approaches in the following five key impact areas:

1. Family Strengthening
2. *Early Identification*
3. Oral Health
4. Quality Early Learning
5. System Sustainability.

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<sup>1</sup> First 5 Association. <http://first5association.org/>

This paper was commissioned by the **First 5 Association of California** to take a deeper look at how counties can improve their impact in *Early Identification*, specifically through developmental screenings.

Currently, developmental screenings happen inconsistently in California. These developmental screenings are a very important first step in the process of identifying children who have a developmental delay and may be eligible for free services. Some counties, like Orange County, screen all children at age 4 prior to entering kindergarten at the school district, and continue to screen children every year until 3<sup>rd</sup> grade. Other counties offer screening services through partnerships at the hospital or community organizations.

This report highlights the policy issues surrounding the need for universal developmental screening. Further, as developmental screenings are only effective if they lead to services for children that need them, this report also gives background information and best practices on early care models that connect children at-risk for or with developmental delays to services provided in their community.

## Early Identification and Intervention

Research suggests approximately 15 percent of all children, or 1 in 6, have a developmental disability.<sup>2</sup> However, not all of these children are being served. Of those that are being served in the special education system, only about half are found prior to kindergarten.<sup>3</sup> Early Identification and Intervention is a top priority for the First 5 county commissions and the Association, because finding children with delays and providing services earlier can improve outcomes for children while preventing further progression of delays.<sup>4</sup> First 5's are committed to identifying children as early as possible, and linking those children to services provided.

A key strategy to identify children who need special services is through *developmental screenings*. **Developmental screening** is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder. While children develop at different paces, developmental screening tools highlight potential areas where the child is behind his or her peers.

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<sup>2</sup> Boyle, CA et al. (2011)

<sup>3</sup> California Department of Education (data sent to in email to Moira Kenny, Executive Director of F5A)

<sup>4</sup> Muschkin, Clara et al (2015)

## Developmental Screenings

First 5 endorses the American Academy of Pediatrics recommendation of having every child developmentally screened at least once prior to entering kindergarten. Developmental screenings do not formally assess a child's development, but rather act as a first step in identifying children who might benefit from a formal assessment. Screening tools have been shown to be very effective at detecting developmental delays (around 85 percent for recommended tools). Using recommended tools, children with developmental delays are nearly three times more likely to be found than with surveillance alone.<sup>5</sup> Below are a description of the common and validated screening tools used by pediatricians, teachers, and parents.<sup>6</sup>

### Common Developmental Screening Tools

#### **PEDS:**

The Parents' Evaluation of Developmental Status is an evidence-based screen that elicits and addresses parents' concerns about children's (ages birth – 8) language, motor, self-help, early academic skills, behavior and social-emotional/mental health. *Effectiveness/Cost:* The PEDS screening tool's accuracy ranges from 73-97%, and costs about \$3.99 to administer.

#### **PEDS:DM**

The Parents' Evaluation of Developmental Status: Developmental Milestones (PEDS:DM) test is a surveillance and screening tool for children 0-8 years old that evaluates children's skills in developmental and mental health, including expressive and receptive language, fine and gross motor skills, self-help, academics, and social-emotional skills. *Effectiveness/Cost:* The PEDS:DM screening tool's accuracy ranges from 70-94%, and costs about \$6.10 to administer.

#### **ASQ**

While pediatricians generally use a PEDS screening tool, another common developmental screening tool is the Ages and Stages Questionnaire (ASQ), which is a questionnaire that anyone who comes in contact with the child can perform (examples include a parent, a pediatrician, a child care provider, a teacher). The ASQ tests communication, gross motor, fine motor, problem solving, and personal-social skills of a child three months to five years old, at varying intervals (21 total tests). *Effectiveness/Cost:* The ASQ screening tool has an accuracy of 77-92%, but costs \$17.28 to administer.

For more information on these tests, and for a list of other recommended tools, please see Appendix G.1.

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<sup>5</sup> Around 85% with recommended tools vs 30% with surveillance.

<sup>6</sup> Table adapted from PEDStest.com

## First 5 Investments in Early Intervention

First 5 county commissions, with support from First 5 California and the First 5 Association, have prioritized early intervention, and have made significant investments in screening children for developmental delays in order to serve them earlier.

Funding for this particular issue comes from various sources, depending on the county. Some counties have strategic partnerships with non-profits or hospitals to share the costs of screening; others have received grants for their programs and are able to use grant money for that purpose. Many First 5 county commissions use some of their general funds to support screening. In the 2013-2014, First 5 county commissions combined invested \$48 million in screening and interventions, paying for over 129,000 children's screenings, 24,000 of which received follow-up services.

### FY 2013-14 FIRST 5 INVESTMENTS

**\$48 million** in screenings and interventions for developmental delays

Over **129,000 children** received comprehensive screenings and/or assessments

Nearly **24,000 children** received follow-up

## Why Screen?

Why does the government have an interest in screening children for developmental delays in the first place? While research shows 12-16 percent of children have some type of developmental delay, only about half of those children with developmental delays are found prior to kindergarten.<sup>7</sup> By the time a child reaches 5 years old, about 90 percent of his or her brain has developed, so it is critical to find children with delays as early as possible to treat any delay and prevent the need for future services.<sup>8</sup>

At the same time, screening is actually mandated by federal law. First, the Affordable Care Act (ACA) mandates that all health care plans include developmental screening for children ages 0-3 years old. Secondly, the Individual with Disabilities Education Act (IDEA) requires that school districts locate, identify and evaluate all children with disabilities from birth through age 22.

First 5 Association has developed an infographic that highlights the need for this service, which can be found in Appendix B.

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<sup>7</sup> Mackrides, Paula, and Susan Ryherd (2011)

<sup>8</sup> Zero to Three – [http://main.zerotothree.org/site/PageServer?pagename=ter\\_key\\_brainFAQ](http://main.zerotothree.org/site/PageServer?pagename=ter_key_brainFAQ)

## Mandates to Screen Children for Developmental Delays

### *Affordable Care Act Requirement*

Screening children for developmental delays is indeed mandated by the federal Affordable Care Act. Per HHS.gov, “If you have a new health insurance plan or insurance policy beginning on or after September 23, 2010, the following preventive services must be covered without your having to pay a copayment or co-insurance or meet your deductible. This applies only when these services are delivered by a network provider.”<sup>9</sup> A list of the 26 Required Preventative Services for Children can be found in Appendix C. Number 8 on that list is “Developmental screening for children under age 3, and surveillance throughout childhood.” The American Academy of Pediatrics, in coordination with Bright Futures (a national health promotion and prevention initiative, led by the American Academy of Pediatrics), recommended that these screenings be done at 9, 18, and 30 months. The full recommendation can be found in Appendix D. Furthermore, the AAP Policy Publications released an algorithm in 2008 of how to find children with developmental delays for pediatricians. This can be found in Appendix E.

While the mandate requires that health plans offer free screenings, it is generally believed by advocates (and pediatricians) that screenings are not being routinely conducted. Unfortunately, there is no data collected at the office-level or at the health-plan level.<sup>10</sup> The National Survey of Children’s Health indicated that less than one-third of 10 month to 5 year olds received any developmental screening in the past year.<sup>11</sup>

On both a national and statewide basis, there is no or little enforcement of this mandate. One avenue would be a HEDIS measure, would need to be adopted at the federal level.<sup>12</sup> If it were included in the HEDIS measure, there would need to be more data collection for enforcement. Without data collection, this mandate carries little weight.

### *Individuals with Disabilities Education Act Requirement*

States must provide free educational services to children with disabilities (ages 3-22) according to the federal Individuals with Disabilities Education Act (IDEA), Part B. IDEA also mandates that schools “locate, identify and evaluate all children with disabilities from birth through age 21,” which is often referred to as the **child find system**. Like the ACA,

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<sup>9</sup> “Preventative Services Covered Under the Affordable Care Act,” US Department of Health and Human Services

<sup>10</sup> In a systematic way. Some health plans may collect this information.

<sup>11</sup> Child and Adolescent Health Measurement Initiative. 2011/12 National Survey of Children’s Health. [www.childhealthdata.org](http://www.childhealthdata.org)

<sup>12</sup> HEDIS is a tool used by more than 90 percent of America’s health plans to measure performance on important dimensions of care and service. Because so many plans collect HEDIS data, and because the measures are so specifically defined, HEDIS makes it possible to compare the performance of health plans on an “apples-to-apples” basis. Health plans also use HEDIS results themselves to see where they need to focus their improvement efforts.

there is little enforcement on the “find” part of this system. On the other hand, there have been multiple lawsuits that enforce the “service” part of the IDEA requirement.<sup>13</sup>

The rules around the mandate that schools “locate, identify, and evaluate” are often criticized for a lack of clarity: *How hard must schools look for these children?* What are the punishments if a school district doesn’t “look hard enough?”

In terms of services, IDEA Part C provides funding for states that serve infancies and toddlers through age 2 with a developmental delay, and requires that these children be served, but does not specify how to find these children. Part B of the Act also provides funding for children being served in school districts ages 0-22 years.

## CHIPRA

Title IV of the Children’s Health Insurance Program Reauthorization Act (CHIPRA) of 2009 “encourages” voluntary, standardized reporting of a core set of child health quality measures.<sup>14</sup> One of these 24 measures is “Developmental Screening in the First 3 Years of Life.” Both the National Center for Quality Assurance and the Child and Adolescent Health Measurement Initiative (NCQA and CAHMI respectively) attempt to collect this data through surveys. It is unclear that these survey data measurements carry any weight, or that any health plan could be fined or penalized for not having certain screening rates.

## Benefits of Screening and Serving Kids Earlier

Numerous organizations in California, including Children Now, Help Me Grow California, and First 5 are pushing for universal developmental screening. This push comes from evidence that the optimal time to detect and address developmental concerns are while the child’s brain is still forming, when they are most receptive to intervention.

When screening tools most commonly used have high rates of accuracy, there are few cons for children to be screened for developmental delays. In the spring of 2014, the US Department of Education and the Department of Health and Human Services (HHS) launched “Birth to 5: Watch Me Thrive!” - a collaborative effort to encourage developmental and behavioral screening for children. One goal of the program is simply to raise awareness of child development.

*“The optimal time to detect and address concerns of developmental delays is early in life, when children’s brains are still forming and are most receptive to intervention. Early detection and treatment services can vastly improve developmental outcomes for children with special needs and prevent further progression of delays.”*

- First 5 Association

<sup>13</sup> Example: *Winkelman v. Parma City School District*, U.S. , 127 S.Ct. 1994 (2007)

<sup>14</sup> “CHIPRA Core Set.” National Committee on Quality Assurance.



## Parental Engagement

Parental engagement is often cited as a critical factor for a child's development. When a child is developmentally screened, it engages the parent to be involved in the child's development, regardless of the outcome of the screening. If a child is developing in a typical fashion, parents can still increase their awareness of developmental expectations, and learn about the next developmental milestones. If a child presents a slight delay in development, but not to the point of eligibility for intervention services, developmental screenings can highlight the areas where parents need to become more engaged by performing or partaking in developmental activities or services (often times as simple as "talk to your child more") in order to prevent the need for more intensive interventions later on. Finally, if a child shows developmental delays to a point where interventions are necessary, the child may be more formally assessed and connected to services provided through IDEA required services for children with disabilities. Earlier interventions, for example, preschool, have been shown to prevent the need for more special education later in life.<sup>15,16</sup>

## Closing the Achievement Gap

Furthermore, developmental delays occur disproportionately in low-income children. In fact, children who have parents lacking high school diplomas are three times as likely to be at high risk for developmental delay than children with parents with any higher education.<sup>17</sup> While the awareness of the importance of early childhood education has increased, the differences in risk for developmental delay between high and low income has actually increased since 2003.<sup>18</sup> Without intervention, these delays can set these children back in school and in life, which could be a factor in persistent poverty.

A much-cited study by University of Kansas Researchers Betty Hart and Todd Risley found that a child from a low income family hears 30 million less words before the age of 3 than a child from a middle to high income family, also known as the "30



### Birth to 5: Watch Me Thrive!

#### Press Release

*"Early screening can lead to better access to services and supports, which can enhance children's learning and development, minimize developmental delays, and result in more positive outcomes in school and life."*

Michael Yudin, Assistant Secretary  
U.S. Office of Special Education and  
Rehabilitation Services

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<sup>15</sup> Tekolste, K (2010)

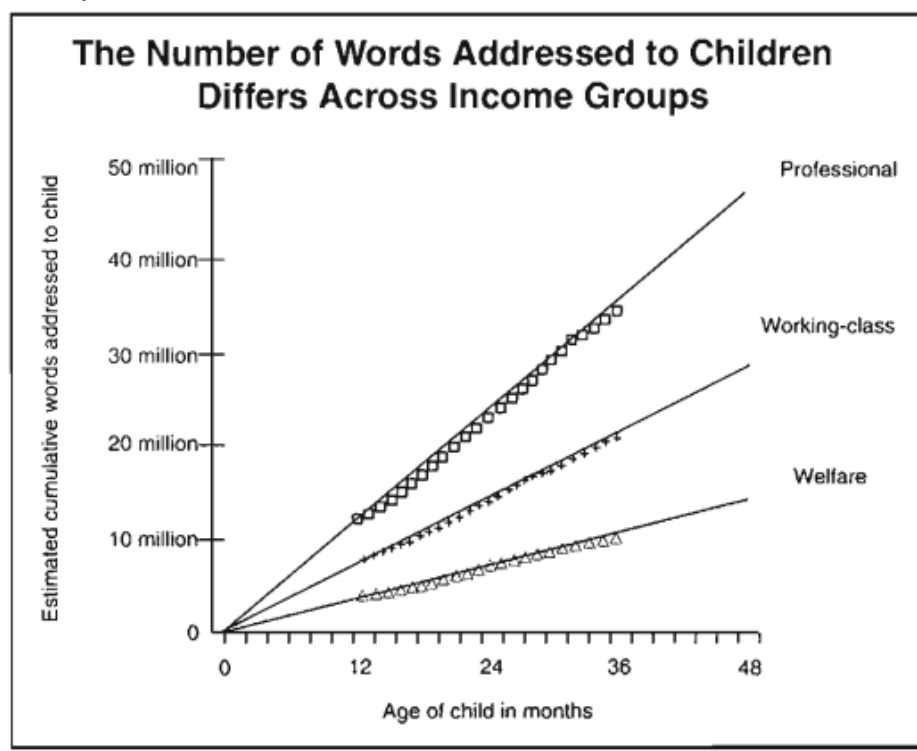
<sup>16</sup> Muschkin, Clara et al (2015)

<sup>17</sup> *Screening and Risk for Developmental Delay*. Child Trends (2013)

<sup>18</sup> *Ibid.*



million word gap.”<sup>19</sup> Follow up studies showed that these differences in language interactions affect a child’s performance later in life.<sup>20</sup> Programs like Hilary Clinton’s *Too Small to Fail* (a joint venture between the Clinton Foundation and Next Generation) are aiming to address this problem with media campaigns like “Talking is Teaching: Talk, Read, Sing,” which has been implemented in a number of cities, including Oakland, CA. The effectiveness of these campaigns could be strong evidence and basis for more early intervention and parent outreach.



Source: “The Early Catastrophe”  
<http://www.aft.org/sites/default/files/periodicals/TheEarlyCatastrophe.pdf>

For more research on investments in early care and education, First 5 Association generally looks to Heckman Equation at <http://heckmanequation.org/> for quality literature.

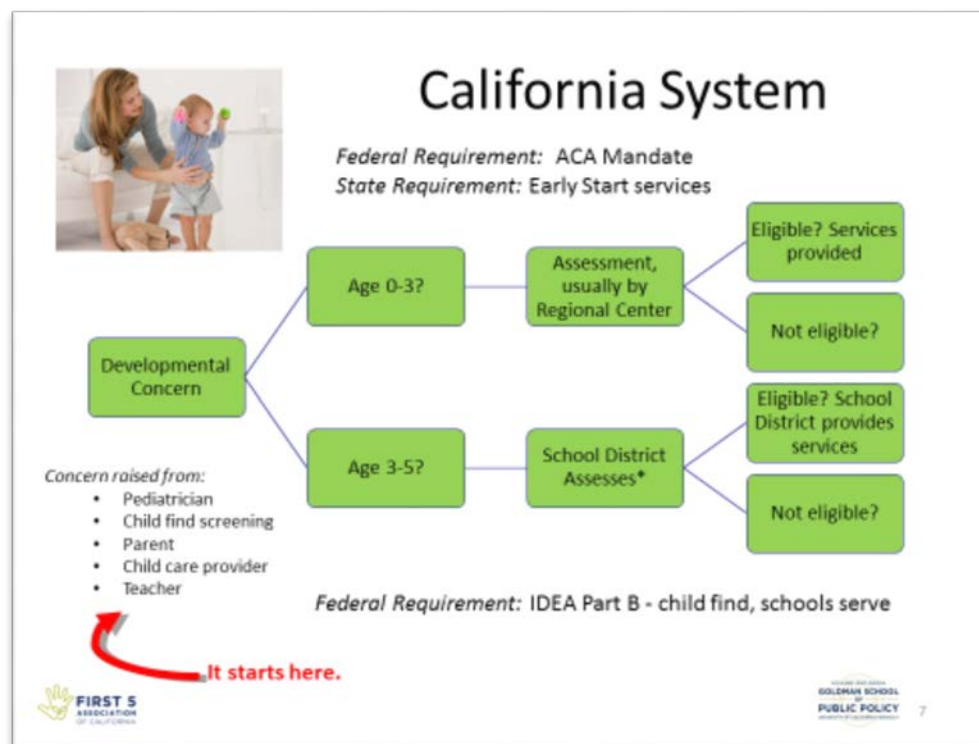
<sup>19</sup> Hart, Betty, and Todd R. Risley (2003)

<sup>20</sup> *The Thirty Million Word Gap*, Rice University

# California's Fragmented System

*"While the benefits of routine screening and early intervention are widely known, the service environments that address children's early developmental needs are often **fragmented, under-resourced, and lacking in capacity** to detect concerns early on." - First 5 Association of California*

There are 3 million children ages 0-5 in California, 4,700 pediatricians, over 20,000 child care providers, 21 regional centers, 58 First 5 county commissions, over 1000 school districts, and numerous nonprofits or community based organizations working on early child care and education.<sup>21</sup> If a child is screened and the child presents a mild to severe developmental delay, or if a parent has a concern about the child's development, it is very difficult for a parent to navigate the system and know what the child is eligible for. Parents are not fully aware of what services their child is entitled to for free, or what services are available if their child has a developmental delay not severe enough to qualify for free services. The process for screening to services (or what used to be referred to as SART: Screening, Assessment, Referral, Treatment) is shown below.

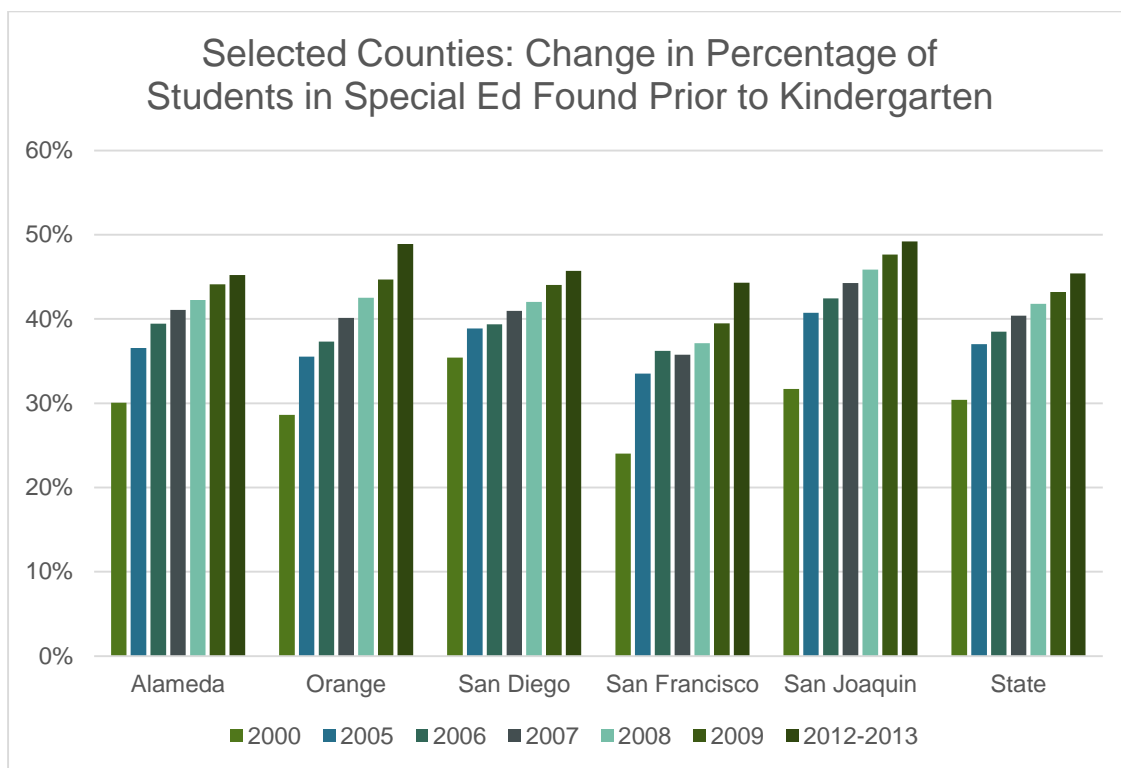


<sup>21</sup> Sources: kidsdata.org, BLS, CA DDS, CCSA

Children ages 0-3 who are determined “eligible” for services, are connected to free services provided by Regional Centers, and children ages 3-5 determined “eligible” are served at school districts. Eligibility requirements for Early Start, from the California Department of Developmental Services can be found in Appendix F. More information about eligibility requirements and steps to receiving services, can be found the “Special Education Rights and Responsibilities” in Appendix N.

