THE EARLY IDENTIFICATION AND INTERVENTION SYSTEM IN SAN MATEO COUNTY

An Environmental Scan | March 2021

FIRST 5
SAN MATEO COUNTY

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Thank you to the San Mateo County pediatricians who participated in the survey.

In appreciation of the many families with young children with special needs in San Mateo County and the providers and systems working together to ensure their optimal health and development.

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PREFACE

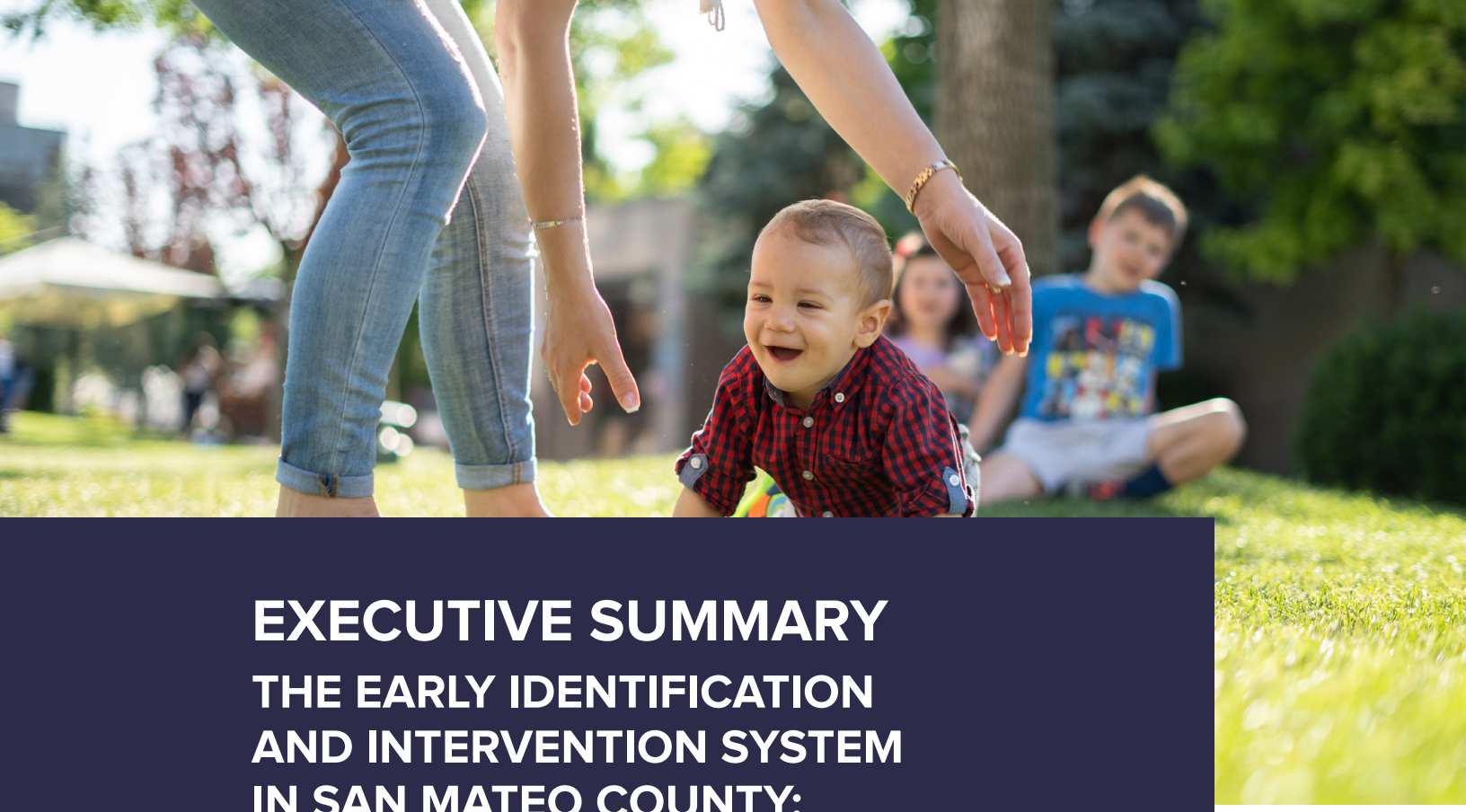
First 5 San Mateo County (F5SMC) has long prioritized the importance of identifying children with special needs as early as possible and linking them to the services and supports that they need to thrive.