## Progress in California

Despite the fragmentation, California is doing something right. Awareness about early care and education has been growing and programs are being implemented to reach children with special needs earlier. From 2000 to 2013, the state as a whole increased the rate at which children with special education needs were found prior to kindergarten by nearly 50 percent. In 2000, only about 30 percent of children with special needs were identified prior to kindergarten, whereas in 2012, that rate jumped to 45 percent.<sup>22</sup>



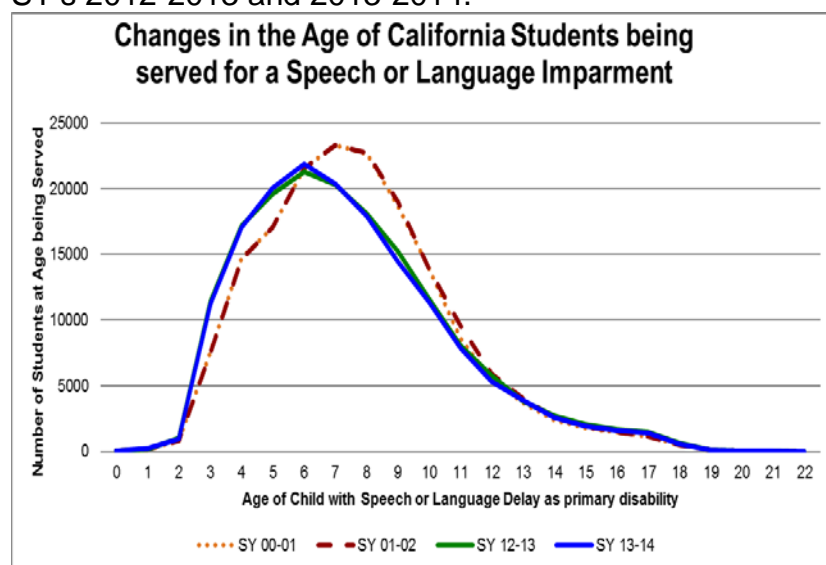
Source: California Department of Education

For all counties, please see Appendix H.

<sup>22</sup> California Department of Education

## Focus: Speech and Language Impairments

Another achievement is that children in California with speech or language delays – an issue that some children face that can potentially be corrected or prevented with proper intervention – are being served at earlier ages. Of the children receiving special education services through school districts in California (which primarily begin at age 4 but in some cases earlier), about 24 percent were identified as having a Speech and Language Impairment as their primary disability in 2013.<sup>23</sup> However, for children being served at ages 0-3, speech and language impairment make up an even larger portion of children being served at Regional Centers.<sup>24</sup> Taking a closer look at speech and language impairments, the state has made significant progress as a whole identifying and serving children earlier. The graph below shows special education data collected at the California Department of Education: the number of children being served for a speech or language delay as their primary disability for each age (ages 0-22). The distribution of age has shifted over the 13 years of data available, with the modal age in both School Years 2000-2001 and 2001-2002 being 7 years old to the modal age of 6 years old in SY's 2012-2013 and 2013-2014.



23 "Special Education - Enrollment by Age and Disability." *California Department of Education DataQuest*.

24 For example, in San Diego, about 80% of developmental concerns are related to speech and language according to First 5 SD.

## WHERE DID THIS DATA COME FROM?

This data came from the California Department of Education, via its DataQuest system.

To find this data, go to:

<http://data1.cde.ca.gov/dataquest/>, select level (State, County, District, etc.), then select "Special Education" under Student Demographics. This data was collected by choosing the report "Enrollment by Age and Disability" for each year from SY 00-01 to SY 13-14. In these charts, all other categorizations of disabilities were dropped except Speech and Language Impairment (students who have a Speech or Language Impairment as their primary disability). To create similar charts, put the data into Excel, and use a Pivot Table. For simplicity, the charts included in this report leave out the years 2002-2012 so that the overall change is more apparent instead of gradual.

For this project, charts were created for the following counties: Alameda, Contra Costa, Fresno, Orange, San Diego, San Joaquin, San Francisco, Santa Clara, Santa Cruz, Solano, and Ventura. Results for selected counties can be found in Appendix J.

For these counties, the same data was collected for Autism (enrollment by age for years 2000-2014), but as that was the not focus of the report, no charts were created. First 5 Association has access to all the data collected for this report.

## Universal Screening Status

While the state seems to be improving in reaching children earlier, it is hard to determine what has been the root cause of that shift. First 5 county commissions have pushed for an increase in developmental screenings, but data on screenings is not being systematically collected at the county or state level, so it would be hard to say that the shift is due to an increase in developmental screenings. The 2011/12 National Survey of Children's Health indicated that only 28.5 percent of parents of a 10 month to 5 year old child in California answered "Yes" to the following question: "During the past 12 months, was your child screened for being at risk for developmental, behavioral and social delays using a parent-reported standardized screening tool during a health care visit?"<sup>25</sup> The national average was recorded as 30.8 percent. This data point is lower than the 2009/2010 National Survey of Children with Special Health Care Needs, where 37.4 percent of parents reported that their child (age 1-5) received some type of standardized *developmental behavioral* screening within the last 12 months.<sup>26</sup> In that study, California was slightly above the national average at 38.5 percent.

It is important to note that these were *parent surveys*, so it could be that a child was screened, and the parent was unaware of the screening. In the year 2000, the "National Survey of Early Childhood Health," asked a different question to parent of a children age 4-35 months to address that very concern. The survey asked whether the child's pediatric provider ever told parents that he or she was doing a "developmental assessment" and/or whether the parents recalled explicit components of a DA, such as stacking blocks or throwing a ball. In this study, about 45 percent of parents recall a developmental assessment had been done, and about 35 percent of children were asked by their health care providers to pick up small object or do related tasks (suggesting that a developmental assessment was being done).<sup>27</sup> Results by state were unavailable (or difficult to obtain) and this specific survey is no longer being conducted by the CDC.

First 5 believes that pediatricians should be reporting the number of children they screen to some regulatory agency, instead of relying on parent survey data. If this were to happen, there would be a better understanding of how many children are truly being screened, and there would be a mechanism to determine whether or not health plans are obeying the mandate.

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25 "2011/12 National Survey of Children's Health." Child Health Data. <http://childhealthdata.org/browse/survey/results?q=2212&r=6>

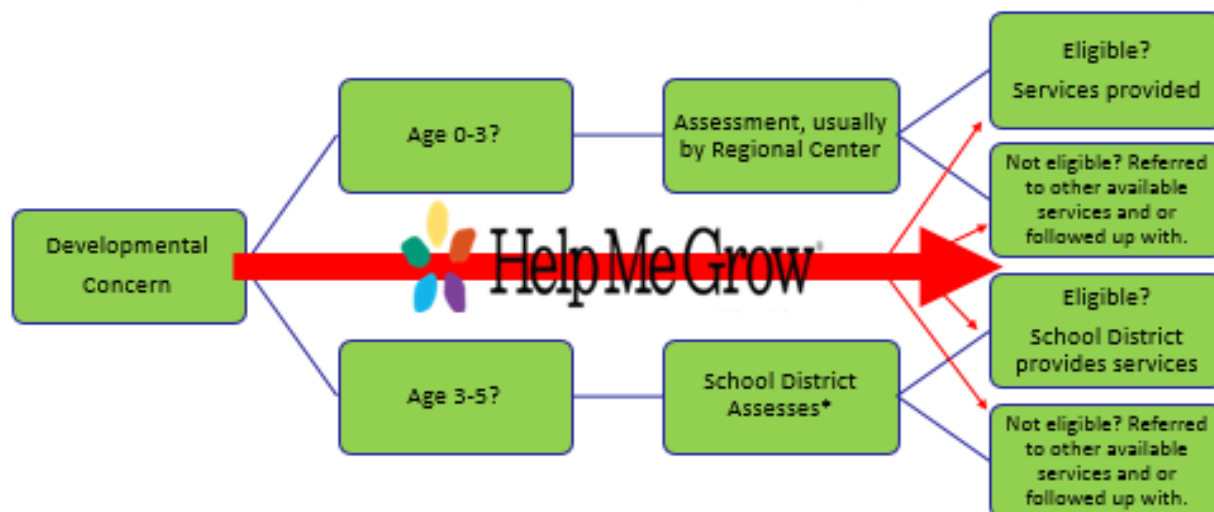
26 The same question except the "parent-reported standardized developmental behavioral screening..." – from the "2009/2010 National Survey of Children with Special Health Care Needs." Child Health Data - <http://childhealthdata.org/browse/survey/results?q=2124&r=1&r2=6>

27 *Summary Statistics From the National Survey of Early Childhood Health, 2000.* (June 2002). [http://www.cdc.gov/nchs/data/series/sr\\_15/sr15\\_003.pdf](http://www.cdc.gov/nchs/data/series/sr_15/sr15_003.pdf)

## Coordination Model: Help Me Grow

Many counties are aiming to increase developmental screenings and improve coordination between systems. “Help Me Grow” is a model designed to navigate parents through fragmented early care systems, and connect children with developmental concerns with available services in their communities. Looking again at the services model below, Help Me Grow guides a parent with an initial developmental concern and links that parent to services for their child. If a child has not been screened, Help Me Grow connects the parent to screening services available (in California, this is often through First 5).

Once a child has been screened, Help Me Grow will ensure the child is fully assessed within a reasonable amount of time. If a child is eligible for services, Help Me Grow will follow up and ensure the child is receiving the services a child is eligible for. Help Me Grow is particularly important for the children who are not eligible to receive free services.



According to Janis Burger, Executive Director of First 5 Alameda, before Help Me Grow, children who received a formal assessment and did not meet the criteria for free services often “fell off the map.” Help Me Grow tracks children once they become involved in their system. Furthermore, as seen in Appendix N, which overviews “Special Education Rights and Responsibilities,” regional centers and school districts have 60 days from the assessment to develop an Individual Education Plan (IEP) for students eligible for services. For children who are assessed at a regional center and are about to turn 3 years, the regional centers must pass along the information to a school district. From there, the school district might reassess the child, and or need to create an IEP in 60 days. While there are processes in place to attempt to ensure a smooth transition, many children get lost in this area. Serving this particular group of children is also where Help Me Grow can be highly valuable.



## History on HMG<sup>28</sup>

The statewide program “Help Me Grow” (“HMG”) began in the Connecticut Office of Early Childhood in 1998, and was designed to identify children at risk for developmental or behavioral problems and to connect these children to existing community resources.<sup>29</sup> The first replication of the model began in 2005 in Orange County, and since then the model has been replicated in 23 different states.

The HMG model is designed to support child health care providers as well as early care and education providers, human service providers, and families in effective developmental surveillance and screening to promote early detection and intervention.

The idea of HMG was to develop a system that facilitates greater access to and collaboration among professionals (i.e., child health care, early child care, and human service providers), nonprofit organizations, and government agencies committed to promoting optimal child development. HMG works in places like California both despite the fragmentation, and because of it. **Help Me Grow is a system that builds collaboration across sectors, including child health care, early care and education, and family support.** Through comprehensive physician and community outreach and centralized information and referral centers, families are linked with needed programs and services.

Help Me Grow recognized four components of an early care system that are critical to helping identify and serve at-risk children:

1. Health Care Provider Outreach
2. Community Outreach
3. Centralized Telephone Access Point
4. Data Collection.

These four components may not be exclusive to Help Me Grow systems, but are the foundation to Help Me Grow’s success.

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<sup>28</sup> Help Me Grow National - <http://www.helpmegrownational.org/pages/what-is-hmg/program-history.php>

<sup>29</sup> “Help Me Grow.” United Way of Connecticut.



## Four Core Components of the Help Me Grow System

1. **Child health care provider outreach** to support early detection and intervention.
2. **Community outreach** to promote the use of HMG and provide networking opportunities among families and service providers.
3. **Centralized telephone access point** for connecting children and their families to services and care coordination.
4. **Data collection** to understand all aspects of the HMG system, including identification of gaps and barriers.

## Strengths of the Help Me Grow Model

HMG has used the community and health provider outreach to increase the awareness of the need for developmental screenings. More importantly, once a child has been screened, HMG's Care Coordinators are familiar with all of the services available to children in that county, and connect the parents accordingly. As mentioned previously, HMG coordinators **follow up** with parents to ensure the child was able to receive services. Help Me Grow staff members have said that pediatricians often do not perform screening because they are unaware of the services that can be provided to children with mild, moderate, or severe developmental delays. The availability of easily accessible resources through HMG has been reported to assist pediatricians to conduct screenings in large part because it resolves one of the most oft-heard barriers to screening cited by pediatricians: the fear that they (pediatricians) will find problems they cannot solve.

The HMG model includes methods for continuous quality improvement. Ongoing data collection and analysis helps identify gaps in and barriers to the system. A National HMG office assists states (and counties in CA) to ensure "fidelity to the model."

According to HMG, the telephone services have proven to be an effective single point of access to community resources, as it is an easy message to parents: "If you have a concern about your child's development, call this number." The number of calls to these telephone hotlines implementing HMG continue to increase and the number of children connected to services have increased on an annual basis.<sup>30</sup>

HMG National assists affiliate states and counties in developing systems that identify at-risk children and help families find community-based programs and services. While some

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<sup>30</sup> Per Orange and Alameda County data.



affiliates take longer to implement the Help Me Grow model, no state or county has left the Help Me Grow system once joining. All affiliates have expressed satisfaction with the system.

## **Help Me Grow: Focus on Data Collection**

A primary emphasis of Help Me Grow is data collection to track the services offered to children. Data collected from Help Me Grow Affiliates includes, but may not be limited to, the following:

- Access point to Help Me Grow
- Ages of children served / Gender and Ethnicity of children served
- Health Insurance Type
- Child's relationship to HMG caller
- Caregiver's primary language
- Concern of parent at time of contact, and length of time of that concern
- Referrals provided by HMG
- Status of children reached during "care coordination" → Connected, not connected, pending, unknown
- Barriers to accessing services → Ex: Caregiver follow through, scheduling, transportation, cost
- Ways learned about HMG → Ex: Pediatrician, Early Head Start, Community Agency, School District

## *Improving HMG Data*

In order for public systems to fully understand and assess the impact of HMG, there is a need for longitudinal data collection that follow children after referral to services. The data collected may be skewed because it is from a universe that is too narrow and too predetermined, as it only collects information from children referred to Help Me Grow. Could there be even more coordination between data collected at the school districts? For example, should Help Me Grow connect with school districts to collect information about how long a child is served? San Francisco School District is the only district that has that data readily available. Help Me Grow would provide better information if this type of data could be collected.

HMG requires an Annual Report from all partners – which includes both state and counties – to report on the data collected. This allows them to measure their impact and see how the Help Me Grow model is making a difference in those areas. Each HMG affiliate releases those reports individually, and it is difficult to see how the HMG model is working without collective longitudinal research. To increase transparency and provide evidence of effectiveness, Help Me Grow National is in the process of developing a comprehensive data system. For more on those plans, see Appendix L.

# Policy Options

After considering the urgent need for developmental screening in order to earlier identify and serve kids with need, First 5 should consider the following policy options:

1. Legislative Resolution that encourages early developmental services
2. Push to include developmental screenings as part of Department of Managed Health Care's health plan oversight.
3. First 5 Commissions pay for universal screenings through health care providers for ages 0-3 and/or through school districts for ages 3-5.
4. Push for coordinated models that emphasize screening and increased data collection

## 1. Legislative Resolution

Initially First 5 Association and partners considered a bill to mandate developmental screenings, but as developmental screenings are already mandated by federal law, First 5 and other stakeholders drafted a legislative resolution encouraging early developmental supports for children. This draft legislative resolution language can be found in Appendix M.

**Effectiveness:** Legislative Resolutions generally carry very little weight. It is likely that nothing will change in the system as a result of this being passed. However, the awareness of the issue may be raised in the legislature – potentially such that if future legislative action is needed, the education of the state legislature on the issue has already been done.

**Risks:** There are no risks associated with this policy option.

**Costs:** The costs of implementing this are negligible outside of staff time and efforts.

## 2. DMHC Oversight

The ACA specifically requires developmental screening for children ages 0-3, and IDEA indirectly requires screening in order to locate children with disabilities, data collection on how many children are being screened is lacking. As previously mentioned, the available state-wide data on screening in health care offices comes from a parent survey via the National Survey on Children's Health.

On December 13, 2013, Children Now, First 5 Association of California, and Help Me Grow California wrote a joint letter to the California Department of Insurance, and the Department of Managed Health Care, which protects consumers' health care rights;

and wrote a similar letter to the Department of Managed Health Care and the Department of Health Care Services, which funds health care services for Medi-Cal members. These letters requested responses to the following questions:

- 1) Have your departments shared the information with health plans/insurers about the requirement that they are to provide 26 preventive services for children with no cost-sharing requirements?
- 2) Do you have any mechanisms in place to monitor if health plans/insurers are complying with this requirement?
- 3) Can you provide specific information, such as utilization data, regarding each of the required services? We are particularly interested in knowing how many young children are receiving developmental and autism screenings, as well as behavioral assessments, at no cost as a result of these laws.

Letters signed by:

Ted Lempert, President of Children Now

Moiria Kenney, PhD, Executive Director of First 5 Association of California

Patsy Hampton, Project Director of Help Me Grow California

On January 21, 2014, the Department of Health Care Services responded to the letter, suggesting that some of the information was available on the website in the “Quality Improvement & Performance Measurement Reports.” In the 2013 HEDIS Aggregate Report for the Medi-Cal Managed Care Program, there was data on “Children and Adolescents’ Access to Primary Care Practitioners” as well as “Well-Child Visits in the Third, Fourth, Fifth, and Sixth Years of Life” but there was no data on how many children were being screened for developmental delays by pediatricians in the health plans.<sup>31</sup>

**Effectiveness:** This will only be effective if DMHC has data to show whether or not pediatricians are screening. DMHC regulates health plans, and not providers, so in this option, the responsibility is actually on the health plans to require providers to report the information to the health plan, and then the health plan would provide that information to DMHC. If developmental screenings become part of the DMHC audit of a health plan, and the plan “offers” developmental

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31 "2013 HEDIS® Aggregate Report for the Medi-Cal Managed Care Program."

screenings, it is unclear whether or not DMHC would be able to fine or penalize the plan without complaints from parents or pediatricians.

**Risks:** With the still somewhat recent passage of the ACA, the Department of Managed Care has competing priorities. It is unclear how much resources would need to be involved to get DMHC to prioritize this policy area. It might be more beneficial to wait for a clear policy window when early care and education are prioritized in the Executive branch, and then make the request.

**Costs:** The staff time and resources spent on this policy option may be higher than the legislative resolution, but it might be more worthwhile. The costs to the health plans, if implemented correctly, and tracked appropriately are unknown. However, costs to health plans (and providers) will likely be considered as part of the political feasibility if this were to ever become a bill that requires pediatricians or health plans to collect the data required to regulate this.

### 3. Pay for Screenings

One way to guarantee universal screening is to pay for it. First 5 county commissions could pay for school readiness nurses at each school district, much like Orange County does. Orange County screens every child beginning at age 4 every year until they reach the 3<sup>rd</sup> grade through school readiness nurses, which is the closest model to universal screening in California. However, if First 5 wants to screen children ages 0-3, there needs to be a partnership with pediatricians. First 5 county commissions could use part of their general funds to reimburse pediatricians for all screening, with the caveat that they would need to report data on all children seen.

**Effectiveness:** This option would achieve universal screening, as well as increased data collection.

**Risks:** Diverting funds away from other important programs that First 5 Commissions administer would be politically challenging, and likely impossible for some counties. This is especially the case because this payment would go toward something that health plans (and Medi-Cal) should be paying for already.

**Costs:** School readiness nurses make up nearly 15 percent of the Children & Family Commission of Orange County (First 5 OC) budget.<sup>32</sup> The costs of pursuing this option for some counties will likely prevent this from being implemented.

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<sup>32</sup> Orange County Children and Family Commission 2014 Annual Report - [http://occhildrenandfamilies.com/wp-content/uploads/2014/12/Performance-Report\\_Early-Learning.2014.pdf](http://occhildrenandfamilies.com/wp-content/uploads/2014/12/Performance-Report_Early-Learning.2014.pdf)

## 4. Coordinated Models

The four core components of the Help Me Grow model can improve early identification and interventions. While many counties provide outreach to health care providers and communities, counties without the Help Me Grow model do not have a single telephone access point, and lack data collection. The Help Me Grow model itself is not necessary to provide coordination between systems, as San Diego has shown a coordinated system without the Help Me Grow model.<sup>33</sup> However, the following analysis will consider an implementation of Help me Grow.

**Effectiveness:** Help Me Grow is seen to be an effective model, but more longitudinal research is needed to support this claim (HMG National Data Center will likely release research on the effectiveness of the model in the next year). For more on HMG effectiveness and strengths, see pages 20-23.

**Risks:** Help Me Grow's single-phone access point can only be effective if there is awareness about the program. Counties with different demographics may face constraints in capacity – a lack of resources available for English language learners for example.

**Costs:** HMG state affiliates pay \$2,500, but counties do not incur direct costs. Counties may need to reorganize or build capacity but those costs are different per county. The implementation of Help Me Grow may look different for each county, and therefore could have wide ranging costs.

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<sup>33</sup> The Special Needs Project also was a coordinated model with data collection that should be further researched.

## More Considerations for First 5

Another option to consider could have been to prioritize funding not on screening, but on the prevention of speech and language developmental delays through other interventions. Consider funding programs like “Providence Talks” in Rhode Island or “Baby College” in the Harlem Children’s Zone. These programs are costly, but have shown to be very effective.

Providence Talks was funded by a Michael Bloomberg grant in order to address the 30 million word gap. It essentially is like a pedometer but for the number of words you say to your child instead of the number of steps you take. “Early results demonstrate that simple access to information can be powerful. In one pilot study, caretakers presented with data on their child’s vocabulary development increased their adult daily word count by 55% on average.” For more information: <http://www.providencetalks.org/about/>.

Baby College in Harlem’s Children Zone has graduated 5,000 children, 100% of which tested school ready. For more: <http://hcz.org/our-programs/the-baby-college/>.

Aside from these programs, other non-profits like “Too Small To Fail” a joint venture between the Clinton Foundation and Next Generation (in partnership with Zero to Three), try to increase awareness of the 30 million word gap and train parents to interact with their child in a way that helps the child develop properly.

While this option would aim to prevent developmental delays from occurring, and should target low-income children. However, if funds are diverted away from screening, and, given the high cost nature of these programs, if all children cannot take part in the program, then children with delays could be at risk of being found even later.

## Looking Forward

First 5 Association of California is in the process of hiring a Legislative Director. While this analysis will inform that person on developmental screenings in California, moving forward, it is important that this person consider political feasibility, implementation feasibility, effectiveness, cost, and efficiency when developing legislative strategies to address the need for universal developmental screening.

To maximize the effectiveness of the policy strategies mentioned, First 5 Association should consider the following:

1. *Legislative Resolution* – In order to increase awareness of the resolution, F5A could work with county commissions to draft press releases upon the resolution passing.
2. *Regulatory Option* – Instead of pushing DMHC, F5A could work with National partners to try to get developmental screenings in the HEDIS measurement.
3. *Paying for Screenings* – F5A could work with county commissions to restructure budgets that allow for developmental screenings, showing how best practice counties make it possible. Alternatively or additionally, F5A could look for grant opportunities through foundations or non-profits with similar missions.
4. *Help Me Grow* - If a county or state wants to replicate the HMG model, Help Me Grow National provides toolkits and support in any implementation plan. However, prior to becoming an affiliate state, it is very difficult for a county to determine whether or not HMG is right for them. The ease and cost of implementation of Help Me Grow will be a critical element in the decision making process of counties considering affiliation with Help Me Grow, and there is a lack of messaging. First 5 Association, in collaboration with Patsy Hampton, Help Me Grow California representative, should put together estimated resources needed by county size to assist counties in deciding whether or not HMG is right for them.

Ultimately, a child's development begins and ends in the home. If parents are unresponsive, even a system that calls for follow-ups with parents will not work if the parents do not follow up themselves. Parental education must be part of any solution.

Finally, it is important to recognize that the end goal of developmental screening is to quickly identify children at risk for developmental delays and treat them as early as possible. To address this end goal more directly, other policy alternatives should be considered.

# Appendix

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### **Other Resources**

Zero to Three - <http://www.zerotothree.org/>

Help Me Grow National - <http://www.helpmegrownational.org/>

California Department of Education DataQuest - <http://data1.cde.ca.gov/dataquest/>

First 5 California - <http://www.first5california.com/>

Children & Families Commission of Orange County - <http://occhildrenandfamilies.com/>

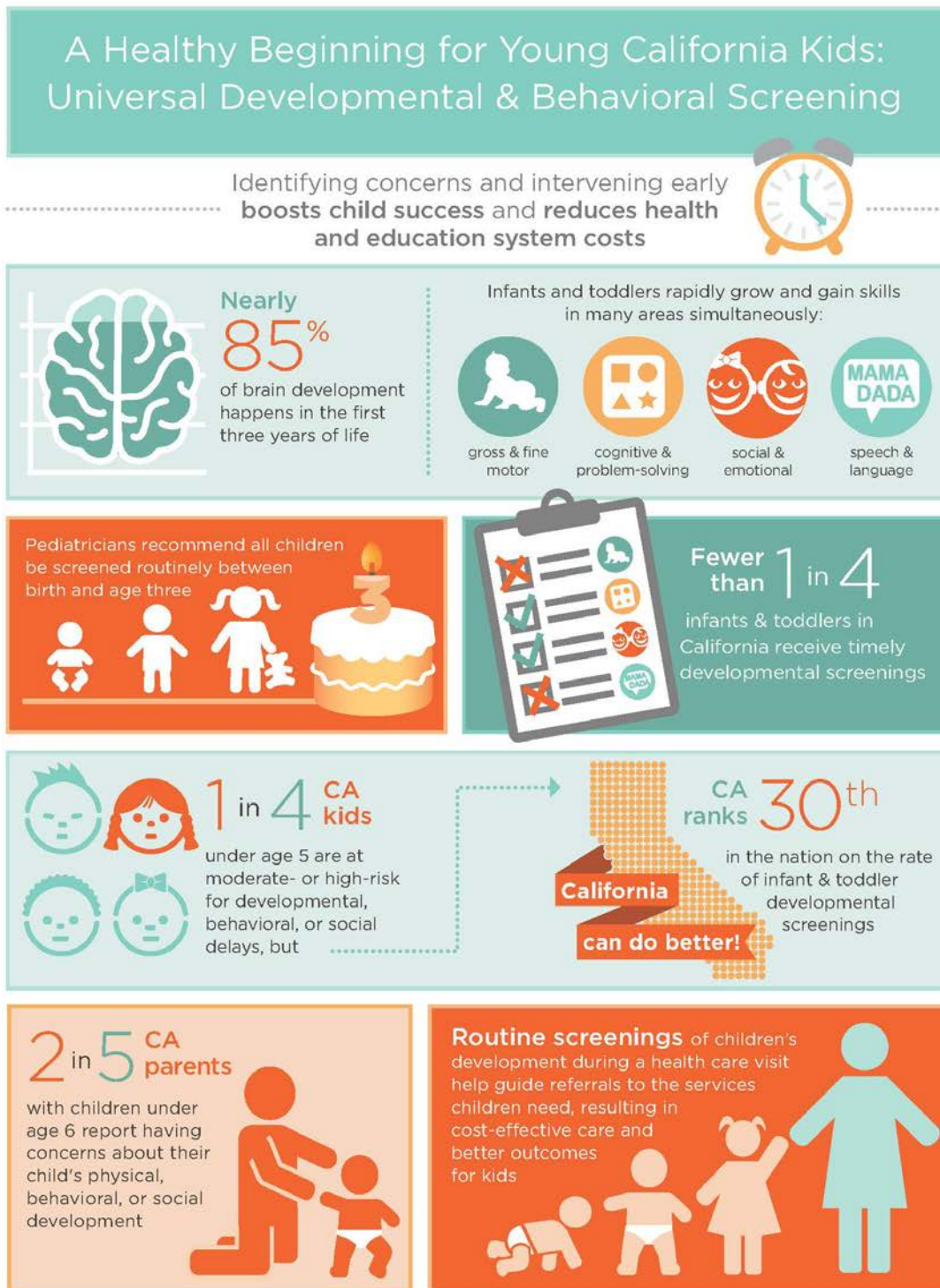
Too Small To Fail - <http://toosmall.org/>

More on Developmental Screening Tools: <http://www.nectac.org/~pdfs/pubs/screening.pdf>

Special Needs Project Program Evaluation:

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## B. Infographic on Screening



For sources see [childrennow.org/dev-info-sources](http://childrennow.org/dev-info-sources)



FIRST 5  
ASSOCIATION  
OF CALIFORNIA

CHILDREN NOW

## C. ACA Mandate

Per hhs.gov: “If you have a new health insurance plan or insurance policy beginning on or after September 23, 2010, the following preventive services must be covered without your having to pay a copayment or co-insurance or meet your deductible. This applies only when these services are delivered by a network provider.”

### Attachment: 26 Required Preventive Services for Children

1. **Alcohol and Drug Use** assessments for adolescents
2. **Autism** screening for children at 18 and 24 months
3. **Behavioral** assessments for children of all ages Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
4. **Blood Pressure** screening for children Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
5. **Cervical Dysplasia** screening for sexually active females
6. **Congenital Hypothyroidism** screening for newborns
7. **Depression** screening for adolescents
8. **Developmental** screening for children under age 3, and surveillance throughout childhood
9. **Dyslipidemia** screening for children at higher risk of lipid disorders Ages: 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
10. **Fluoride Chemoprevention** supplements for children without fluoride in their water source
11. **Gonorrhea** preventive medication for the eyes of all newborns
12. **Hearing** screening for all newborns
13. **Height, Weight and Body Mass Index** measurements for children Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
14. **Hematocrit or Hemoglobin** screening for children
15. **Hemoglobinopathies** or sickle cell screening for newborns
16. **HIV** screening for adolescents at higher risk
17. **Immunization** vaccines for children from birth to age 18 —doses, recommended ages, and recommended populations vary:
  - Diphtheria, Tetanus, Pertussis
  - Haemophilus influenzae type b
  - Hepatitis A
  - Hepatitis B
  - Human Papillomavirus
  - Inactivated Poliovirus
  - Influenza (Flu Shot)
  - Measles, Mumps, Rubella
  - Meningococcal
  - Pneumococcal
  - Rotavirus
  - Varicella Learn more about immunizations and see the latest vaccine schedules.
18. **Iron** supplements for children ages 6 to 12 months at risk for anemia
19. **Lead** screening for children at risk of exposure
20. **Medical History** for all children throughout development Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
21. **Obesity** screening and counseling
22. **Oral Health** risk assessment for young children Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years.
23. **Phenylketonuria (PKU)** screening for this genetic disorder in newborns
24. **Sexually Transmitted Infection (STI)** prevention counseling and screening for adolescents at higher risk
25. **Tuberculin** testing for children at higher risk of tuberculosis Ages: 0 to 11 months, 1 to 4 years, 5 to 10 years, 11 to 14 years, 15 to 17 years.
26. **Vision** screening for all children

Source: <http://www.hhs.gov/healthcare/facts/factsheets/2010/07/preventive-services-list.html#CoveredPreventiveServicesforChildren>



## D. AAP Recommendations



### Recommendations for Preventive Pediatric Health Care Bright Futures/American Academy of Pediatrics



Each child and family is unique; therefore, these Recommendations for Preventive Pediatric Health Care are designed for the care of children who are receiving competent parenting, have no manifestations of any important health problems, and are growing and developing in satisfactory fashion. Additional visits may become necessary if circumstances suggest variations from normal.

Developmental, psychosocial, and chronic disease issues for children and adolescents may require frequent counseling and treatment visits separate from preventive care visits.

These guidelines represent a consensus by the American Academy of Pediatrics (AAP) and Bright Futures. The AAP continues to emphasize the great importance of continuity of care in comprehensive health supervision and the need to avoid fragmentation of care.

Refer to the specific guidance by age as listed in Bright Futures guidelines (Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents*. 3<sup>rd</sup> ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008).

The recommendations in this statement do not indicate an exclusive course of treatment or standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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AGE	Prenatal	Newborn	3-5 d	By 1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	30 mo	3 y	4 y	5 y	6 y	7 y	8 y	9 y	10 y	11 y	12 y	13 y	14 y	15 y	16 y	17 y	18 y	19 y	20 y	21 y
HISTORY Initial/Interval	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
MEASUREMENTS																																
Length/Height and Weight		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Head Circumference		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Weight for Length		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Body Mass Index <sup>1</sup>																																
Blood Pressure <sup>2</sup>		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
SENSORY SCREENING																																
Vision		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Hearing		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
DEVELOPMENTAL/BEHAVIORAL ASSESSMENT																																
Developmental Screening <sup>3</sup>									•																							
Autism Screening <sup>10</sup>																																
Developmental Surveillance																																
Psychosocial/Behavioral Assessment																																
Alcohol and Drug Use Assessment <sup>11</sup>																																
Depression Screening <sup>12</sup>																																
PHYSICAL EXAMINATION																																
Newborn Blood Screening <sup>13</sup>		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Critical Congenital Heart Defect Screening <sup>14</sup>		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Immunization <sup>15</sup>		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Hematoctrit or Hemoglobin <sup>16</sup>						•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Lead Screening <sup>17</sup>						•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Tuberculosis Testing <sup>18</sup>						•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Dyslipidemia Screening <sup>19</sup>																																
ST/HSV Screening <sup>20</sup>																																
Cervical Dysplasia Screening <sup>21</sup>																																
ORAL HEALTH <sup>22</sup>									•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
ANTICIPATORY GUIDANCE	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•

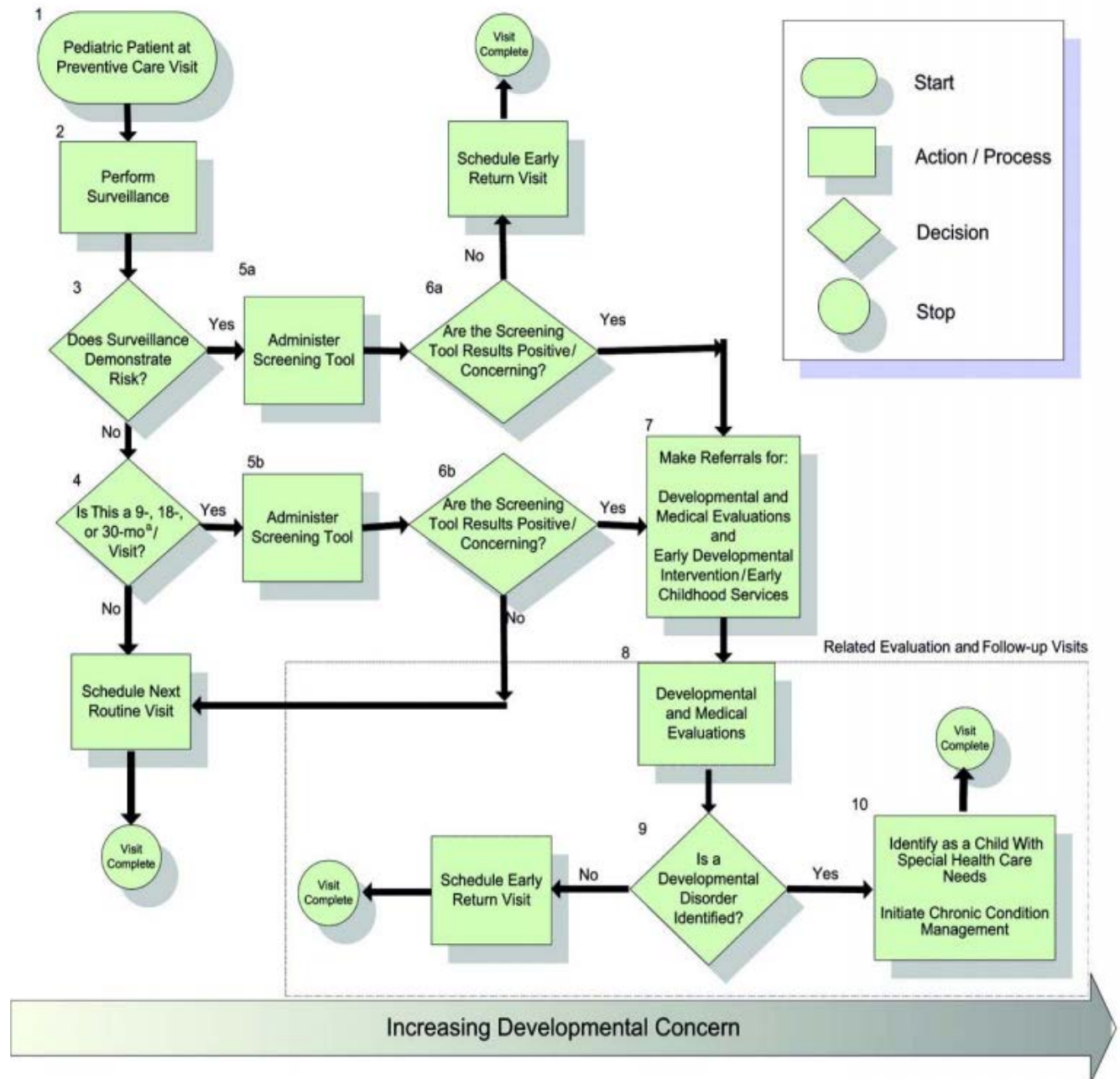
- If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.
- A prenatal visit is recommended for parents who are at high risk, for first-time parents, and for those who request a conference. The prenatal visit should include anticipatory guidance, pertinent medical history, and a discussion of benefits of breastfeeding and planned method of feeding, per the 2009 AAP statement "The Prenatal Visit" (<http://pediatrics.aappublications.org/content/124/5/1222.full>).
- Every infant should have a newborn evaluation after birth, and breastfeeding should be encouraged (and instruction and support should be offered).
- Every infant should have an evaluation within 3 to 5 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding infants should receive formal breastfeeding evaluation, and their mothers should receive encouragement and instruction, as recommended in the 2012 AAP statement "Breastfeeding and the Use of Human Milk" (<http://pediatrics.aappublications.org/content/129/5/1077.full>). Newborn infants discharged less than 48 hours after delivery must be examined within 48 hours of discharge, per the 2010 AAP statement "Hospital Stay for Healthy Term Newborns" (<http://pediatrics.aappublications.org/content/125/4/625.full>).
- Screen, per the 2007 AAP statement "Expert Committee Recommendations Regarding the Prevention, Assessment, and Treatment of Child and Adolescent Overweight and Obesity: Summary Report" ([http://pediatrics.aappublications.org/content/120/Supplement\\_4/5164.full](http://pediatrics.aappublications.org/content/120/Supplement_4/5164.full)).
- Blood pressure measurement in infants and children with specific risk conditions should be performed at visits before age 3 years.
- If the patient is uncooperative, rescreen within 6 months, per the 2007 AAP statement "Eye Examination in Infants, Children, and Young Adults by Pediatricians" (<http://pediatrics.aappublications.org/content/111/4/602.full>).
- All newborns should be screened, per the AAP statement "Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs" (<http://pediatrics.aappublications.org/content/120/4/918.full>).
- See 2005 AAP statement "Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening" (<http://pediatrics.aappublications.org/content/116/1/106.full>).
- Screening should occur per the 2007 AAP statement "Identification and Evaluation of Children with Autism Spectrum Disorders" (<http://pediatrics.aappublications.org/content/120/5/1183.full>).

- A recommended screening tool is available at <http://www.cdc.gov/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>.
- Recommended screening using the Patient Health Questionnaire (PHQ-9) or other tools available in the GLAD-PC toolkit and at <http://www.aap.org/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>.
- At each visit, age-appropriate physical examination is essential, with infant totally undressed and older children undressed and suitably draped. See 2011 AAP statement "Use of Physical Examination in the Pediatric Patient" (<http://pediatrics.aappublications.org/content/127/2/297.full>).
- These may be modified, depending on entry point into schedule and individual need.
- The Recommended Uniform Newborn Screening Panel (<http://www.hhs.gov/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>), as determined by The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, and state newborn screening laws/regulations (<http://www.hhs.gov/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>), establish the criteria for and coverage of newborn screening procedures and programs. Follow-up must be provided, as appropriate, by the pediatrician.
- Screening for critical congenital heart disease using pulse oximetry should be performed in newborns, after 24 hours of age, before discharge from the hospital, per the 2011 AAP statement "Endorsement of Health and Human Services Recommendation for Pulse Oximetry Screening for Critical Congenital Heart Disease" (<http://pediatrics.aappublications.org/content/125/1/190.full>).
- Schedules, per the AAP Committee on Infectious Diseases, are available at: <http://www.aap.org/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>.
- See 2010 AAP statement "Diagnosis and Prevention of Iron Deficiency and Iron Deficiency Anemia in Infants and Young Children (0-3 Years of Age)" (<http://pediatrics.aappublications.org/content/125/4/625.full>).
- For children at risk of lead exposure, see the 2012 CDC Advisory Committee on Childhood Lead Poisoning Prevention statement "Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention" (<http://www.cdc.gov/lead/lead9000.PDF>).