The F5SMC Strategic Plan for 2020-2025 explicitly calls out the intent for our investments to "bolster ongoing efforts to address systemic issues that impact access to and quality of these services" as a primary goal. Stakeholder feedback over time and throughout the planning process has identified timely access to early intervention services as a priority.

As we reflect on our systems in the spirit of continuous growth, we know it's more critical than ever to examine the disproportionate impacts they have on families, particularly on families of color, and embrace a trauma-informed, family-centered lens. With direct feedback from families, we see the potential for our system of care to reflect the equity we strive for as a society.

The information gathered as a part of this scan highlights critical barriers and potential opportunities for local stakeholders to consider in an effort to mitigate these challenges. This scan serves as the basis for a collective call to action to address these barriers through a multi-tiered approach with emphasis at the state and local levels, involving service recipients, providers, policy makers, and funders in a model of shared leadership and innovative solution-finding. In essence, this scan invites us all to come together to fulfill our collective vision for our children in San Mateo County, Success for Every Child.

> "REAL AND EQUITABLE PROGRESS REQUIRES EXCEPTIONAL ATTENTION TO THE DETAILED AND OFTEN MUNDANE WORK OF NOTICING WHAT IS INVISIBLE TO MANY."
>
> — FSG, THE WATER OF SYSTEMS CHANGE, 2018



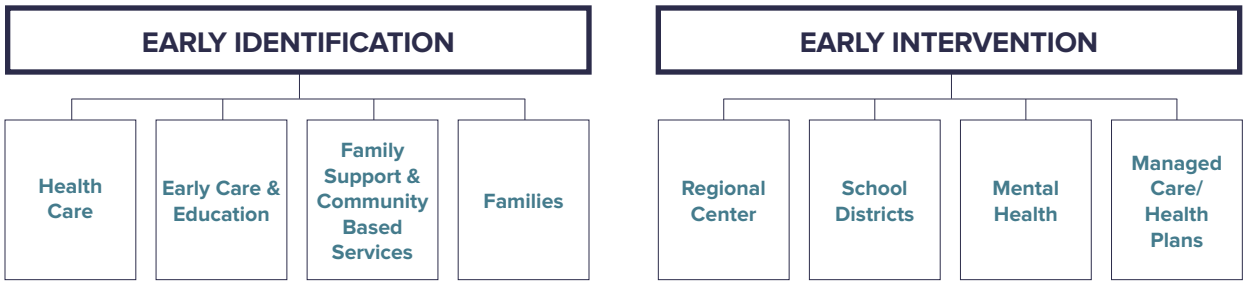
EXECUTIVE SUMMARY

THE EARLY IDENTIFICATION AND INTERVENTION SYSTEM IN SAN MATEO COUNTY: *AN ENVIRONMENTAL SCAN*

First 5 San Mateo County invests in early childhood development issues through combined financial investments in direct services and systems level work.

Most recently, First 5 SMC launched Help Me Grow San Mateo County, a special needs initiative bolstering the continuum of services that identifies and treats young children with special needs as part of an ongoing effort to address systemic issues that impact access to and quality of services. Timely access to early intervention services was an issue raised in the planning process for the 2020-2023 funding cycle. The information gathered as a part of this scan highlights critical barriers and opportunities for local stakeholders to consider in efforts to mitigate these barriers.

Figure 1: Early Identification and Intervention System Components



Despite a well-established EII system and collective efforts to find and support children with special needs, there is still a significant gap between the estimates of children with significant delays and the number of children receiving EII services.

This gap clearly indicates that many more children would benefit from services to promote their optimal development during the critical early years and highlights the need to improve how children are being identified and connected to the EII system in San Mateo County.

Described below are key barriers identified as impacting children's access to EII services and some potential opportunities to address these barriers at a local level.

BARRIER:

Children with delays are not being identified early.

The CDC estimates that 1 in 5 or 17% of children have developmental delays. However, only 7% of children ages 0-5 receive developmental services in San Mateo County. Developmental screenings are recommended for all children at 9, 18 and 24 months, although only 1 in 5 or 21% of children receive developmental screenings in San Mateo County.

OPPORTUNITY 1:

Expand early identification through shared responsibility for Child Find and increased access to developmental screenings for all children in primary care, early care and learning and family support settings.

Strategies to consider might include collaborative partnerships with GGRC to further expand Child Find efforts; leveraging existing screening resources, such as online ASQ screenings through Help Me Grow; or expanded outreach to pediatric practices to increase developmental screenings.

BARRIER:

Barriers to access are based on a model that relies on IDEA mandated services and overlooks a network of invaluable community-based interventions and services available to serve children in inclusive and family-centered settings.

OPPORTUNITY 2:

Shift our concept of EII from detect and refer to a focus on providing a continuum of services for children at-risk and matching services to the unique needs of children and families. Moving to a framework that includes a system of tiered interventions available to meet the needs of all young children and their families has the potential to serve many more children at risk, including those with mild to moderate delays, while continuing to serve children with significant delays.

BARRIER:

When children are referred for early intervention services, their families and referring providers encounter barriers to accessing services.

Families may find the referral process confusing or may not understand how their child would benefit from these services. Sixty percent of pediatric providers surveyed indicated that the referral process was challenging or particularly challenging.

OPPORTUNITY 3:

Make high quality care coordination available to all young children with special needs to ensure they receive timely and appropriate developmental services.

Pediatric and community care coordination for families seeking services for their child with special needs ensures that children are linked to services.

BARRIER:

Even when referrals for early intervention are successful, the assessment process for early intervention often extends beyond the mandated 45-day timeline.

In 2018, 60.61% of infants received timely services (45 days) for IFSPs from GGRC in comparison to the California average for timely services of 82.44%.

OPPORTUNITY 4:

Support families to receive timely access to assessment through 1) targeted care coordination to support linkage to services, 2) an alternative dispute resolution process, and 3) increased collaboration with GGRC to better understand the mechanisms to address systemic barriers such as timelines more expediently and partner on solutions.

Due to their rapid growth and brain development from 0-3 years, timely access to EII services is of critical importance for young children. While parents have rights to pursue legal action for delays and disagreements, enhanced care coordination and access to a transparent alternative process to resolve disagreements could provide quicker resolution and access to services.

BARRIER:

In complex systems such as the EII system, transparency of metrics and sharing of data across agencies is needed to accurately describe how well the system is doing in meeting goals, to plan improvements, and to measure their effectiveness and continue to adjust.

OPPORTUNITY 5:

Promote transparency and interagency data sharing to fully understand the current landscape of EII services, make informed decisions where to target systems improvement efforts and to ensure that children with special needs are being connected to services. For example, a shared screening database countywide would provide accurate baseline data, reduce duplication of services, and provide a way to measure progress towards the goals of identifying children early in order to connect them to developmental services.

NEXT STEPS

If systems change means “shifting the conditions that keep problems in place,” the conditions that we most need to shift will need to address resource flows to ensure coordinated policies for a high quality EII system. The next steps in addressing systemic barriers will require collaborative development of shared priorities and action for local system change efforts. Aligning our local efforts with organizations advocating for policy, budget and legislative change addressing systemic barriers with transparency and accountability at the state level, such as the First 5 Center for Children’s Policy is highly recommended.

“CHILDREN DESERVE OUR COLLECTIVE ATTENTION AND ACTION. WE LOOK FORWARD TO CO-CREATING SOLUTIONS THAT MOVE THE EII SYSTEM TO A MORE ROBUST AND SUSTAINABLE REALITY FOR CHILDREN, FAMILIES AND PROVIDERS.”

— MICHELLE BLAKELY, FIRST 5 SAN MATEO COUNTY

INTRODUCTION

Experts agree that the foundations of lifelong health are built in the early years and that early detection of developmental concerns and connection to services lead to the best outcomes for young children.

Early detection is critical for children who experience developmental or behavioral problems.[1] For young children who have developmental delays, early intervention services can improve development in many domains such as language and communication,[2, 3] cognitive,[4] and behavioral or social-emotional. Early identification and intervention (EII) reduces the need for life-long developmental services and special education,[6] improves child nutrition and health, and reduces child abuse and neglect.[7] In San Mateo County, the Early Identification and Intervention (EII) system encompasses a network of agencies and programs providing services for young children with special needs and their families ranging from early childhood education to specialized services such as physical and occupational therapy, speech therapy, special education, behavioral therapy and early childhood mental health to medical services for children with special health care needs.

The system for finding and connecting young children with special needs to EII relies on the combined efforts of the regional center, community-based initiatives and providers serving young children and their families. Early identification activities include developmental screenings and referrals for further evaluation and services and are conducted in medical, early education and family support settings.