- Perform risk assessments or screenings as appropriate, based on universal screening requirements for patients with Medicaid or in high prevalence areas.
- Tuberculosis testing per recommendations of the Committee on Infectious Diseases, published in the current edition of AAP Red Book: Report of the Committee on Infectious Diseases. Testing should be performed on recognition of high-risk factors.
- See AAP-endorsed 2011 guidelines from the National Heart Blood and Lung Institute, "Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents" (<http://www.heart.org/healthguidelines>).
- Adolescents should be screened for sexually transmitted infections (STIs) per recommendations in the current edition of the AAP Red Book: Report of the Committee on Infectious Diseases. Additionally, all adolescents should be screened for HIV according to the AAP statement (<http://pediatrics.aappublications.org/content/128/5/1023.full>) once between the ages of 15 and 18, making every effort to preserve confidentiality of the adolescent. Those at increased risk of HIV infection, including those who are sexually active, participate in injection drug use, or are being tested for other STIs, should be tested for HIV and reassessed annually.
- See USPSTF recommendations (<http://www.uspreventiveservicestaskforce.org/uspstf/uspstf.htm>). Indications for pelvic examinations prior to age 21 are noted in the 2010 AAP statement "Gynecologic Examination for Adolescents in the Pediatric Office Setting" (<http://pediatrics.aappublications.org/content/125/5/958.full>).
- Refer to a dental home, if available. If not available, perform a risk assessment (<http://www.aap.org/nczod/ncdd/2012/04/2012AAPScreeningTool.pdf>). If primary water source is deficient in fluoride, consider oral fluoride supplementation. For those at high risk, consider application of fluoride varnish for caries prevention. See 2008 AAP statement "Preventive Oral Health Intervention for Pediatricians" (<http://pediatrics.aappublications.org/content/122/6/1387.full>) and 2009 AAP statement "Oral Health Risk Assessment: Establishment of the Dental Home" (<http://pediatrics.aappublications.org/content/119/5/1113.full>).

KEY • = to be performed ★ = risk assessment to be performed with appropriate action to follow, if positive ← • → = range during which a service may be provided

## E. Flow Chart for Developmental Screenings (per AAP)



Pediatric Patient at Preventive Care Visit

1. Developmental concerns should be included as one of several health topics addressed at each pediatric preventive care visit throughout the first 5 years of life.<sup>6</sup>

2. **Developmental surveillance** is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems. There are 5 components of developmental surveillance: eliciting and attending to the parents' concerns about their child's development, documenting and maintaining a developmental history, making accurate observations of the child, identifying the risk and protective factors, and maintaining an accurate record and documenting the process and findings.

Perform Surveillance

Does Surveillance Demonstrate Risk?

3. The concerns of both parents and child health professionals should be included in determining whether surveillance suggests the child may be at risk of developmental delay. If either parents or the child health professional express concern about the child's development, a developmental screening to address the concern specifically should be conducted.

4. All children should receive developmental screening using a standardized test. In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9-, 18-, and 30-month<sup>a</sup> visits. Additionally, autism-specific screening is recommended for all children at the 18-month visit.

Is This a 9-, 18-, or 30-mo<sup>a</sup> Visit?

Administer Screening Tool

5a and 5b. **Developmental screening** is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder. Developmental screening that targets the area of concern is indicated whenever a problem is identified during developmental surveillance.

6a and 6b. When the results of the periodic screening tool are normal, the child health professional can inform the parents and continue with other aspects of the preventive visit. When a screening tool is administered as a result of concerns about development, an early return visit to provide additional developmental surveillance should be scheduled even if the screening tool results do not indicate a risk of delay.

Make Referrals for:  
Developmental and Medical Evaluations and  
Early Developmental Intervention/Early Childhood Services

Developmental and Medical Evaluations

7–8. If screening results are concerning, the child should be scheduled for developmental and medical evaluations. **Developmental evaluation** is aimed at identifying the specific developmental disorder or disorders affecting the child. In addition to the developmental evaluation, a **medical diagnostic evaluation** to identify an underlying etiology should be undertaken. **Early developmental intervention/early childhood services** can be particularly valuable when a child is first identified to be at high risk of delayed development, because these programs often provide evaluation services and can offer other services to the child and family even before an evaluation is complete.<sup>25</sup> Establishing an effective and efficient partnership with early childhood professionals is an important component of successful care coordination for children.<sup>40</sup>

Are the Screening Tool Results Positive/Concerning?

9. If a developmental disorder is identified, the child should be identified as a child with special health care needs and chronic condition management should be initiated (see No. 10 below). If a developmental disorder is not identified through medical and developmental evaluation, the child should be scheduled for an early return visit for further surveillance. More frequent visits, with particular attention paid to areas of concern, will allow the child to be promptly referred for further evaluation if any further evidence of delayed development or a specific disorder emerges.

Is a Developmental Disorder Identified?

Identify as a Child With Special Health Care Needs  
Initiate Chronic Condition Management

10. When a child is discovered to have a significant developmental disorder, that child becomes a child with special health care needs, even if that child does not have a specific disease etiology identified. Such a child should be identified by the medical home for appropriate chronic condition management and regular monitoring and entered into the practice's children and youth with special health care needs registry.<sup>41</sup>

Source: American Academy of Pediatrics

<http://pediatrics.aappublications.org/content/118/1/405.full.pdf+html>



## F. Eligibility Requirements for Services

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Source: <http://www.dds.ca.gov/EarlyStart/WhatsES.cfm>

*Per California law:*

“Infants and toddlers from birth to age 36 months may be eligible for early intervention services through Early Start if, through documented evaluation and assessment, they meet one of the criteria listed below:

- have a developmental delay of at least 33% in one or more areas of either cognitive, communication, social or emotional, adaptive, or physical and motor development including vision and hearing; or
- have an established risk condition of known etiology, with a high probability of resulting in delayed development; or
- be considered at high risk of having a substantial developmental disability due to a combination of biomedical risk factors of which are diagnosed by qualified personnel”

### **Cost to Parent**

“There is no cost for evaluation, assessment and service coordination. Public or private insurance is accessed for medically necessary therapy services including speech, physical and occupational therapies. Services that are not covered by insurance will be purchased or provided by regional centers or local education agencies.”



## G. Screening Tools Information

### 1. More Information on Most Commonly Used Tools

#### PEDS

PEDS TOOLS					
PEDS TOOLS	Age range	Purpose and Description	Scoring	Accuracy	Time Frame/Costs*
<p><b>Parents' Evaluations of Developmental Status (PEDS).</b> (2013) PEDSTest.com, LLC, 1013 Austin Court, Nolensville, TN 37135 (615-776-4121) (\$36.00). <a href="http://www.pedstest.com">www.pedstest.com</a></p> <p><b>Training Options:</b> offers through its website self-training/train-the-trainer support via downloadable slide shows with notes, case examples, pre-post-test questions, FAQs, participant handouts, website discussion list (covering all screens), short videos, with some live training available.</p> <p><b>Electronic Options:</b> PEDS (along with the PEDS:DM and the M-CHAT) are available online with automated scoring, referral letters, take-home parent summary reports, billing/procedure codes. PEDS Online also generates a user-database for Quality Improvement initiatives and research projects (<a href="http://www.pedstest.com/online">www.pedstest.com/online</a>)</p>	Birth to 8 years	<p><b>Purpose:</b> Screening/surveillance of development/social-emotional/behavior/mental status</p> <p><b>Description:</b> 10 questions eliciting parents' (and providers') verbatim concerns in English, Spanish, Vietnamese, Arabic plus and 20 other languages with others in-progress. Items are written at the 4<sup>th</sup> - 5<sup>th</sup> grade level. PEDS Longitudinal Score and Interpretation Forms assign risk levels, track decision-making and offer specific guidance on how best to address concerns. Provides screening, longitudinal surveillance and triage for developmental as well as behavioral/social-emotional/mental health problems. PEDS should be used in conjunction with the PEDS:DM (below) to decide when parent education versus referrals are needed for children at moderate- but not high-risk.</p>	Identifies when to: Refer and what types of referrals are needed; Advise parents; Monitor vigilantly; Screen further (or refer for screening); or Reassure.	<p><b>By age:</b></p> <p>Sensitivity: 91% - 97%</p> <p>Specificity: 73% - 86%</p> <p><b>By disabilities, i.e., learning, intellectual, language, mental health, and autism spectrum, and motor disorders,</b></p> <p>Sensitivity: 71% - 87%</p>	<p>Scoring time: 1 min.</p> <p>Scoring cost: \$1.20</p> <p>Materials: \$0.39</p> <p><b>Total Self-Report: \$1.59</b></p> <p>Interview Time: 2 min.</p> <p>Interview Cost: \$2.40</p> <p>Scoring/Materials: \$1.59</p> <p><b>Total Interview: \$3.99</b></p>

## PEDS:DM

<p><b>PEDS: Developmental Milestones (Screening Version) (PEDS:DM) (2008)</b>  PEDSTest.com, LLC 1013 Austin Court, Nolensville, TN 37135 (615-776-4121) (\$275.00).  <a href="http://www.pedstest.com">www.pedstest.com</a></p> <p><b>Training Options:</b> offers through its website self-training/train-the-trainer support via downloadable slide shows with notes, case examples, pre-post-test questions, participant handouts, FAQs, website discussion list (covering all screens), short videos, with some live training available. The PEDS:DM manual includes extensive suggestions for training medical students, residents, and nurses.</p> <p><b>Electronic Options:</b> See PEDS (above).</p>	<p>Birth to 8 years</p>	<p><b>Purpose:</b> Screening/ surveillance of developmental and social-emotional/mental health milestones</p> <p><b>Description:</b> PEDS-DM is designed to replace informal milestones checklists (such as key items from other measures) with evidence. It consists of 6 – 8 items at each age level. Each item taps a different domain: fine/gross motor, self-help, academics, expressive and receptive language, and social-emotional. The PEDS:DM provides screening, triage, and surveillance via a longitudinal score form for tracking milestones progress. Written at the 2<sup>nd</sup> to 3<sup>rd</sup> grade level and can be completed by parent self-report, interview, or administered directly to children. Forms are laminated and completed with a dry erase marker. Supplemental measures focused on AAP policy include the M-CHAT, Family Psychosocial Screen, Pictorial PSC-17, the SWILS, the Vanderbilt ADHD scale, and the Brigance Parent-Child Interactions Scale.</p> <p>When combined with PEDS, ensures full compliance with AAP policy. In English, Spanish, Taiwanese, Arabic, Portuguese, French, with other languages in process. An Assessment Level version is available for high-risk follow-up and provides age-equivalent as well as cutoff scores.</p>	<p>Pass/Fail cutoffs tied to performance above and below the 16<sup>th</sup> percentile for each item and its domain.</p>	<p><b>By age,</b>  Sensitivity:  70% - 94%;  Specificity:  77% - 93%</p> <p><b>By performance on diagnostic measures per domain:</b>  Sensitivity:  75% - .87%;  Specificity:  71% - 88%</p> <p><b>By disabilities, i.e., autism spectrum disorder, sensitivity = 79% - 82%</b></p>	<p>Scoring time:  1 min  Scoring cost: \$1.20  Materials:  \$0.02</p> <p><b>Total Self-Report: \$1.22</b></p> <p>Interview Time: 3 min  Scoring/ Materials:  \$1.22</p> <p><b>Total Interview: \$3.82</b></p> <p>Direct Admin: 4 min  Scoring/ Materials:  \$1.22</p> <p><b>Total Direct Admin: \$6.10</b></p>
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## Ages and Stages Questionnaire

### ASQ TOOLS

ASQ TOOLS	Age range	Purpose and Description	Scoring	Accuracy	Time Frame/Costs*
<p><b>Ages &amp; Stages Questionnaires®, Third Edition (ASQ-3™)</b> (2009). Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285. (800-638-3775) (\$295.00). Materials kit (\$295.00). <a href="http://www.agesandstages.com">www.agesandstages.com</a>.</p> <p><b>Training Options:</b> DVDs for purchase, case examples, teaching activities related to ASQ content, and live training</p> <p><b>Electronic Options:</b> see ASQ:SE</p>	1 - 66 mos.	<p><b>Purpose:</b> Screening/surveillance of developmental status.</p> <p><b>Description:</b> Parents indicate children's developmental skills on 30 items plus overall concerns. The ASQ has a different form (6-8 pages) for each age interval. Written at the 4<sup>th</sup> – 6<sup>th</sup> grade level. Can be used in mass mail-outs for child find programs. Manual contains detailed instructions for organizing child-find programs and includes activity handouts for parents. The ASQ-3 is available in English, Spanish, French, Korean, Norwegian, Galician, and several other languages.</p> <p>Because the ASQ does not screen for social-emotional/behavioral or mental health problems, problematic results call for administration of the ASQ: SE (described below)</p>	Cutoff scores in 5 developmental domains: Indicate need for referral or monitoring.	<p><b>By age,</b></p> <p>Sensitivity: 82% - 89%</p> <p>Specificity: 77% - 92%</p> <p><b>By domain,</b></p> <p>Sensitivity: 83%</p> <p>Specificity: 91%</p> <p><b>By disabilities, i.e., motor impairment, intellectual disabilities,</b></p> <p>Sensitivity: 87%</p>	<p>Scoring time: 2 min</p> <p>Scoring cost: \$2.40</p> <p>Print Materials: \$~0.36 - \$0.48</p> <p><b>Total Self-Report: \$2.76 - \$2.88</b></p> <p>Interview Time: 12 min.</p> <p>Interview Cost: \$14.40</p> <p>Scoring/ Materials: \$2.76 - \$2.88</p> <p><b>Total Interview: \$17.28</b></p>

## 2. American Academy of Pediatrics Table of Recommended Tools

**TABLE 1 Developmental Screening Tools**

	Description	Age Range	No. of Items	Administration Time	Psychometric Properties <sup>a</sup>	Scoring Method	Cultural Considerations	Purchase/Obtainment Information	Key References
General developmental screening tool									
Ages & Stages Questionnaires (ASQ)	Parent-completed questionnaire; series of 19 age-specific questionnaires screening communication, gross motor, fine motor, problem-solving, and personal adaptive skills; results in pass/fail score for domains	4–60 mo	30	10–15 min	Normed on 2008 children from diverse ethnic and socioeconomic backgrounds, including Spanish speaking; sensitivity: 0.70–0.90 (moderate to high); specificity: 0.76–0.91 (moderate to high)	Risk categorization; provides a cutoff score in 5 domains of development that indicates possible need for further evaluation	English, Spanish, French, and Korean versions available	Paul H. Brookes Publishing Co; 800/638-3775; www.brookespublishing.com	Squires J, Potter L, Bricker D. <i>The ASQ User's Guide</i> . 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co; 1999
Battelle Developmental Inventory Screening Tool, 2nd ed (BDI-ST)	Directly administered tool; designed to screen personal-social, adaptive, motor, communication, and cognitive development; results in pass/fail score and age equivalent; can be modified for children with special needs	Birth to 95 mo	100	10–15 min (<3 y old) or 20–30 min (≥3 y old)	Normed on 2500 children; demographic information matched 2000 US Census data; additional bias reviews performed to adjust for gender and ethnicity concerns; sensitivity: 0.72–0.93 (moderate to high); specificity: 0.79–0.88 (moderate)	Quantitative; scaled scores in all 5 domains are compared with cutoffs to determine need for referral	English and Spanish versions available	Riverside Publishing Co; 800/323-9540; www.riverpub.com	Newborg J. <i>Battelle Developmental Inventory</i> . 2nd ed. Itasca, IL: Riverside Publishing; 2004
Bayley Infant Neurodevelopmental Screen (BINS)	Directly administered tool; series of 6 item sets screening basic neurologic functions; receptive functions (visual, auditory, and tactile input); expressive functions (oral, fine, and gross motor skills); and cognitive processes; results in risk category (low, moderate, high risk)	3–24 mo	11–13	10 min	Normed on ~1700 children, stratified on age, to match the 2000 US Census; sensitivity: 0.75–0.86 (moderate); specificity: 0.75–0.86 (moderate)	Risk categorization; children are graded as low, moderate, or high risk in each of 4 conceptual domains by use of 2 cutoff scores	English and Spanish versions available	Psychological Corp; 800/211-8378; www.harcourtassessment.com	Aylward GP. <i>Bayley Infant Neurodevelopmental Screener</i> . San Antonio, TX: Psychological Corp; 1995; Aylward GP, Verhulst SJ, Bell S. Predictive utility of the BINS-II Infant Neurodevelopmental Screener (BINS) risk status classifications: clinical interpretation and application. <i>Dev Med Child Neurol</i> . 2000; 42:25–31
Brigance Screens-II	Directly administered tool; series of 9 forms screening articulation, expressive and receptive language, gross motor, fine motor, general knowledge and personal social skills and pre-academic skills (when appropriate); for 0–23 mo, can also use parent report	0–90 mo	8–10	10–15 min	Normed on 1156 children from 29 clinical sites in 21 states; sensitivity: 0.70–0.80 (moderate); specificity: 0.70–0.80 (moderate)	All results are criterion based; no normative data are presented	English and Spanish versions available	Curriculum Associates Inc; 800/225-0248; www.curriculumassociates.com	Glascow FP. <i>Technical Report for the Brigance Screens</i> . North Billerica, MA: Curriculum Associates Inc; 2005; Glascow FP. The Brigance Infant-Toddler Screen (BITS): standardization and validation. <i>J Dev Behav Pediatr</i> . 2002;23: 145–150
Child Development Inventory (CDI)	Parent-completed questionnaire; measures social, self-help, motor, language, and general development skills; results in developmental quotients and age equivalents for different developmental domains; suitable for more in-depth evaluation	18 mo–6 y	300	30–50 min	Normative sample included 568 children from south St Paul, MN, a primarily white, working class community; Dolg et al included 43 children from a high-risk follow-up program, which included 69% with high school education or less and 81% Medicaid; sensitivity: 0.80–1.0 (moderate to high); specificity: 0.94–0.96 (high)	Quantitative; provides age equivalents in each domain as well as SDs	English and Spanish versions available	Behavior Science Systems Inc; 612/850-8700; www.childdevrev.com	Iretton H. <i>Child Development Inventory Manual</i> . Minneapolis, MN: Behavior Science Systems Inc; 1992; Dolg KB, Macias MM, Saylor CF, Craver JR, Ingram PE. The Child Development Inventory: a developmental outcome measure for follow-up of the high risk infant. <i>J Pediatr</i> . 1999;135:358–362

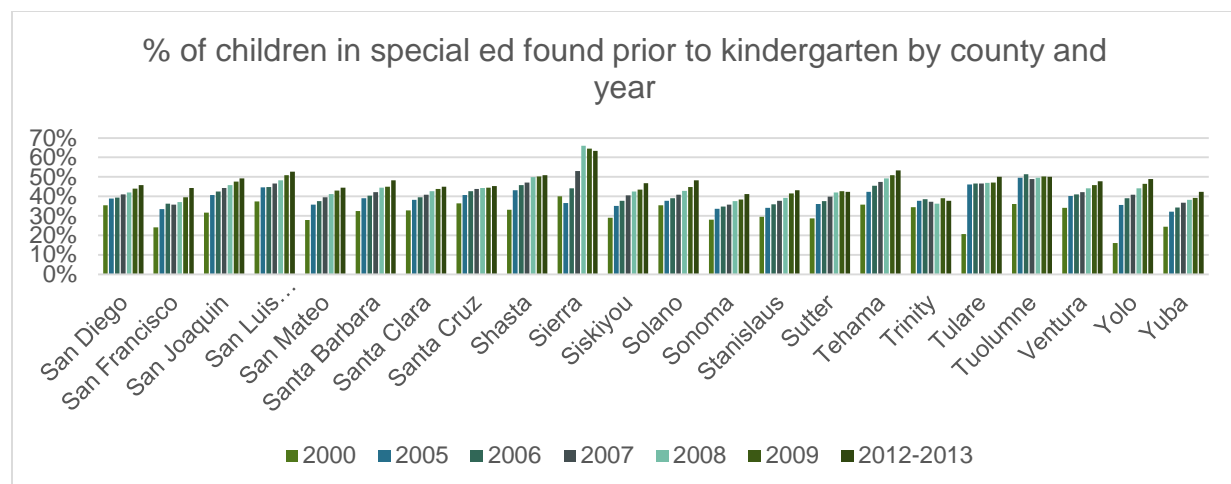
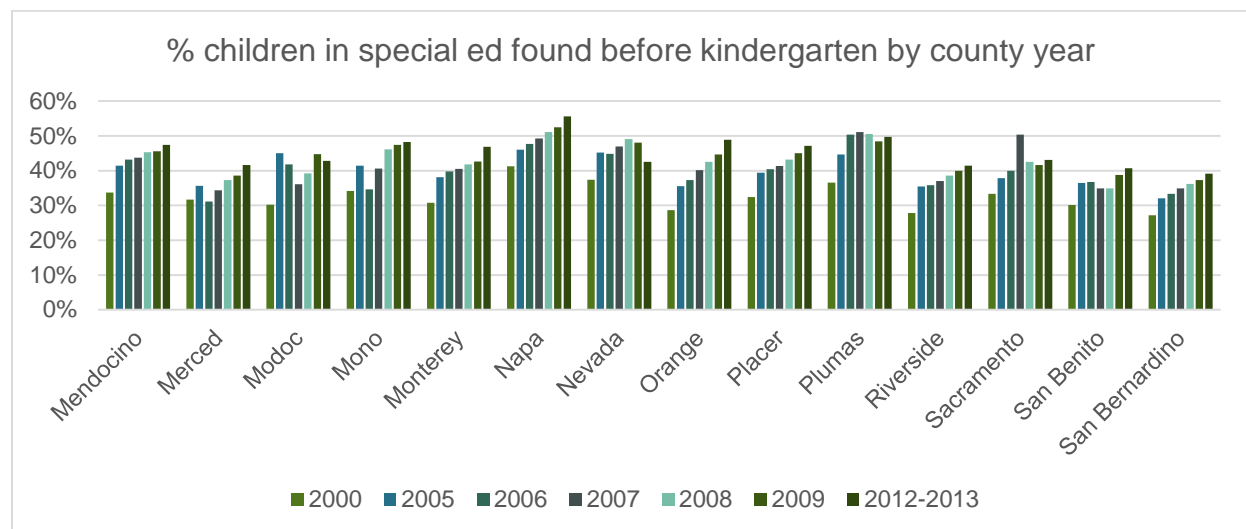
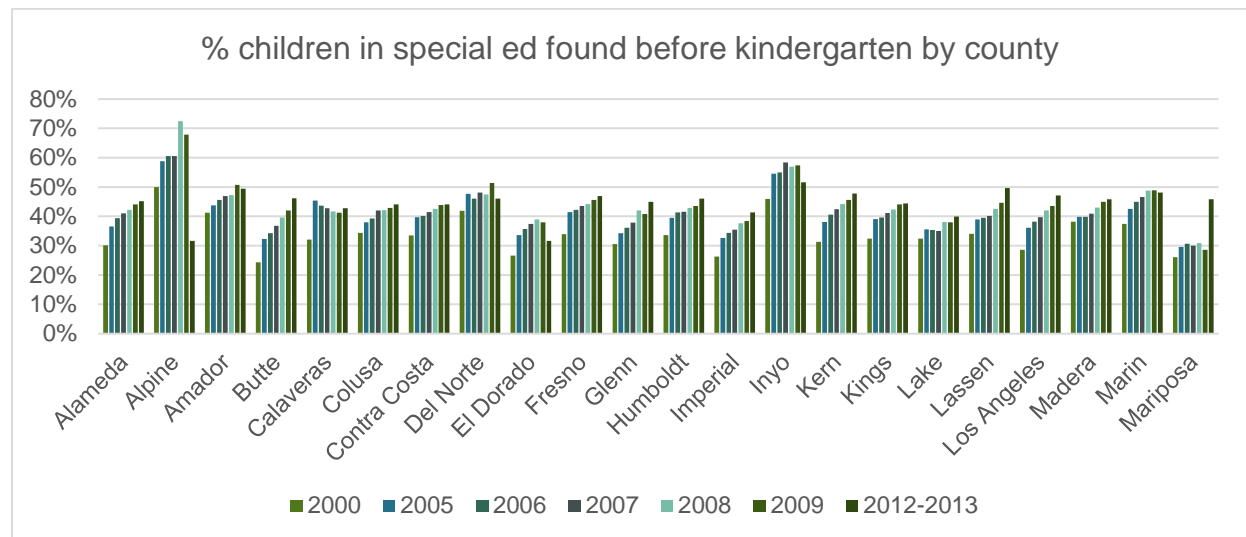
TABLE 1 Continued