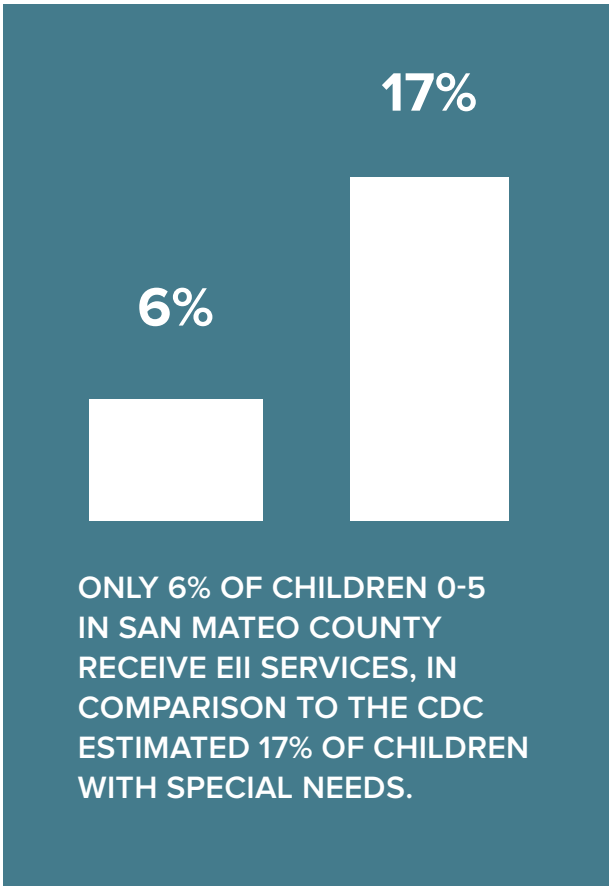
DEFINITION OF CHILDREN WITH SPECIAL NEEDS:

THOSE CHILDREN WHO HAVE OR ARE AT RISK FOR A CHRONIC PHYSICAL, DEVELOPMENTAL, BEHAVIORAL, OR EMOTIONAL CONDITION AND WHO ALSO REQUIRE HEALTH AND RELATED SERVICES OF A TYPE OR AMOUNT BEYOND THAT REQUIRED BY CHILDREN GENERALLY.

— MATERNAL CHILD AND HEALTH BUREAU, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

San Mateo County is home to 49,557 young children from birth through 5 years.[8] While most children are developing typically and meeting developmental milestones, the Centers for Disease Control (CDC) and American Academy of Pediatrics (AAP) estimate that 17% or 1 in 6 children have a disability or significant developmental delay.[9] **Based on GGRC and San Mateo Special Education Local Plan Area (SELPA) reported data, only 6% of children 0-5 years in San Mateo County currently receive EII or preschool special education services.**

Despite a well-established EII system and our combined efforts to find and support children with special needs, there is a gap between the estimates of children with significant delays and the number of children receiving EII services. This gap clearly indicates that many more children would benefit from services to promote their optimal development during the critical early years and highlight the need to improve how children are being identified and connected to the EII system in San Mateo County.



ONLY 6% OF CHILDREN 0-5 IN SAN MATEO COUNTY RECEIVE EII SERVICES, IN COMPARISON TO THE CDC ESTIMATED 17% OF CHILDREN WITH SPECIAL NEEDS.

THE PURPOSE OF THIS ENVIRONMENTAL SCAN IS:

1. to describe the EII system in San Mateo County,
2. to report on barriers to EII services and
3. to highlight opportunities to reduce barriers and improve the local system of care.

For purposes of this paper, the early identification and intervention system (EII) consists of entities that serve children ages 0 to 5 and that:

- Conduct surveillance, screening and/or formal assessment for developmental delays, behavioral concerns, and disabilities.
- Provide care coordination and/or navigation support for families with children who have, or are at risk for, developmental delays, behavioral concerns, and disabilities.
- Deliver intervention services for children with or at risk for developmental delays, behavioral concerns, and disabilities

While the landscape of EII includes both Early Start for 0-3 and Preschool Special Education for 3-5, the selected focus of this paper is access to EII services for the youngest and most vulnerable children from 0-3 years and their families.

PART 1: THE EARLY IDENTIFICATION AND INTERVENTION SYSTEM IN SAN MATEO COUNTY

San Mateo County has a well-established EII system including services mandated by the Individuals With Disabilities Education Act (IDEA) and a network of agencies and programs that provide services for young children and their families. Services range from community-based services, home visiting, family support services and early childhood education to specialized services such as physical and occupational therapy, speech therapy, special education, behavioral therapy to medical services for children with special health care needs.

IDEA MANDATED SERVICES

Based on the federal Individuals with Disabilities Education Act (IDEA), EII services are available for children with disabilities from birth to 3 years through Part C and for children 3-5 years with specific disabilities impacting educational outcomes through Part B.

In California, the Department of Developmental Services (DDS) is responsible for Part C early intervention or Early Start services for infants and toddlers and contracts with 21 Regional Centers to administer EII services. The California Department of Education (CDE) administers Part B Special Education services with public schools responsible for providing appropriate services for children 3-5 years.

In San Mateo County, Golden Gate Regional Center (GGRC) provides Early Start services including outreach, referrals, assessments and evaluation, Individualized Family Service Plans (IFSP), developmental services delivered by contracted specialized service providers, and transition services to school district services for children at 3 years.

During the past year, 1,657 children in San Mateo County 0-3 years received Early Start services.[10] In 2019, GGRC received 995 referrals with 717 cases assigned for assessment. However, in 2020, only 843 referrals were received with 576 cases assigned for assessment. The 15% decrease in referrals and 20% decrease in assessments are attributed to local impacts of COVID.

Despite a decrease in referrals, GGRC is notable as the only Regional Center that pivoted and continued to provide services for children beyond 3 years who could not be transitioned during school closures due to COVID.

The number of children in Early Start represents 7% of children ages 0-3 in San Mateo County in favorable comparison to the statewide rate of 3%. However, both the local and statewide Early Start enrollment rates are significantly lower that the CDC estimates of 17%. These discrepancies indicate systemic issues related to policy and resources for early intervention systems that need to be addressed at state and federal levels.[11] Statewide issues, including how system complexity and narrow eligibility criteria constrain access to developmental services, are clearly identified and described in a recent paper from The First 5 Center for Children's Policy: "Early Identification and Intervention for California's Infants and Toddlers: 6 Key Takeaways."[12]

IN 2020, 1,504 CHILDREN 3-5 YEARS OR 5.6% OF CHILDREN 3-5 YEARS COUNTYWIDE RECEIVED EII SERVICES THROUGH PART B. USING CDC ESTIMATES OF 17% OF CHILDREN WITH SIGNIFICANT DEVELOPMENTAL DELAYS, AS MANY AS 3,022 CHILDREN WOULD BENEFIT FROM THESE SERVICES AND MANY PRESCHOOL AGE CHILDREN ARE MISSING OPPORTUNITIES FOR SERVICES THAT WOULD OPTIMIZE THEIR EDUCATIONAL OUTCOMES.

In San Mateo County, Part B preschool special education services for children 3-5 years are provided by 20 local education agencies (LEAs). Services include assessment and evaluation for eligibility, an Individualized Education Plan (IEP) focused on the child's goals, special education; related services such as physical, occupational, and speech therapy, and supplementary aids and services, such as adaptive equipment or special communication systems.[13] The San Mateo County Special Education Local Plan Area (SELPA) provides technical assistance and oversight support, acts as an intermediary between the state and school districts, and provides communication and dispute resolution services when appropriate for parents and school districts.[14]

In 2020, 1,504 children 3-5 years or 5.6% of children 3-5 years countywide received EII services through Part B. Using CDC estimates of 17% of children with significant developmental delays, as many as 3,022 children would benefit from these services and many preschool age children are missing opportunities for services that would optimize their educational outcomes.

SERVICES FOR YOUNG CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES

The full range of programs and agencies that provide services for children 0-5 with special needs and their families are too numerous to cite here, however, key programs and agencies are included below.

The Family Resource Center at AbilityPath offers information, education and peer-to-peer support to families and caregivers of children of all ages with disabilities.

Family Health Services, part of San Mateo County Health, offers prenatal services, well-child check-ups, developmental screenings, support for children with special health needs, parenting classes, home visits, and additional services to support and promote the health and wellbeing of children and families.