	Description	Age Range	No. of Items	Administration Time	Psychometric Properties <sup>a</sup>	Scoring Method	Cultural Considerations	Purchase/Obtainment Information	Key References
Child Development Review-Parent Questionnaire (CDR-PQ)	Parent-completed questionnaire; professional-completed child development chart measures social, self-help, motor, and language skills	18 mo to 5 y	6 open-ended questions and a 26-item possible-problems checklist to be completed by the parent, followed by 99 items crossing the 5 domains, which may be used by the professional as an observation guide or parent-interview guide	10–20 min	Standardized with 220 children aged 3–4 y from primarily white, working class families in south St Paul, MN; sensitivity: 0.68 (low); specificity: 0.88 (moderate)	Risk categorization; parents' responses to the 6 questions and problems checklist are classified as indicating (1) no problem; (2) a possible problem; or (3) a possible major problem	English and Spanish versions available	Behavior Science Systems Inc	Iretton H. <i>Child Development Review Manual</i> . Minneapolis, MN: Behavior Science Systems; 2004
Denver-II Developmental Screening Test	Directly administered tool; designed to screen expressive and receptive language, gross motor, fine motor, and personal-social skills; results in risk category (normal, questionable, abnormal)	0–6 y	125	10–20 min	Normed on 2096 term children in Colorado; diversified in terms of age, place of residence, ethnicity/cultural background, and maternal education; sensitivity: 0.56–0.83 (low to moderate); specificity: 0.43–0.80 (low to moderate)	Risk categorization; pass or fail for each question, and these responses are compared with age-based norms to classify children as in the normal range, suspect, or delayed	English and Spanish versions available	Denver Developmental Materials: 800/419-4729; www.denverii.com	Frankenburg WK, Camp BW, Van Natta PA. Validity of the Denver Developmental Screening Test. <i>Child Dev</i> . 1971;42:475–485; Glascoe FP, Byrne KE, Ashford LG, Johnson KL, Chang B, Strickland B. Accuracy of the Denver-II in developmental screening. <i>Pediatrics</i> . 1992; 89:1221–1225
Infant Development Inventory	Parent-completed questionnaire; measures social, self-help, motor, and language skills	0–18 mo	4 open-ended questions followed by 87 items crossing the 5 domains	5–10 min	Studied in 86 high-risk 8-month-olds seen in a perinatal follow-up program and compared with the Bayley scales; sensitivity: 0.85 (moderate); specificity: 0.77 (moderate)	Risk categorization; delayed or not delayed	English and Spanish versions available	Behavior Science Systems Inc	Creighton DE, Sauve RS. The Minnesota Infant Development Inventory in the developmental screening of high-risk infants at 8 mo. <i>Can J Behav Sci</i> . 1988;20 (special issue):424–433
Parents' Evaluation of Developmental Status (PEDS)	Parent-interview form; designed to screen for developmental and behavioral problems needing further evaluation; single response form used for all ages; may be useful as a surveillance tool	0–8 y	10	2–10 min	Standardized with 771 children from diverse ethnic and socioeconomic backgrounds, including Spanish speaking; sensitivity: 0.74–0.79 (moderate); specificity: 0.70–0.80 (moderate)	Risk categorization; provides algorithm to guide need for referral, additional screening, or continued surveillance	English, Spanish, Vietnamese, Arabic, Swahili, Indonesian, Chinese, Taiwanese, French, Somali, Portuguese, Malaysian, Thai, and Laotian versions available	Ellsworth & Vandemeer Press LLC: 888/729-1697; www.pedstest.com	
Language and cognitive screening tools Capute Scales (also known as Cognitive Adaptive Test/Clinical Linguistic Auditory Milestone Scale [CAT/CLAMS])	Directly administered tool; measures visual-motor/problem solving (CAT), and expressive and receptive language (CLAMS); results in developmental quotient and age equivalent	3–36 mo	100	15–20 min	Standardized on 1055 North American children aged 2–36 mo; correlations high with Bayley Scales of Infant Development; sensitivity: 0.21–0.67 in low-risk population (low) and 0.05–0.88 in high-risk populations (low to high); specificity: 0.95–1.00 in low-risk population (high) and 0.82–0.98 in high-risk populations (moderate to high)	Quantitative (developmental age levels and quotient)	English, Spanish, and Russian versions available	Paul H. Brookes Publishing Co	Voigt RG, Brown FR III, Fraley JK, et al. Concurrent and predictive validity of the cognitive adaptive test/clinical linguistic and auditory milestone scale (CAT/CLAMS) and the Mental Developmental Index of the Bayley Scales of Infant Development. <i>Clin Pediatr (Phila)</i> . 2003;42: 427–432



Communication and Symbolic Behavior Scales-Developmental Profile (CSBS-DP); Infant Toddler Checklist	Standardized tool for screening of communication and symbolic abilities up to the 24-mo level; the Infant Toddler Checklist is a 1-page parent-completed screening tool	6–24 mo	24	5–10 min	Standardized on 2188 North American children aged 6–24 mo; correlations: 0.39–0.75 with Mullen Scales at 2 y of age; sensitivity: 0.76–0.88 in low- and at-risk children at 2 y of age (moderate); specificity: 0.82–0.87 in low- and at-risk children at 2 y of age (moderate)	Risk categorization (concern/no concern)	English version available	Paul H. Brookes Publishing Co	Wetherby AM, Prizant BM. <i>Communication and Symbolic Behavior Scales: Developmental Profile</i> . Baltimore, MD: Paul H. Brookes Publishing Co; 2002
Early Language Milestone Scale (ELM Scale-2)	Assesses speech and language development from birth to 36 mo	0–36 mo	43	1–10 min	Small cross-sectional standardization sample of 191 children; 235 children for speech intelligibility item; sensitivity: 0.83–1.00 in low- and high-risk populations (moderate to high); specificity: 0.68–1.00 in low- and high-risk populations (low to high)	Quantitative (age equivalent, percentile, standard score)	English version available	Pro-Ed Inc: 800/897-3202; <a href="http://www.proedinc.com">www.proedinc.com</a>	Coplan J. <i>Early Language Milestone Scale</i> . Austin, TX: Pro-Ed Inc; 1993; Coplan J, Gleason JR. Test-retest and interobserver reliability of the Early Language Milestone Scale, second edition. <i>J Pediatr Health Care</i> . 1993;7:212–219
Motor screening tools Early Motor Pattern Profile (EMPP)	Physician-administered standard examination of movement, tone, and reflex development; simple 3-point scoring system	6–12 mo	15	5–10 min	Single published report of 1247 high-risk infants; sensitivity: 0.87–0.92 (moderate to high); specificity: 0.98 (high)	Risk categorization (normal/suspect/abnormal)	English version available	See key references	Morgan AM, Aldag JC. Early identification of cerebral palsy using a profile of abnormal motor patterns. <i>Pediatrics</i> . 1996;98:692–697
Motor Quotient (MQ)	Uses simple ratio quotient with gross motor milestones for detecting delayed motor development	8–18 mo	11 total milestones; 1 per visit	1–3 min	Single published report of 144 referred children; sensitivity: 0.87 (moderate); specificity: 0.89 (moderate)	Quantitative (developmental age levels and quotient)	English version available	See key references	Capute AJ, Shapiro BK. The motor quotient: a method for the early detection of motor delay. <i>Am J Dis Child</i> . 1985;139:940–942
Autism screening tools Checklist for Autism in Toddlers (CHAT)	Parent-completed questionnaire or interview and directly administered items designed to identify children at risk of autism from the general population	18–24 mo	14 (No. of questions/items [averaged])	5 min	Original standardization sample included 41 siblings of children with autism and 50 controls 18 mo of age in Great Britain; 6-y follow-up on 16 235 children validated using ADI-R and ICD-10 criteria resulted in low sensitivity, high specificity; revised version in process of being normed ("Q-CHAT"); sensitivity: 0.38–0.65 (low); specificity: 0.98–1.0 (high)	Risk categorization (pass/fail)	English version available	Public domain: <a href="http://www.nas.org.uk/profess/CHAT">www.nas.org.uk/profess/CHAT</a>	Baird G, Charman T, Baron-Cohen S, et al. A screening instrument for autism at 18 mo of age: a 6-y follow-up study. <i>J Am Acad Child Adolesc Psychiatry</i> . 2000;39:694–702; Baron-Cohen S, Allen J, Gillberg C. Can autism be detected at 18 mo? The needle, the haystack, and the CHAT. <i>Br J Psychiatry</i> . 1992;161:839–843
Modified Checklist for Autism in Toddlers (M-CHAT)	Parent-completed questionnaire designed to identify children at risk of autism from the general population	16–48 mo	23 (No. of questions/items [averaged])	5–10 min	Standardization sample included 1293 children screened, 58 evaluated, and 39 diagnosed with an autistic spectrum disorder; validated using ADI-R, ADOS-G, CARS, DSM-IV; sensitivity: 0.85–0.87 (moderate); specificity: 0.93–0.99 (high)	Risk categorization (pass/fail)	English, Spanish, Turkish, Chinese, and Japanese versions available	Public domain: <a href="http://www.firstsigns.com">www.firstsigns.com</a>	Dumont-Mathieu T, Fein D. Screening for autism in young children: the Modified Checklist for Autism in Toddlers (M-CHAT) and other measures. <i>Ment Retard Dev Disabil Res Rev</i> . 2005;11:253–262; Robins DL, Fein D, Barton ML, Green JA. The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. <i>J Autism Dev Disord</i> . 2001;31:131–144

## H. Rates of Finding Children Pre-K



## **I. Best Practices/Case Studies**

When this project began, the focus of interviews of county officials was on the cost of providing services. The idea was that counties that successfully “shifted the curve” (see Appendix J) were potentially saving money in the long run by doing so. The data was not readily available, or the data available was not particularly meaningful. However, the process of attempting to gather that information yielded illuminating insights about how county’s systems worked, and how developmental screening was a large part of finding and serving children earlier.

### *Summary of Best Practice Counties*

Each county faces different types of challenges and therefore approaches early identification and intervention in different ways. First 5 Association believes the elements of the Help Me Grow system are critical in improving early identification. Keeping that structure in mind, best practices include:

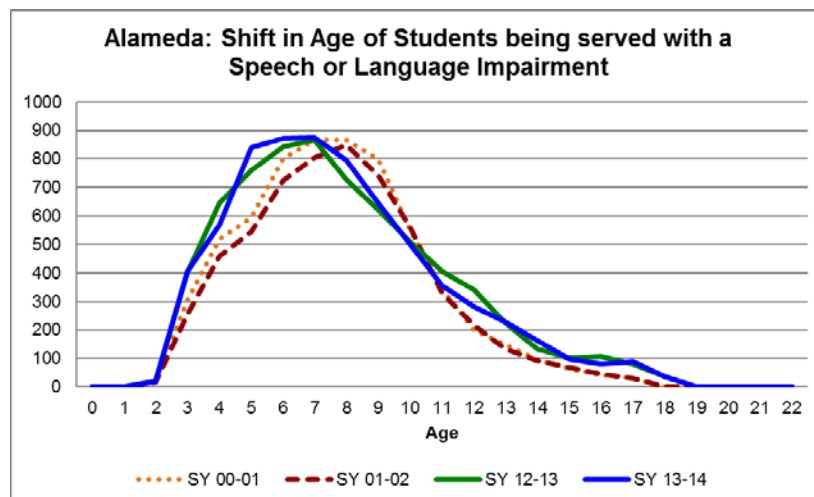
1. **Child Health Care Provider Outreach**
  - a. San Diego partners with hospitals to increase screening efforts among pediatricians.
  - b. San Joaquin trains pediatrician on developmental tools.
2. **Community Outreach**
  - a. Orange County (as well as others) organizes Health Fair events that provide developmental screenings at the event.
  - b. Orange County pays for school readiness nurses at each school district.
  - c. Alameda mails ASQ’s to parents with concerns about their child.
3. **Centralized Telephone Access Point**
  - a. All Help Me Grow counties have a centralized telephone access point.
  - b. San Diego has a phone line for parents with developmental concerns for each region within San Diego.
4. **Data Collection**
  - a. San Francisco School District uses a statistician to collect information on special education.
  - b. All Help Me Grow counties collect data through the Help Me Grow platform.



## Alameda<sup>34</sup>

First 5 Alameda's strategy for serving children with developmental concerns is the "Healthy Child Develop Initiative." Alameda was an early adopter of the Help Me Grow system, beginning in 2005, shortly after Orange County – and this affiliation has been the mechanism for the Initiative. According to First 5 Alameda's website, "If a child has a developmental concern or a parent is worried about their child, we partner with families to help them understand their child's needs and get connected to services and supports." Through Help Me Grow, if any parent that calls with a concern about a child's development and the child has not been screened, Alameda will mail a copy of an ASQ screening tool for the child's specific age. The parent can fill out the ASQ and mail it back to their Help Me Grow Coordinator. The Help Me Grow Coordinator can then make a recommendation to the parent based on the results and the family navigation team plays a critical role in ensuring that the family actually connects to the recommended services. This "care coordination" approach is critical for helping families receive the assistance they need.

The call center received over 1,500 calls in 2013, a 16 percent increase from the previous year, indicating that communities are becoming more aware of the centralized telephone access point.

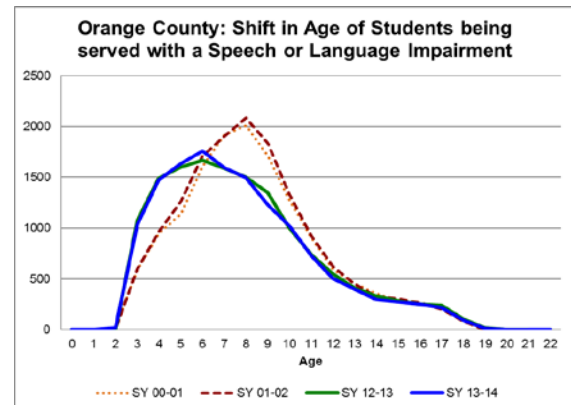


<sup>34</sup> Information on Alameda County provided by: Loren Farrar, Help Me Grow Administrator, as well as the Help Me Grow Alameda and First 5 Alameda websites.

## Orange County<sup>35</sup>

**Orange County has a stated goal to identify children at age 3 or 4, early enough to where they are already improved and caught up by kindergarten.** In Orange County, each school district has a school readiness nurse focused on screening kids in preschool and kindergarten. These nurses use ASQ, a screening tool used to identify a child not meeting the norms for child development. Children are screened *annually* by school districts from 3 years old until kindergarten.

Looking at the speech and language chart for Orange County, approximately the same number of children are being served, but children are being served earlier (which may prevent the need for later services). Of the charts created for this report, Orange County had the clearest change from serving children older in 2000, to serving children earlier in 2014.



**Outreach to Communities:** Orange County puts on Health Fair events that offer free developmental screenings and promotes awareness of services available to parents and children with special needs. Orange County partners with organizations like Mommy & Me and Learning Links, which serve children with special needs and provide preventative care for parents with concerns about their child's development. These are the types of organizations that Help Me Grow would refer a parent to once a concern is raised.

Orange County has also increased education to parents specifically – providing 4-6 week free parent class through school districts.

County representatives say that Help Me Grow is core to Orange County's success in finding and serving children earlier. Orange County has also been a model, or "mentor," for other counties, as it was the first to replicate the Help Me Grow Model and has the longest experience. It works with other counties to share experiences in implementation planning. Orange County also partners with other counties on initiatives like developmental screening.

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<sup>35</sup> Orange County information primarily provided by: Dian Milton and Alyce Mastrianni of the Children and Families Commission of Orange County. Also, other information was from the Children and Families Commission of Orange County website (<http://occhildrenandfamilies.com/>), and the Help Me Grow Orange County website (<http://www.helpmegrowoc.org/>).

## San Diego<sup>36</sup>

San Diego offers care coordination through Healthy Development Services Project.

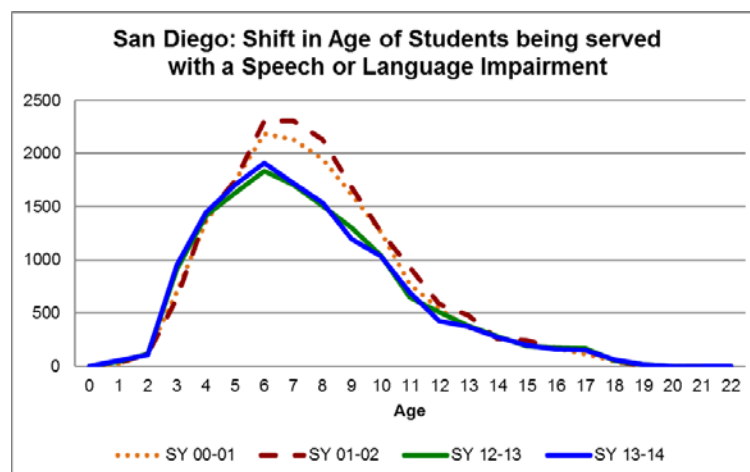
Infants and children grow and develop differently. It is important for parents to know their children are growing and reaching important milestones. First 5 San Diego's Healthy Development Services (HDS) provides no cost developmental checkups for children from birth through 5 years of age, and connects children and families to needed services. First 5 San Diego works with some of the best community agencies in San Diego County to ensure parents and other caregivers have the help they need to promote their children's developmental and behavioral health.

First 5 San Diego's HDS program provides the following services throughout San Diego County:

- **Development** check ups, classes, parent coaching and therapy
- **Behavior** check ups, parent coaching and therapy
- **Speech and Language** check ups, classes and therapy
- **Vision** check ups and help accessing free or discounted eyeglasses
- **Hearing** tests and referrals to a specialist if needed
- **Care Coordination** is provided to help families connect to and utilize First 5 San Diego's Healthy Development Services
- **Parent Education, Support and Empowerment** workshops and referrals
- **Understanding Your Child's Behavior** workshops and referrals
- **Referrals** to other services are provided if needed.

Source: <http://first5sandiego.org/healthy-development-services-providers/>

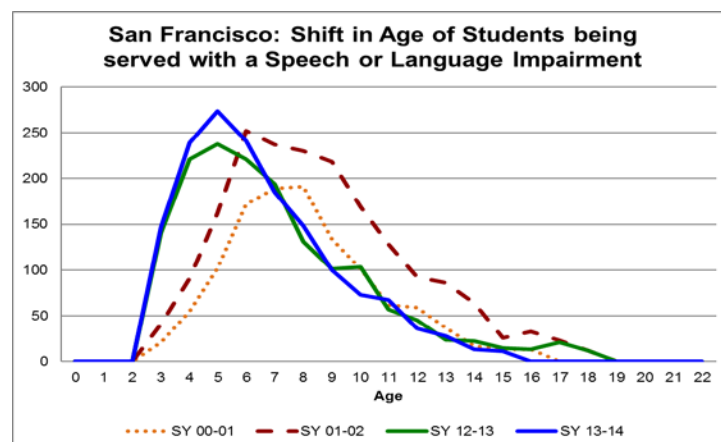
While San Diego is **not** a Help Me Grow affiliate, the same four components are in place in some way. For example, San Diego doesn't have one phone access point for the entire county, but there is one phone access point per region (6 regions). San Diego faces unique challenges with a lack of bilingual speech therapists when also highly needed.



<sup>36</sup> Information on San Diego per First 5 San Diego website, as well as through an interview with Gloria Corral, Assistant Executive Director First 5 San Diego.

## San Francisco<sup>37</sup>

San Francisco County has the benefit of having one school district: San Francisco Unified School District. One notable practice that San Francisco is doing better than any other county in collecting more data on special education children. As seen in the speech and language chart, San Francisco has made a lot of progress as well in finding children with speech or language impairments and serving them earlier. For this project, San Francisco was the only county with the ability to provide data on the age a child entered special education, and the age a child left special education, as well as weekly time served (intervention) in minutes. Recall that speech or language impairments, unlike autism or downs syndrome, is a disability that has the chance of correcting the problem. San Francisco's data is important because it allows for the ability to analyze characteristics of children being served by age.



San Francisco's "Preschool for All" program is likely a large contributor to the county's success in serving children with special needs earlier (see chart above). This initiative was funded through Proposition H, which passed in 2004.<sup>38</sup> The county has also been making great strides in developmental screenings. *"Through contributions from public health nurse consultants, mental health consultants, trained early childhood education providers, and trained FRC staff, a total of 9,091 health and developmental screenings were conducted for children ages 0 to 5."* – First 5 Annual Report.

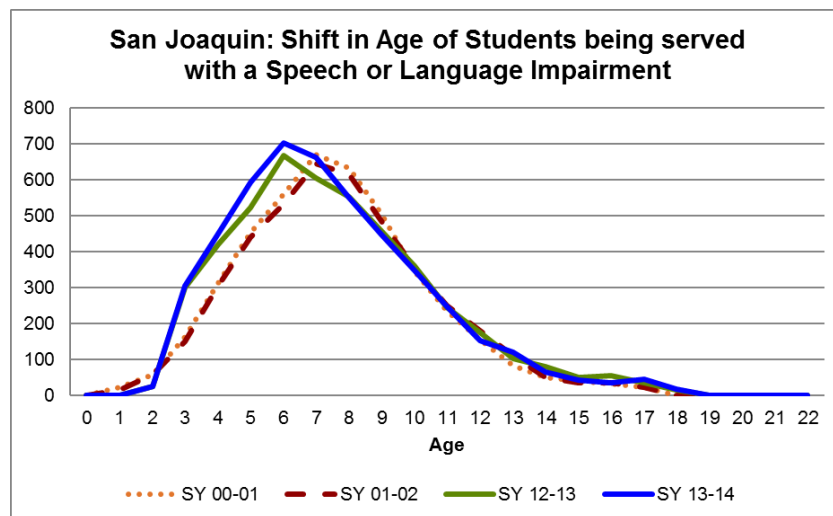
<sup>37</sup> Information on San Francisco was provided by: D.J. Ervin, Senior Statistician at SFUSD, as well as First 5 San Francisco and Help Me Grow San Francisco.

<sup>38</sup> It is important to note that the capacity of preschools is an issue, as there are waitlists for preschools (anecdotal).

## San Joaquin<sup>39</sup>

First 5 San Joaquin has also used the HMG model to coordinate its services for children with developmental delays, and has been focused on ensuring that these services are covered with public funding. Screening costs are largely covered through funding from CalWorks, California's Temporary Aid to Dependent Families or TANF. San Joaquin is a great example of the "health care provider outreach" component. The county focusing on screening through pediatricians at two health clinics serving low-income children – a "Federally Qualified Health Center" (FQHC) and a "FQHC-Look Alike."<sup>40</sup> Around 20 pediatricians have been trained on screening, and Help Me Grow trainers plan on training 10-20 more. This is a new program and they plan on collecting data on how many pediatricians are trained, and the outcomes of those trainings.

**Screenings:** First 5 San Joaquin screened over 2,500 children last year, 800 of which were through preschools. San Joaquin also collected data on the age of children screened, which means that each year the county will be able to determine their impact in early identification.



<sup>39</sup> San Joaquin information was provided primarily by Lani Schiff-Ross, Executive Director of First 5 San Joaquin, as well as from First 5 and Help Me Grow San Joaquin websites.

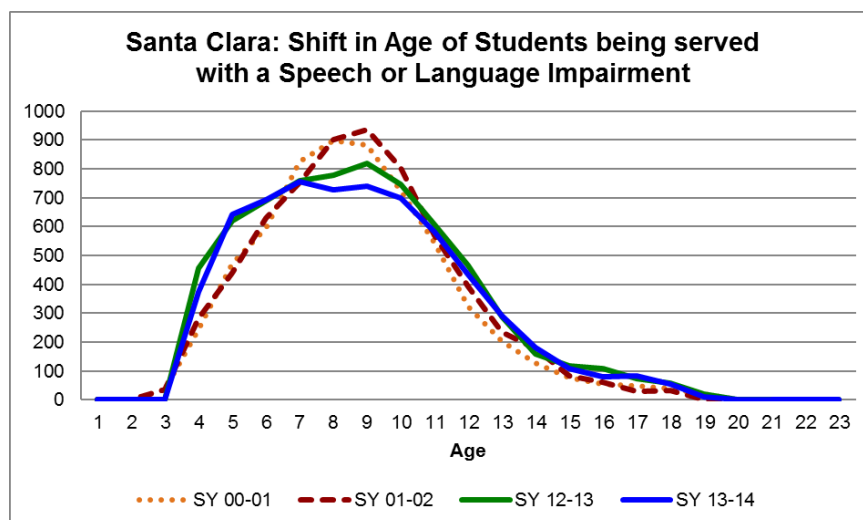
<sup>40</sup> Federally qualified health centers (FQHCs) include all organizations receiving grants under Section 330 of the Public Health Service Act (PHS). FQHCs qualify for enhanced reimbursement from Medicare and Medicaid, as well as other benefits. FQHCs must serve an underserved area or population, offer a sliding fee scale, provide comprehensive services, have an ongoing quality assurance program, and have a governing board of directors. Certain tribal organizations and FQHC Look-Alikes (an organization that meets PHS Section 330 eligibility requirements, but does not receive grant funding) also may receive special Medicare and Medicaid reimbursement.

## Santa Clara

According to First 5 Santa Clara's website:

*In January 2013, Supervisor Ken Yeager identified the need for more universal and more frequent developmental screenings for young children during their well-child pediatric visits. Supervisor Yeager asked that Santa Clara Valley Medical Center (SCVMC) and Valley Health Center (VHC) clinics perform routine developmental screenings for all children. The MHSA INN-01 Early Childhood Universal Screening Project and FIRST 5's funded Developmental Screening Project were preexisting projects implemented in 2010. Both projects were combined to support the county-wide effort under the Universal Developmental Screening Project.*

First 5 invested a total of \$593,402 in the Project last fiscal year, with \$120,065 of that total leveraged through county mental health department funding.<sup>41</sup>



For more on Santa Clara's universal screening initiative, see:

<http://www.first5kids.org/sites/default/files/download/Universal%20Developmental%20Screening%20Overview%209-3-14.pdf>

First 5 Association should research what factors led to the policy window (other than the leadership of the Supervisor) that led to funding for universal screening in Santa Clara.

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<sup>41</sup> First 5 California Annual Report, 2014

## *Other States*

### **Washington (Help Me Grow Affiliate State)**

#### *Universal Developmental Screening*

Washington created a “Strategic Framework for Universal Developmental Screening for the State of Washington.”<sup>42</sup> First 5 might benefit from learning from Washington’s implementation of that framework. In Washington, there appears to be a high level of support for universal screening, and a plan in place to help promote it. Furthermore, there is a legislative initiative that may be able to help ensure screenings as it comes with funding for pediatricians.

#### *Washington Universal Screening Advocacy:*

Per a Washington State Department of Health press release: “Medicaid Coverage for Primary Care Providers Be prepared this legislative session for some exciting discussions around UDS. Senator Frockt and Representative Riccelli are sponsoring companion Senate/House bills stating that the Health Care Authority shall require universal developmental screening and provider payment for autism and developmental delays as recommended by the Bright Futures guidelines (subject to the availability of funds). The bill has a roughly \$4.6m fiscal impact for the biennium. The WA Chapter of the American Academy of Pediatrics advocates that the research around the benefits of early identification and treatment of developmental delays is clear.”<sup>43</sup>

### **Other**

New York is another state pushing for Universal Screening through legislative measures. First 5 Association should watch to see if any legislative action on developmental screenings happen in New York, or other states around the country.

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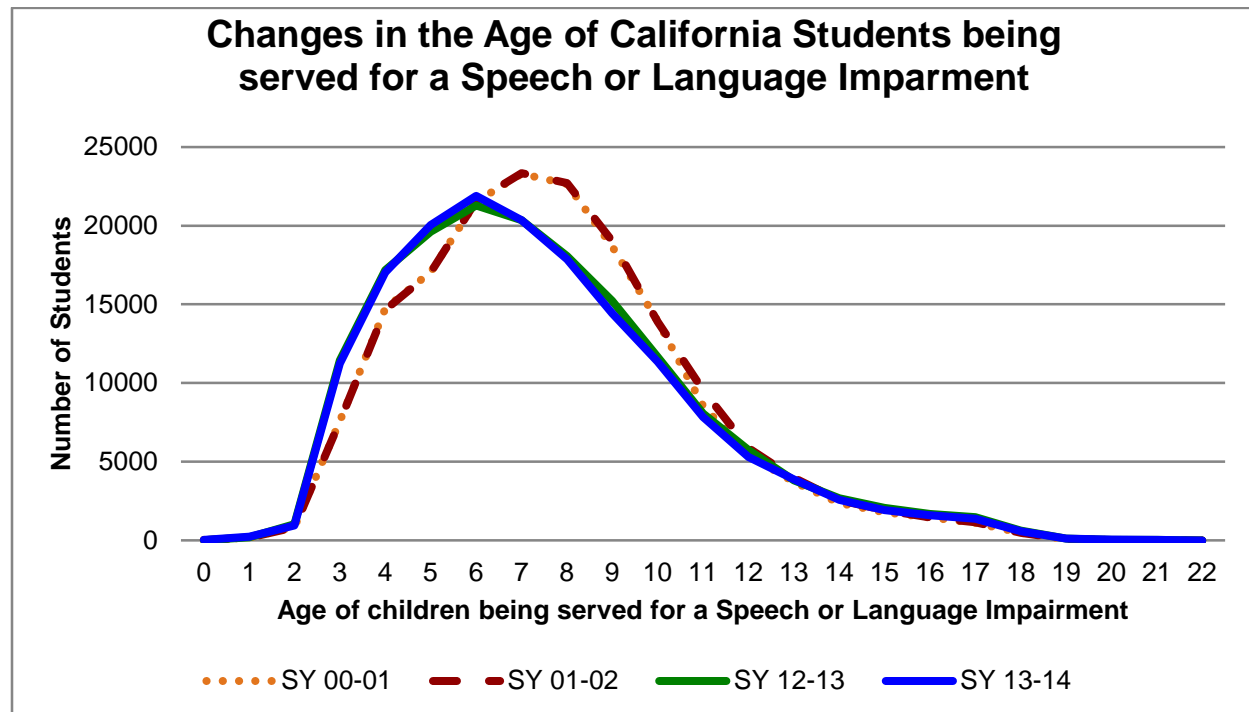
<sup>42</sup> [http://medicalhome.org/4Download/wg\\_devscreen/framework.pdf](http://medicalhome.org/4Download/wg_devscreen/framework.pdf)

<sup>43</sup> <http://www.doh.wa.gov/Portals/1/Documents/Pubs/910-919-UDS-E-updateWinter2015.pdf>