California Children's Services (CCS) is a state program that provides services for children with special health care needs i.e., specified diseases or health conditions. Services include arranging, directing, and paying for medical care, occupational and physical therapy, equipment, and rehabilitation. CCS served 235 children ages 0-1 and 1,327 children ages 1-21 in 2014.[15]

MEDI-CAL MANAGED CARE PLANS ARE RESPONSIBLE FOR THE COORDINATION OF CARE FOR ALL MEDICALLY NECESSARY EARLY AND PERIODIC SCREENING DIAGNOSTIC AND TREATMENT (EPSDT) SERVICES DELIVERED WITHIN AND OUTSIDE THE MANAGED CARE PLAN FOR ALL CHILDREN, NOT JUST MEDICALLY COMPLEX. EPSDT IS THE BROAD SET OF PREVENTION AND TREATMENT BENEFITS CHILDREN ARE ENTITLED TO UNDER FEDERAL LAW.

Children with special health care needs receive services through their health insurance which includes coverage for specialized services, such as medical, physical, occupational, speech and language, or behavioral health therapy, based on referral or diagnosis by a physician. For low-income families, the Health Plan of San Mateo (HPSM) provides Medi-Cal services for 32.7% of children 0-1 and 29.2% of children 1-21 in the county.[16] Medi-Cal managed care plans are responsible for the coordination of care for all medically necessary Early and Periodic Screening Diagnostic and Treatment (EPSDT) services delivered within and outside the managed care plan for all children, not just medically complex. EPSDT is the broad set of prevention and treatment benefits children are entitled to under federal law. [17, 18]

Additionally, a wide range of private health insurance plans also include coverage for specialized services for enrolled children based on referral by a physician.

At the systems level, First 5 San Mateo County invests in an Integrated Systems for Children With Special Needs initiative to prioritize a comprehensive Help Me Grow model, including community and provider outreach, a centralized access point, developmental and social-emotional screenings, and care coordination to ensure linkage to services, as well as strategic services and supports to fill critical gaps in the local landscape of care. First 5 San Mateo County acts as the backbone for this initiative with AbilityPath designated as the lead agency coordinating funded partners including Family Resource Center, Legal Aid Society, Life Steps Foundation, Silicon Valley Community Foundation, Stanford Children's Health: Developmental Behavioral Pediatrics and Government and Community Affairs, and Star Vista.

Figure 1: Early Identification and Intervention System in San Mateo County

Note: The examples provided indicate key agencies and types of services in the EII system and do not represent a complete listing of the numerous agencies and programs.

EARLY IDENTIFICATION				EARLY INTERVENTION			
Health	**Early Learning**	**Family Support**	**Families**	**Regional Center**	**School Districts**	**Mental Health**	**Health**
Pediatricians and child health care providers	Public and private preschools	Home visiting	Family Resource Center	Golden Gate Regional Center	Preschool Special Education	SMC Health: Behavioral Health & Recovery Svcs	Medi-Cal: Health Plan of San Mateo, includes CCS.
FQHCs	Head Start and Early Head Start	Parent education and parent-child groups	Help Me Grow	Specialized Services for PT, OT, SLT, etc.	Specialized Services for PT, OT, SLT, etc.	Magellan	San Mateo County Health
San Mateo County Health Clinics	Family Child Care	First 5 SMC Resilient Families	Life Steps Foundation	Family Resource Center	SELPA	Star Vista	FQHCs
Kaiser, Sutter, and pediatric clinics	SMCOE Quality Counts, The Big Lift	Family Connections	Parca and other family advocates	Specialized service providers	SMCOE Anne Campbell Center	In house clinical services e.g., Kaiser	Pediatric Clinics
SMC Health: Family Health Services	Libraries	Legal Aid Society	Parents Helping Parents		Preschool Inclusion Programs	Private clinicians	Hospitals: Kaiser, LPCH, Mills, Sutter
	Parks & Rec. Depart-ments	Faith based programs	Special Advantage			Early Childhood Mental Health Consultation	Private health insurance

EARLY IDENTIFICATION: How are children with delays detected and connected to early intervention services?

Before they can begin and benefit from EII and special education services, children with special needs must first be identified, referred, complete an intake and evaluation to determine whether they are eligible for services.

There are two methods for detecting and referring a child to Early Intervention.[19] **The first is a referral by a parent or by a provider.** Any parent with a concern may apply to GGRC for evaluation of their child 0-3 years or to their school district for a child 3-5 years.

Providers serving young children and their families may observe children with developmental or behavioral concerns or hear parents' concerns about their child. As trusted partners to families in the community, they can share information and resources with families interested in further services for their child. Some providers offer Ages and Stages Questionnaires (ASQ) screenings and support families through the referral process, including Star Vista, Family Connections. Help Me Grow provides community and family

outreach, information and resources on child development, support for parent and provider questions and concerns, ASQ-3 and ASQ: SE 2 screenings, and linkage to services for families with young children in San Mateo County.

EARLY LEARNING providers are well-positioned to identify developmental concerns and refer for early intervention or school district services. With their knowledge of child development and regular contact with young children and families, they observe and document children's development and behavior over time. They may provide screenings and referrals for children with concerns.

SOME EFFECTIVE POLICIES AND INNOVATIONS DESIGNED TO INCREASE AND EMBED SCREENING IN EARLY LEARNING PROGRAMS ARE DESCRIBED BELOW.

1. Head Start and Early Head Start programs at IHSD and Peninsula Family Services screen all children for developmental and social-emotional development as required in the Performance Standards. Children with special needs are included in programs and families supported with referrals to EII and preschool special education.
2. The Big Lift initiative includes screenings as a measure of program quality and works with preschool classrooms in seven school districts to ensure more at-risk children are ready to thrive in school and in life.
   - 80% or 1,446 Big Lift preschool children were screened in 2018-2019
   - 21% had developmental concerns on the ASQ-3, a 5% increase from previous years
   - 23% had monitoring concerns in one or more developmental areas
   - Screening supports include ASQ-3 and ASQ: SE screening tools, ASQ Online, an ASQ Hub and training and technical assistance to implement screening systems in 6 school districts and programs.
3. The Quality Rating Improvement System (QRIS) sets standards for, supports and monitors early learning program quality. Developmental screening is included as a quality indicator.
   - In 2019-2020, 33 agencies, 79 center-based sites and 20 Family Child Care programs served 3,736 children
   - 51 center-based sites and 3 Family Child Care programs used the ASQ and ASQ: SE and used screening results to support further assessments and referrals
   - QRIS has recently partnered with Help Me Grow to increase and support ASQ screenings in Family Child Care

HEALTH CARE: Because 97.8% of children in San Mateo have health insurance,[20] pediatric health care providers are ideally positioned to identify developmental delays. They see most young children during their first 5 years and have regular opportunities to provide ongoing surveillance during well-child visits, to elicit parent concerns, to screen using validated screening tools and to refer children with concerns for further evaluation and services. The AAP recommends developmental screening at 9, 18 and 24/30 months and autism screening at 18 and 24 months.[21, 22] Screening incentives and training are available for physicians to administer developmental, social-emotional and trauma screenings.[23] In a recent survey of local pediatricians, 41% reported that they administer developmental screenings frequently or always at the recommended intervals.[24]

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provides comprehensive health coverage for children under 21 enrolled

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT) PROVIDES COMPREHENSIVE HEALTH COVERAGE FOR CHILDREN UNDER 21 ENROLLED IN MEDI-CAL, INCLUDING SCREENINGS AS A REQUIRED SERVICE. YET ONLY 21% OR ONLY 1 IN 5 CHILDREN WITH MEDI-CAL WERE SCREENED IN 2019.

in Medi-Cal, including screenings as a required service. Yet only 21% or only 1 in 5 children with Medi-Cal were screened in 2019.[25]

To promote screening and early identification by child health providers, Help Me Grow (HMG) partner Stanford Children's Health provides outreach, resources and training on screening tools and systems and referral pathways for pediatricians.

The Help Me Grow Physician Advisory Group convened by Dr. Neel Patel, HMG Physician Champion, shares information about innovations in screening, including screening tools, resources, policy, and advocacy opportunities among the pediatricians representing the major health systems serving young children, including San Mateo County Health, CCS, Kaiser, PAMF, GGRC, Stanford School of Medicine, Stanford Health Care and Gardner.

CHILD FIND AS THE SECOND METHOD FOR DETECTING AND REFERRING A CHILD TO EARLY INTERVENTION

Both Part C and Part B of IDEA contain explicit requirements for states to actively identify children and determine their eligibility for services.