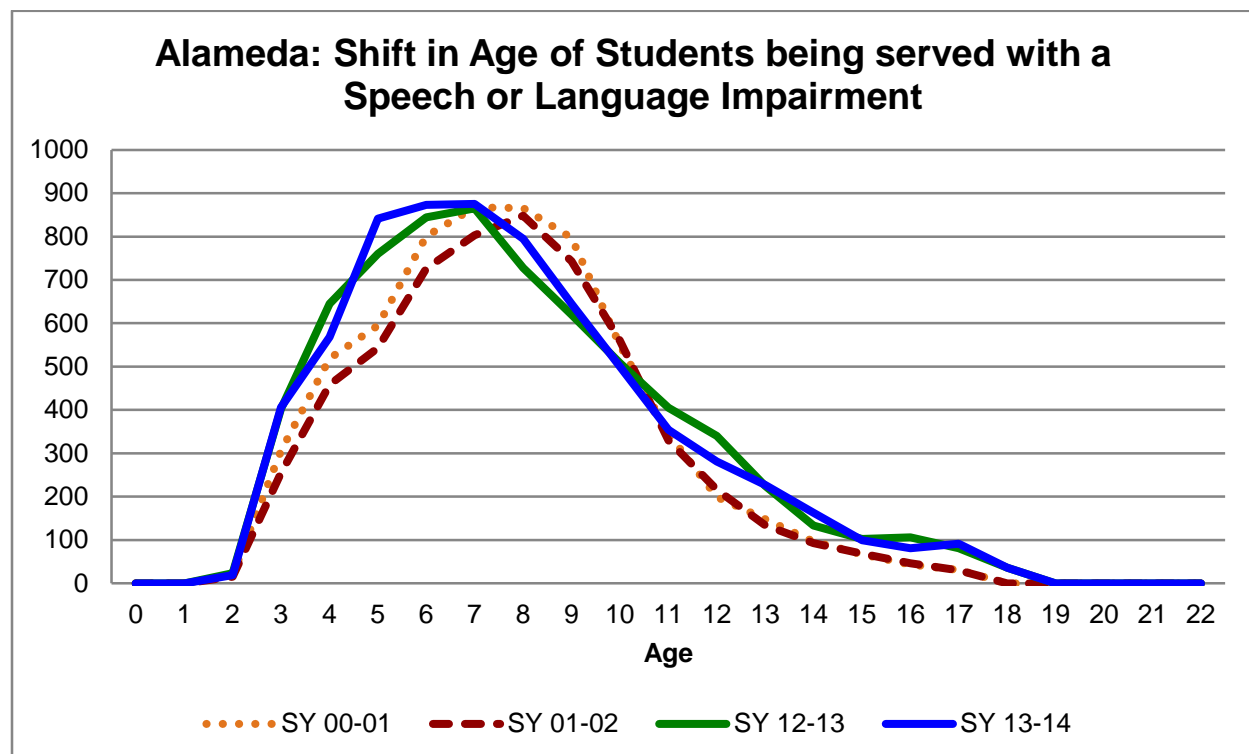


## J. Speech and Language Impairment Graphs by County

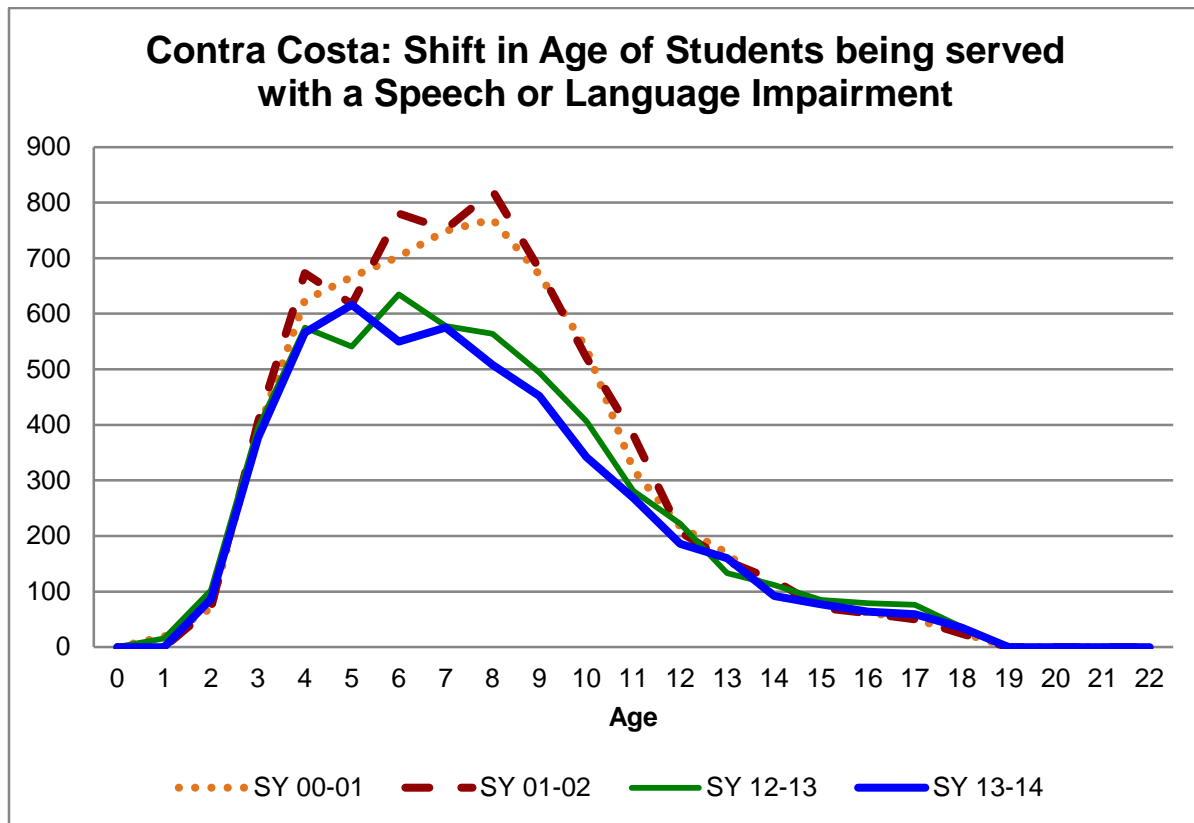
### State



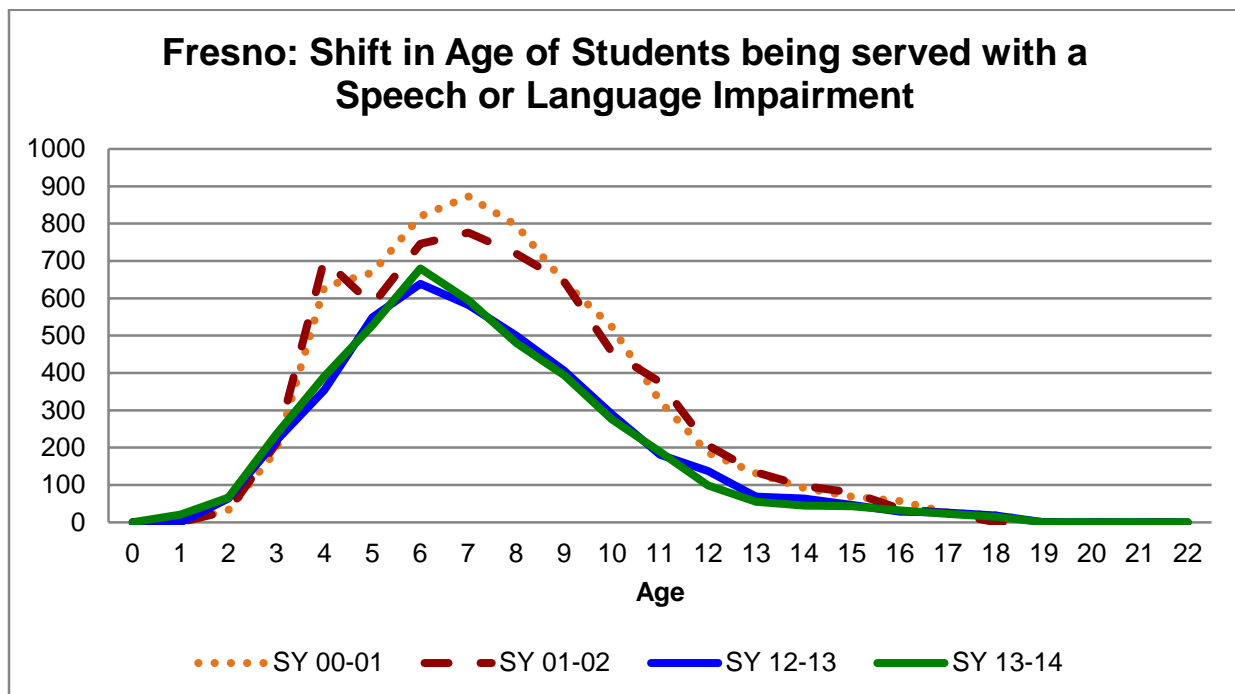
### Alameda



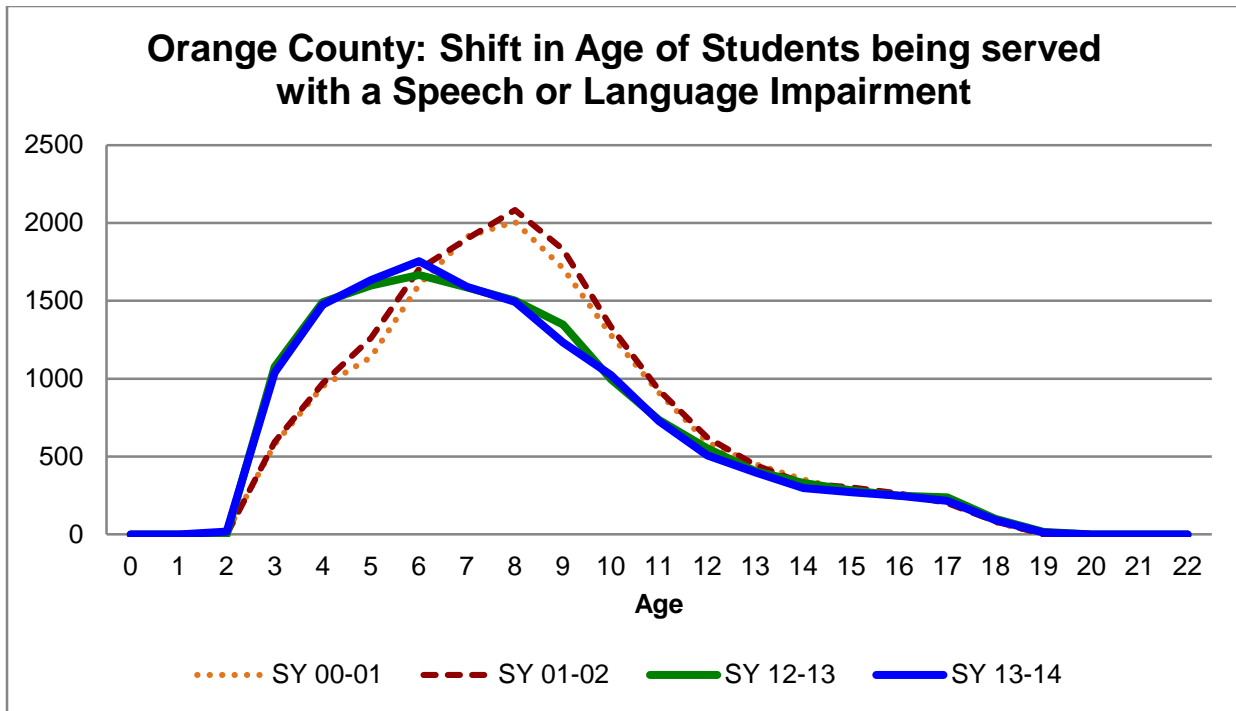
## Contra Costa



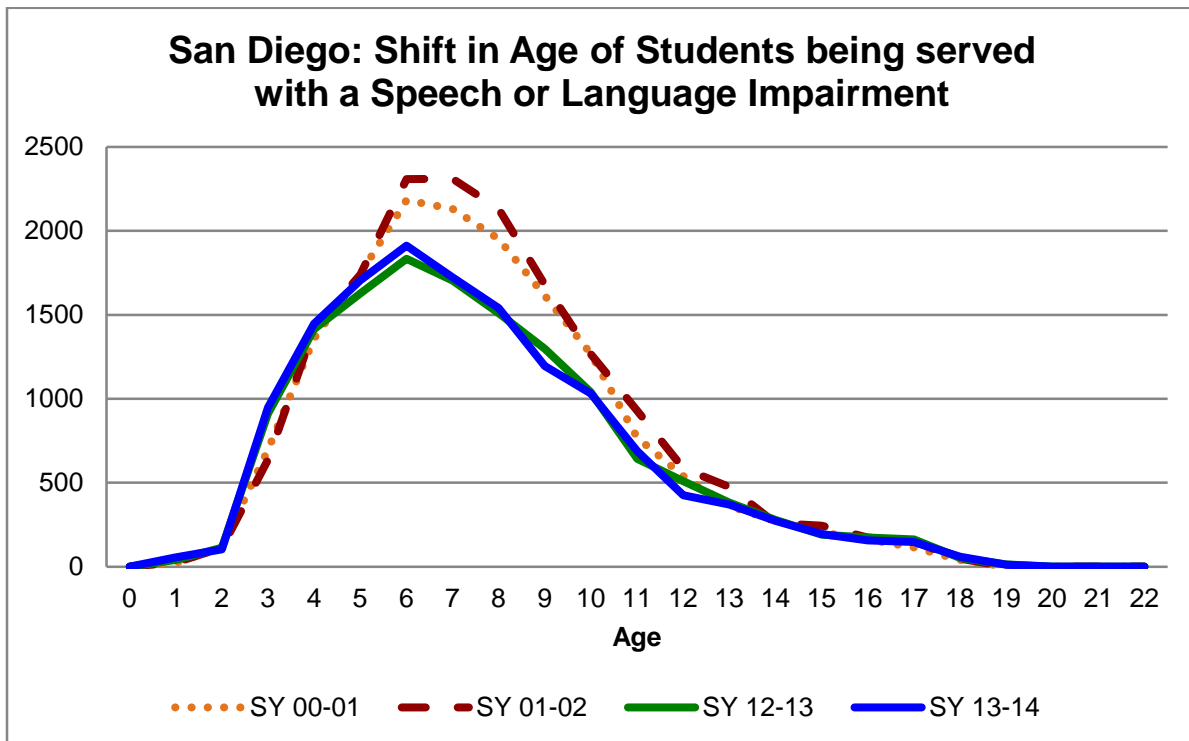
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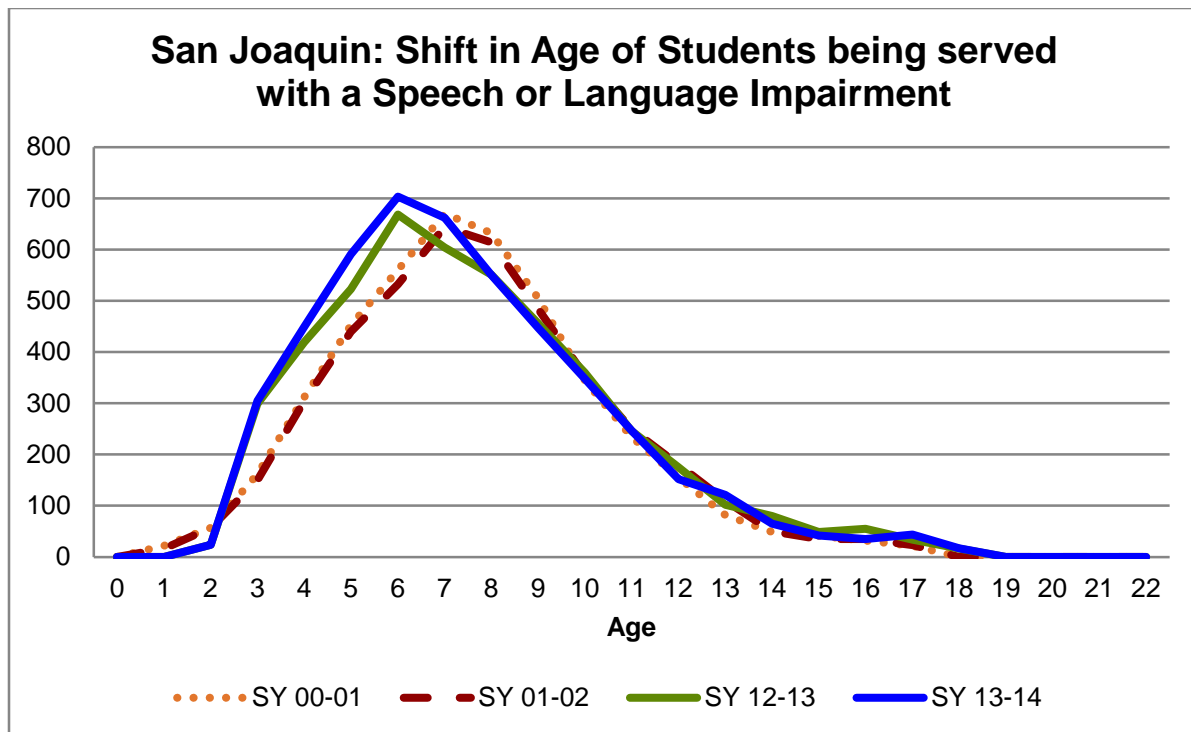
## Orange



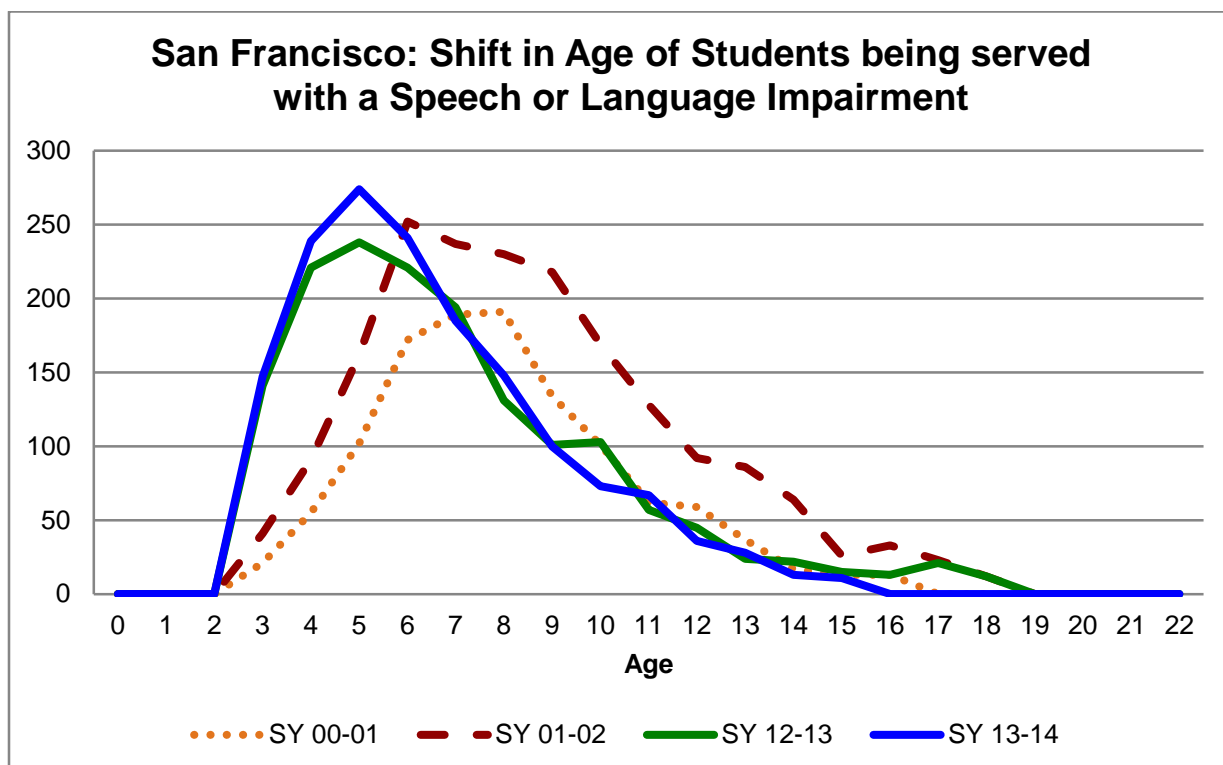
## San Diego



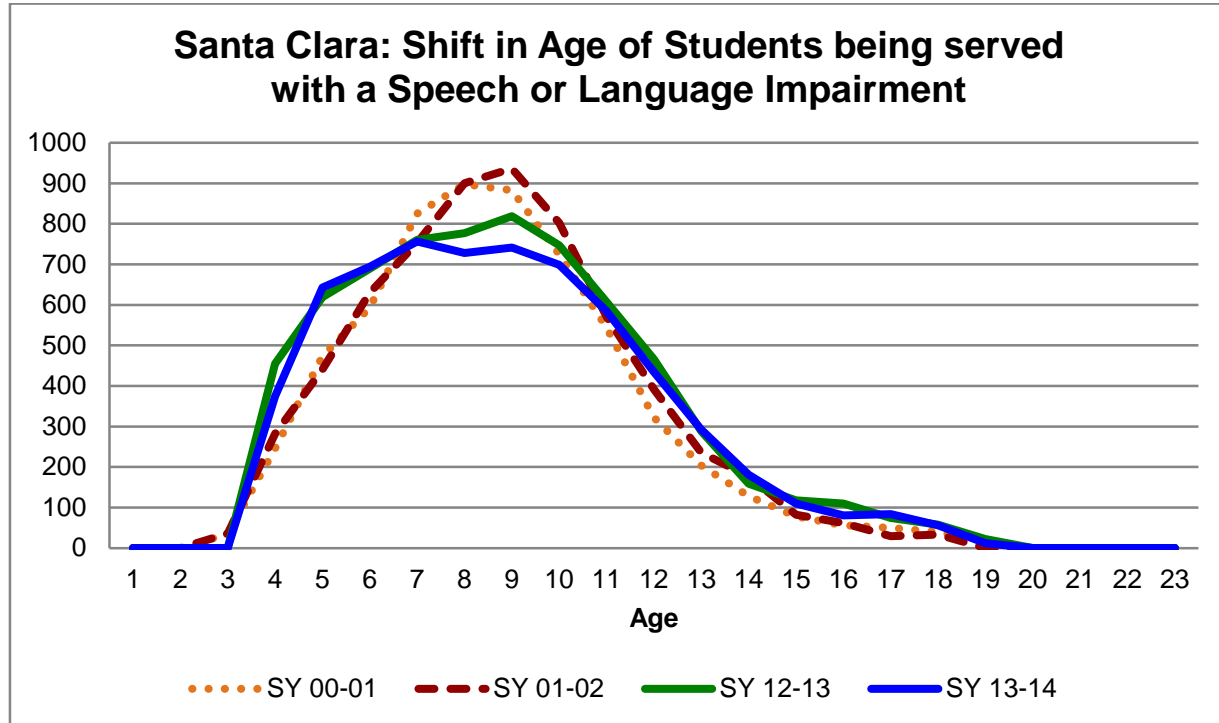
## San Joaquin



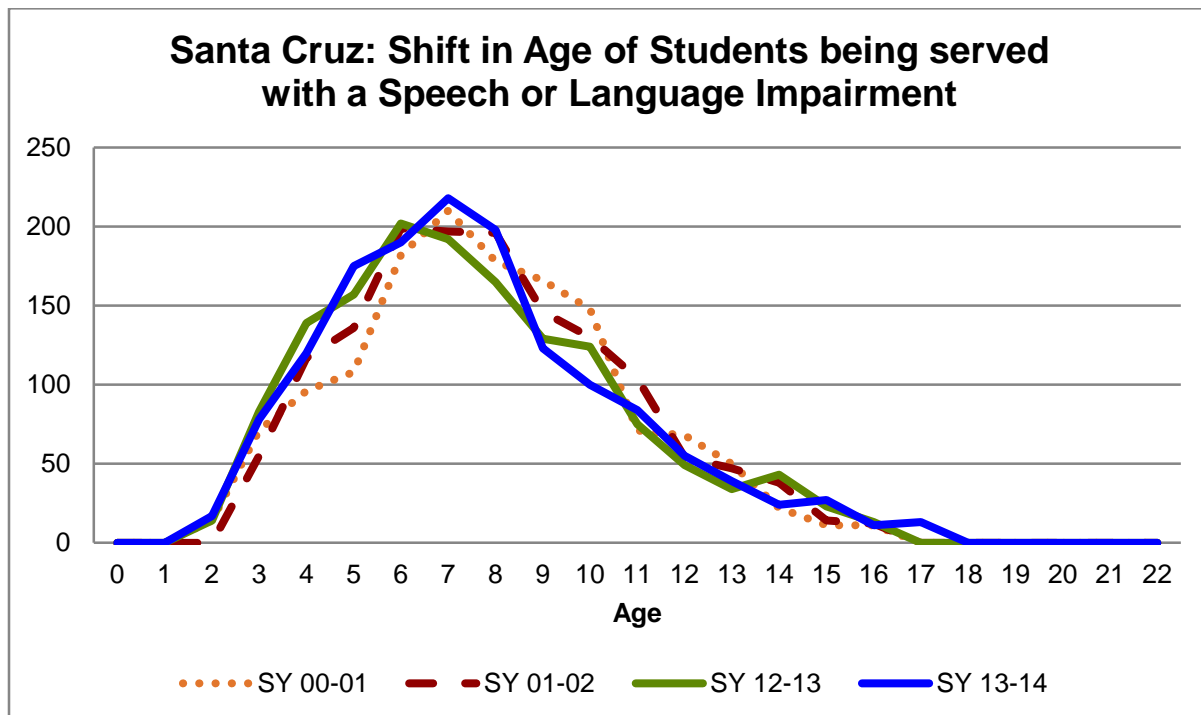
## San Francisco



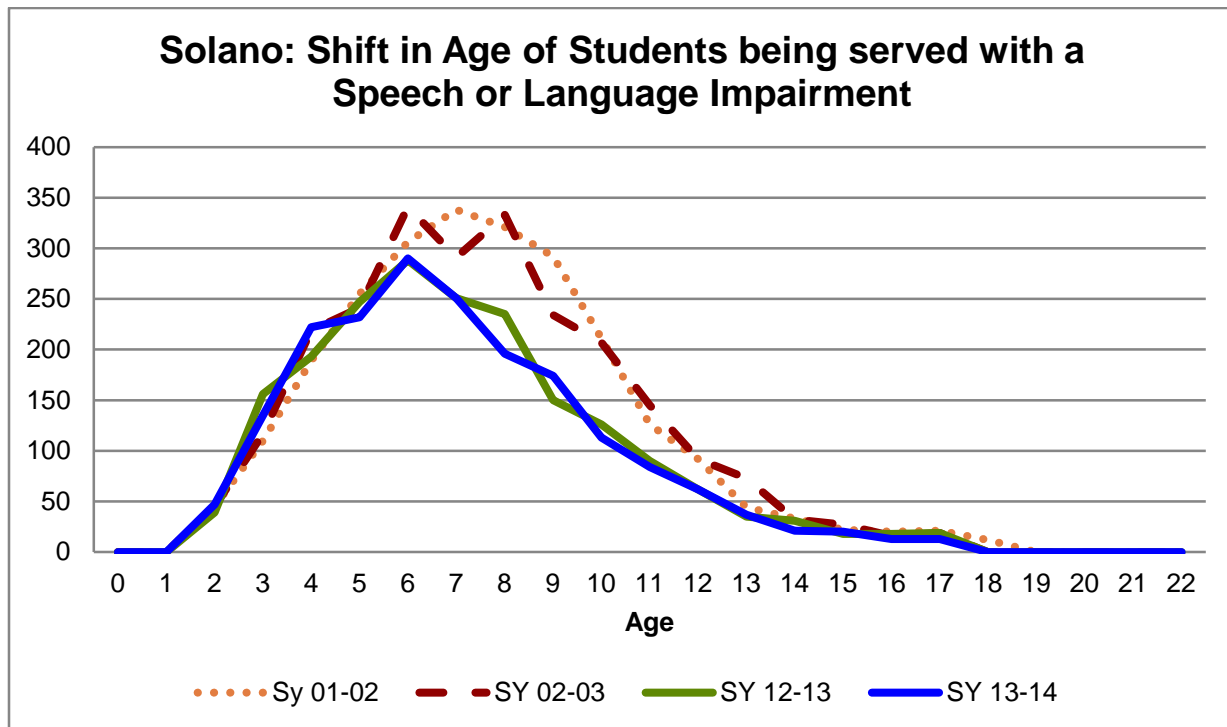
## Santa Clara



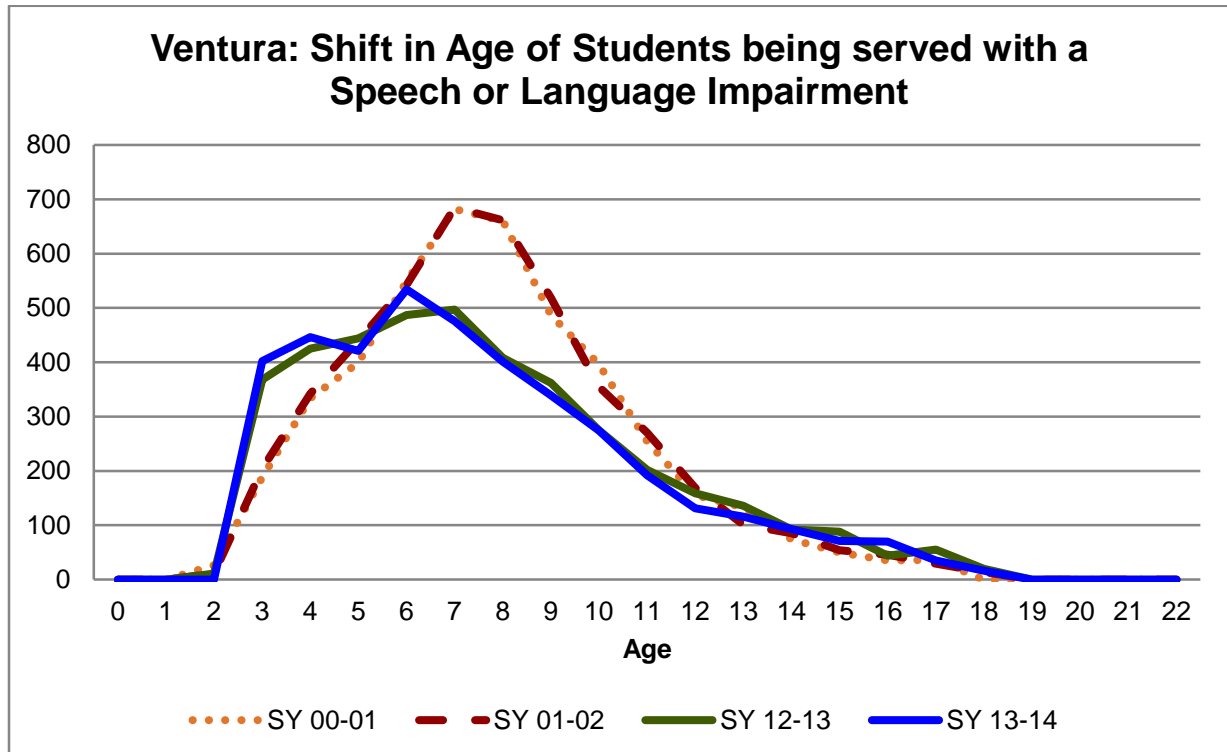
## Santa Cruz



## Solano



## Ventura



## K. Help Me Grow California Report



# HelpMeGrow Affiliate States

# California



# Our System

In 2005, with the launch of Help Me Grow Orange County, California became the second state beyond Connecticut to implement Help Me Grow. Through the support of the Kellogg Foundation, California became a Help Me Grow replication state in 2011 and developed a consortium comprised of Orange, Alameda and Fresno counties, in collaboration with California Project LAUNCH, to implement HMG across the state. The vision of HMG CA is that **all children in California achieve their optimal development and are supported by a system of developmental and behavioral resources in their communities.**

In December 2012, *Help Me Grow* California created a Learning Community of counties and/or regional consortia interested in *HMG* to engage and cultivate counties and regions interested in becoming *HMG* affiliates. To date, eighteen counties participate and are represented by stakeholder groups such as early childhood, mental health, special education, early intervention and health. *HMG* California is in the process of expanding the Learning Community.

## Affiliate since 2011

## Program Manager

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## Organization

WestEd Center for  
Prevention and Early Intervention

## Organizing Entity

California Statewide  
Screening Collaborative

In 2013, HMG California developed an affiliation application process for



Learning Community counties interested in adopting the *Help Me Grow* model. To date, four new counties have submitted applications and have been approved as affiliates: Ventura, Solano, San Francisco and San Joaquin. Additional counties are in the process of preparing applications for submissions.

In 2013, as a result of participating in the Help Me Grow National Replication Project, HMG California embarked on the development of a business plan to support expansion of HMG across the state and establish a state-level infrastructure to support HMG affiliates. As a result, HMG CA will focus on the following four key roles to achieve its mission to grow and sustain the Help Me Grow model in California by cultivating and supporting HMG county affiliates, demonstrating the impact of the Help Me Grow model and serving as a statewide voice for systems and services that promote early childhood development:

1. Provide Support to *HMG* County Affiliates
2. Promote Sustainability and Growth of *HMG* Model
3. Support the Collection and Analysis of Data Statewide
4. Conduct Advocacy & Policy Activities

Through these activities, *HMG-CA* will serve as a statewide organizing entity that guides the development of local affiliates across the state; ensures effective implementation and fidelity to the *HMG* model; provides leadership on state policy issues; and ensures that *HMG* is embedded in efforts to strengthen early childhood systems across the State. *HMG* California is currently seeking funding to implement the activities outlined in the Business Plan.

## How Our State's Strengths Helped Build *Help Me Grow* California

Critical to California's investments in early childhood was the 1998 approval of Proposition 10 by voters, which provided ongoing funds for early childhood efforts for children, ages birth to five, through the First 5 California Commission (First 5 CA) and 58 county commissions. Since its creation, First 5 CA and most First 5 County Commissions have championed and invested in early identification and linkages to developmental and behavioral supports and services for children and their families. First 5 is a key partner in each of the Learning Community counties. Each of our eight local *HMG* affiliates benefit from direct involvement and/or financial support from their First 5 County Commissions.

The *Help Me Grow* system has been gaining recognition across

California as a successful system for early identification, referral and care coordination of children at risk for developmental and behavioral problems. As a result, *HMG CA* has been involved in the planning, named as a promising practice or has been incorporated into program planning for the following state initiatives:

- **The California Home Visiting Program (CHVP)** – *HMG CA* has been identified as a key partner in the planning and implementation of CHVP, and will be included in its service and referral network at the local level.
- **Race to the Top – Early Learning Challenge** – California’s work in this area focuses on improving early learning and development through addressing the health, behavioral and developmental needs of children with high needs to improve school readiness. *HMG CA* was cited as a promising practice in the State’s application.
- **California’s Early Childhood Comprehensive Systems: Building Health Through Integration**
- **(ECCS) federal grant program** - ECCS will build on the existing cross agency system-change efforts led by the California Home Visiting Program, First 5 Association, California Project LAUNCH, Help Me Grow, and Strengthening Families. ECCS will support efforts of select *HMG* counties to engage in cross-sector early identification and follow-up activities relating to mitigating toxic stress and trauma in infancy and early childhood.
- **California Statewide Screening Collaborative (SSC)** – *HMG CA* serves as a key partner on this collaborative designed to enhance state capacity to promote and deliver effective and well-coordinated health, developmental and early mental health screenings throughout California.
- **Project LAUNCH** – A federally funded grant program administered by the Department of Public Health/Maternal Child and Adolescent Health that aims to improve the systems that serve young children and address their physical, emotional, social, cognitive and behavioral growth. *HMG CA* serves as a strategy to promote system coordination, early identification and linkage to services through care coordination.

- **California's 2013 Comprehensive Early Learning Plan (CCELP)** – Developed by the Child Development Division, California Department of Education (CDE), this plan outlines the critical components of an early learning system for children, birth to five that ensures children have the knowledge and skills to achieve long-term success and points to *HMG* as essential elements for any successful system.

## How Our State's Strengths Are Incorporated into Our Model

Orange County, as an early adopter, serves as a mentor for our local implementation. The counties share their skills and experiences to support one another in their adoption of the *HMG* model. Our affiliate counties have built on their existing collaborations, strategies and programs to solidify the core components of *HMG* and our Learning Community has served as a forum for counties to learn from each other. State and local partnerships have been explored to build statewide spread. Among the 18 counties that comprise our affiliates and Learning Community, 8 are also implementing MIECHV, 10 are part of the RTT-ELC, and 5 are implementing both MIECHV and RTT-ELC.

## Lessons Learned: Successes

- Our Learning Community has been a successful approach for counties to deepen their understanding of the *Help Me Grow* approach through site visits, one-on-one conversations and groups discussions on each of the core components.
- As a way to acknowledge the need to collect common data, a Data Workgroup was developed to identify common data indicators for *HMG* California, based on the *HMG* National data indicators.
- Through our affiliate application process, counties are able to articulate plans to expand existing early identification, linkage and coordination systems through the adoption of the *HMG* model.

## Lessons Learned: Challenges

- Funding for state-level coordination of the *HMG* effort is challenging and we continue to seek opportunities through new initiatives. The lack of a full-time coordinator has direct impact on our ability to fully support the Learning Community, new affiliate counties and the spread of the approach throughout the state.
- We lack statewide data that would support the case for a *Help Me Grow* system and/or inform how to strengthen efforts in our state.
- While *Help Me Grow* has been incorporated into plans for state-level initiatives, this integration has not necessarily trickled down to the county level and we continue to lack regular funding streams to support implementation of the system at a local level, beyond the First 5 funding stream
- There is a pervasive belief at state and local levels that *HMG* equals developmental screening. This is likely related to efforts across the state to promote and support developmental screening but changing the understanding of and discourse around *HMG* remains a challenge.



[www.HelpMeGrowNational.org](http://www.HelpMeGrowNational.org)

## L. *Help Me Grow* Data System Overview

<http://www.helpmegrownational.org/pages/hmg-national/data-center.php>

The *Help Me Grow* National Center (*HMG* National) is developing a comprehensive *HMG* data system to support *HMG* affiliates with data collection, tracking and utilization.

Since May 2011, a national data team consisting of *HMG* National staff, TA consultants, United Way of CT/211 Child Development Infoline care coordinators, and *HMG* affiliates has assisted with planning the national data system.

The data system covers all *HMG* core components and specifically addresses: client tracking of children and families; outreach to families and providers of child health care, early care and education, and family support services; developmental screening; and gaps and barriers in resources and services.

The *HMG* data system will be utilized to help demonstrate the impact of *HMG* across the affiliate network in three key areas:

- better outcomes for at-risk children
- families equipped with the knowledge, skills and support to access community-based services through a statewide system
- a proven, effective and efficient system that builds collaboration across service sectors

*HMG* Common Indicators have been designed to track:

- outreach activities
- the total number and characteristics of *HMG* callers
- nature of service requests and presenting issues
- developmental screenings conducted within the *HMG* system
- referrals by *HMG* to service programs
- *HMG* outcomes.

*HMG* National will generate an annual aggregated "Common Indicators Data Report" for the *HMG* National Affiliates Network currently consisting of 19 states. This report is expected to demonstrate the impact of *HMG* and aid both *HMG* National and affiliates with their advocacy and sustainability efforts at state and national levels.

WebDuck Designs, developer of the *HMG* National website, is currently building the data system. *HMG* Connecticut, South Carolina and Utah are field testing the client tracking section. By 2014, *HMG* National anticipates completion of the first Common Indicators Report for the *HMG* National Affiliates network.

## **M. Draft Legislative Resolution**

### **Assembly Concurrent Resolution: Early Identification & Intervention (DRAFT) April 2, 2015**

WHEREAS the period between a child's birth and third birthday is a time of intense and ongoing development, across the cognitive, motor, language, and social-emotional domains; and

WHEREAS positive health and learning outcomes depend upon children continually building new skills and abilities along a developmental trajectory of incremental milestones that begins at birth; and

WHEREAS the Legislature passed Assembly Concurrent Resolution No. 155 in 2014 in recognition that "research over the last two decades in the evolving fields of neuroscience, molecular biology, public health, genomics, and epigenetics reveals that experiences in the first few years of life build changes into the biology of the human body that, in turn, influence the person's physical and mental health over his or her lifetime"; and

WHEREAS adversity during the early years can impair development, and has a cumulative impact, with children exposed to maltreatment and additional risk factors facing increased likelihood of having one or more delays in their cognitive, language, or emotional development; and

WHEREAS unaddressed developmental delays and disabilities result in persistently impaired learning and health outcomes for children; and

WHEREAS it is estimated that 1 in 4 California children have moderate or higher risk for a developmental delay, such as speech/language impairment, and that nationally 1 of every 68 children were affected by autism spectrum disorder in 2014; and

WHEREAS Latino and African American children are more likely to experience barriers in accessing early identification and intervention services; and

WHEREAS the legislature has previously established through the California Early Intervention Services Act (Cal. Gov. Code § 95001) that "there is a need to provide appropriate early intervention services individually designed for infants and toddlers ... who have disabilities or are at risk of having disabilities, to enhance their development and to minimize the potential for developmental delays;" and

WHEREAS the California Early Intervention Services Act additionally established that "early intervention services for infants and toddlers with disabilities or who are at risk of having disabilities represent an investment of resources, in that these services reduce the ultimate costs to our society, by minimizing the need for special education and related services in later school years ....[and that] maximize the potential of the individuals to be effective in the context of daily life and activities;" and

WHEREAS early intervention services include targeted health and education supports for infants and toddlers who have delays or are at risk of having delays, in order to enhance their development, improve school readiness, and minimize the potential for later challenges; and

WHEREAS early identification and intervention is beneficial to children and their families because it strengthens a family's capacity to support their child's growth and development; and

WHEREAS the California Early Intervention Services Act previously established that "the earlier intervention is started, the greater is the ultimate cost-effectiveness and the higher is the educational attainment and quality of life achieved by children with disabilities;" and

WHEREAS experts like the American Academy of Pediatrics recommend routine, regular, formalized developmental and behavioral screening for all infants and toddlers as the most effective way of identifying children in need of supports and services; and

WHEREAS fewer than one-third of California infants and toddlers received the recommended developmental and behavioral screenings according to 2011-12 parent-reported data; and

WHEREAS 41% of parents report having one or more concerns about their child's physical, behavioral or social development; and

WHEREAS nearly 3 out of 4 California children with special health care needs under age 3 do not receive early intervention services they could benefit from, and the 2012 annual report for California's Early Start program shows that it serves fewer infants and toddlers with early intervention services than the national average; and

WHEREAS a system of universal developmental and behavioral screenings should work hand in hand with a robust early intervention system, and be linked by facilitated family-focused referral, care coordination, child centered health homes, and information-sharing mechanisms to guide and support families while maintaining accountability; and

WHEREAS the California Early Intervention Services Act previously established that "the State Department of Developmental Services, the State Department of Education, the State Department of Health Care Services, and the State Department of Social Services coordinate services to infants and toddlers with disabilities and their families;" and

WHEREAS the California Early Intervention Services Act additionally established that "families be well informed, supported, and respected as capable and collaborative decision-makers regarding services for their child." Now therefore, be it



*Resolved by the Assembly of the State of California, the Senate thereof concurring,* that every California child deserves periodic formal assessment of his or her development for the purposes of introducing supports and services if needed; and be it further

*Resolved* that every child who needs supports in order to achieve his or her developmental potential deserves that such services be easily accessible, sufficient, responsive, timely, and of high quality; and be it further

*Resolved* that every parent or caregiver shall be fully engaged and supported throughout early identification and intervention processes; and be it further

*Resolved* that the state shall leverage existing effort and statute to ensure an accountable, results-oriented, and coordinated statewide network of resources, services, systems, and strong local infrastructures, in order to provide family-centered, comprehensive, multi-disciplinary early identification and intervention services and supports to California infants and toddlers; and be it further

*Resolved* that the state shall support and promote community-driven efforts to coordinate referrals and linkages between, and guide families through the complexities of, the early identification and intervention systems, through programs and models such as Help Me Grow California; and be it further

*Resolved* that the state shall invest sufficiently in comprehensive health and early intervention services and supports in order to ensure that they meet the health and learning needs of California's diverse child population, and wisely harness governmental and other resources toward these common goals; and be it further

*Resolved* that these services and supports shall build upon existing efforts, and be embedded and accessible from the places and people that families know and trust, including: pediatric practices and other health settings, community-based organizations, Regional Centers, Early Head Start programs, First 5s, and other local early childhood programs.

## **N. Special Education Rights and Responsibilities**

For questions regarding California practices in serving children with Special Education needs, see: <http://www.disabilityrightsca.org/pubs/504001Ch13.pdf>

## O. Cautionary Findings for First 5 Association

### Lack of Data for Cost Benefit Analysis

After finding the shift in the age at which children with speech or language impairments were being treated, First 5 Association sought to show that serving children earlier was at a cheaper intervention point. There were many ways that this could potentially possibly be shown (although a true randomized control trial, which would be costly and take a long time, would be the best way to prove more than correlation). Some counties were able to provide an average per-child cost of receiving speech and language service, but unable to provide the average cost by age. Some counties were able to provide some details about the types of services children were receiving by age, but unable to show how long those children received services. San Francisco was able to provide the most detail on average cost and average length of service by age, as well as average cost.

If counties want to show that serving children earlier is better and also cheaper, it should consider collecting the following information:

1. Age of child at entry
2. Severity of delay (categorical)
  - a. Diagnosis code
3. Average weekly service minutes
4. English as primary language (binary)
5. Primary Language if not English
6. Income of parents
7. Race/Ethnicity
8. Age at exit – or length of time served in years.
9. Cost of serving child by year
  - a. Cost could be tied to #2, severity of delay, as it's clear that not all 4 year olds cost less to treat than all 8 year olds.
  - b. Lifetime cost of treating child.

## *Special Education Data*

### **Number of Special Education Students**

An interesting finding is that the number of children being served with special education has not increased, but rather the age at which the state is serving the child is decreasing. As stated, providing services earlier is best for the child's development. This looks like a great thing, but interviews with numerous stakeholders have said to consider this data with caution – it might be that school district resources are such that the number of children in special education stays the same because they triage and only provide services to children with the highest needs. Clearly, another area for advocacy is the effectiveness of the K-12 Special Education system and the large variances across districts.

### **Cost Analysis on San Francisco Data**

San Francisco data provided on the age at which a child entered and exited special education, as well as the minutes per week a child was being treated. There was a hope that this data might show that it is “cheaper” to serve children earlier. The idea was that children entering the system at an earlier age might spend less time in the system. However, the data showed the opposite, a slight negative correlation with length of time in service with age (meaning that older children spend less time in service). Even when adjusted for “minutes per week in service” (with the idea that more minutes per week means that the child has a more severe disability) the negative correlation remained. After speaking with numerous stakeholders, it appears that this correlation exists for a particular reason: school districts triage; they serve the students highest needs first. If this is true, it would hugely impact and skew the data.

## *Past Efforts on Developmental Screening*

### **Special Needs Project**

First 5 California and selected counties received funding for “The Special Needs Project,” which targeted screening efforts for groups that are less likely to experience early identification of special needs – English learners, Latinos, and young children. The project was generally seen as a success, and data collection was a big part of it. However, it is not an ongoing initiative, and only selected counties participated.

The Special Needs Project collected data from pediatricians in a way that appears systematic. Perhaps following the model of the Special Needs Project, or using the data system created from the Special Needs Project should be considered. For more information on the Special Needs Project in California, read the [Special Needs Project Final Program Evaluation Report](#).

First 5 Association should consider researching the Special Needs Project and its outcomes further.

## **Statewide Screening Collaborative**

The Statewide Screening Collaborative, launched in 2007, attempts to increase coordination among organizations doing developmental screenings. In 2014, First 5 California wrote the following in its annual report about the Statewide Screening Collaborative:

*First 5 California held a leadership role in the Statewide Screening Collaborative (SSC), a group consisting of multiple State agencies including Public Health and Developmental Services, and stakeholder organizations such as the American Academy of Pediatrics and Kaiser Permanente. First 5 California served on the planning team for SSC and led a work group focused on developmental screening and follow-up activities in the early learning field. In addition, through First 5 California's role in implementing the RTT–ELC grant, support was provided to participating counties on screening and follow-up in early learning settings, specifically around use of the Ages and Stages Questionnaire, a valid and reliable screening tool for early childhood development. - [First 5 California Annual Report](#)*

Unfortunately, the aim of the Statewide Screening Collaborative is not being as fully realized as possible – as no reports have been produced from the Collaborative since 2010. Programs like Help Me Grow, have more localized efforts to coordinate and collaborate with all stakeholders on a local level, and have had more success.

## **First 5 Early Childhood Mental Health Project**

As seen in Appendix G.2., there are several recommended valid tools that child care or health providers, and even parents, can use when screening a child. In 2009, the First 5 Early Childhood Mental Health Project released a report that recommended consolidating the number of screening and assessment tools accepted by providers and reimbursed by Medi-Cal and Healthy Families. There has not been a follow up study to see the progress of these strategic recommendations. It's important to note that this might be a helpful step in enforcement. If a pediatrician only uses a few tools, it would be easier to track and easier for a health plan to reimburse. On the downside, new tools that are as highly effective, and maybe more innovative (online for example), might be dismissed, which could potentially prevent more developmental screenings from occurring.

## **State Action Plan**

In 2013, First 5 Association, Children Now, and Help Me Grow, California developed a “State Action Plan” for universal developmental screening, which focused on policy levers and advocacy efforts. The internal document recommends short and long term legislative strategies to address the need for universal developmental screenings. This report builds off of the information and strategies offered in that plan, and provides updated research on what is being done in the State.

## *Help Me Grow*

### **Screening**

If the Association is focused on ensuring California meets the Federal mandate for universal screening, the Help Me Grow system is not the end-all be-all solution. According to the National Survey on Children's Health, Connecticut (where Help Me Grow was founded) actually has a lower rate of developmental screening in pediatrician offices than California (only 26.6% compared to 28.5%). Help Me Grow programs are also working to correct the idea that "Help Me Grow equals screening," because its primary goal is to help parent to services after a child has been screened or shows some developmental concern. While it is true that if a child has not been screened and a parent calls, Help Me Grow first ensures a child is screened, most of the benefits of HMG come from the follow up and the connection to services.

### **Uncontrollable Barriers to Accessing Services**

According to Orange County Help Me Grow's Annual Report, about 25% of children attempted to link to services were not successfully linked in Orange County. Of these, 50% were due to the caregiver not following through. This pattern is pretty similar in other counties as well. Ultimately, a child's development begins and ends in the home. If parents are unresponsive, even a system that calls for follow-ups with parents will not work if the parents do not follow up themselves. Parental education must be part of any solution.

Thank you to Moira Kenney, Elinor Mattern, and Patsy Hampton at the First 5 Association of California, and to all involved in the project, including several First 5 county commission staff members, county office of education staff members, school district staff members, and Help Me Grow staff members, for providing critical background information, data, and insights that informed this report.

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