It targets primary referral sources including hospitals, including prenatal and postnatal care facilities, physicians, parents, childcare programs and early learning programs, local education agencies and schools, public health facilities, social service agencies and other clinic and health care providers, public agencies, and staff in the child welfare system, including child protective services and foster care, homeless family shelters and domestic violence shelters and agencies.[26]

GGRC is responsible for Child Find for 0-5 in San Mateo County and provides information and outreach to the public and to public agencies about early intervention services.[27]

The GGRC website links to information on their process and services, including pamphlets, maps, flyers and literature for families and professionals interested in regional center services for a child with suspected delays.[28]

DEVELOPMENTAL SURVEILLANCE AND SCREENING

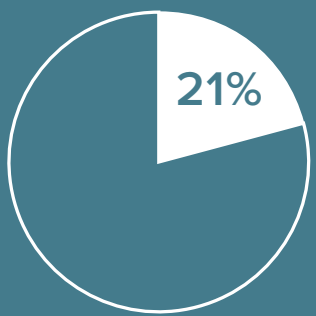
The American Academy of Pediatrics (AAP) recommends surveillance at every visit and screening all children with validated tools at regular intervals.[29]

However, in 2016, only 21% or 1 in 5 children were being screened for developmental or social emotional delays in the medical home.[30]

SURVEILLANCE: Developmental surveillance is a flexible ongoing process used by pediatricians which includes eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children over time, and sharing opinions and concerns with other relevant professionals.[31] Surveillance includes consideration of the child's environment and dynamic development over time.

SCREENING: The use of a standardized tool to identify risk and determine the need for further evaluation.[32] Screening is a highly effective and underutilized strategy for identifying developmental and social-emotional delays. Screening tools that rely on parent reports, such as the Ages and Stages Questionnaires (ASQ) have the additional benefit of eliciting parent concerns and engaging the family in understanding and supporting their child's unique strengths and needs, including when they might benefit from referral for further assessment and services. Currently, training and incentives for developmental, social-emotional and trauma screenings are available to health care providers.[33]

IN 2016, ONLY 21% OR 1 IN 5 CHILDREN WERE BEING SCREENED FOR DEVELOPMENTAL OR SOCIAL EMOTIONAL DELAYS IN THE MEDICAL HOME



PARENT REPORT

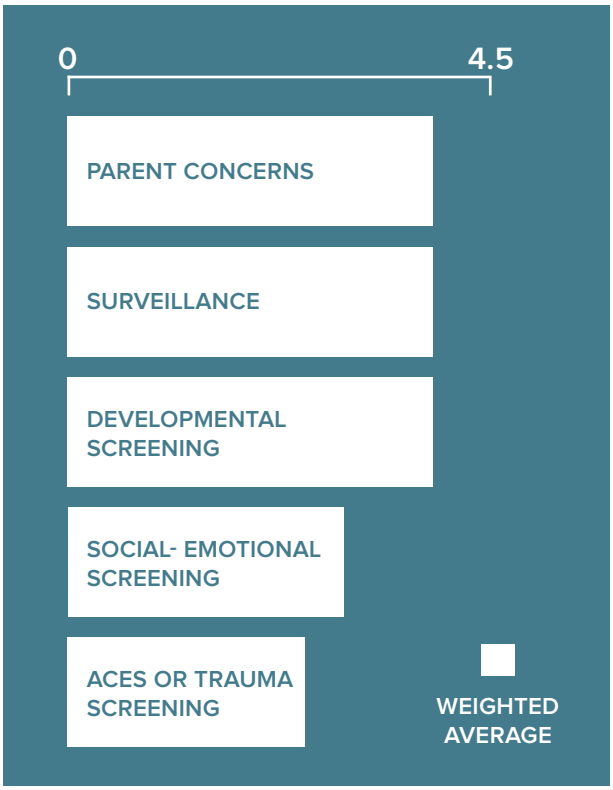
Studies showing that parental report of current skills is predictive of developmental delay and are the basis for development of widely used screening tools that rely on parent report, such as the Ages and Stages Questionnaires (ASQ) and Pediatric Evaluation of Developmental Status (PEDS). [34, 35, 36]

A recent survey of local pediatricians indicates the equal use of parent concerns, surveillance, and developmental screening to identify developmental and social emotional delays as recommended by the AAP.

While developmental surveillance is an important method of detecting delays, the use of standardized developmental screening tools at periodic intervals will increase accuracy. Research in pediatric settings shows that screening tools identify significantly more children with delays than surveillance alone.[38,39,40,41]

Figure 2: How do you identify children with developmental or social-emotional delays?[37]

Survey of San Mateo County Pediatricians, Help Me Grow, January 2021



Local efforts have been made to increase screenings in pediatric clinics because screening tools are so effective in detecting children with developmental disabilities and mental health needs. Recently, the South San Francisco Health Center began exploring implementation of an electronic screening system. Help Me Grow Child Health Provider Outreach provides training on screening tools and systems for pediatric clinics. Help Me Grow San Mateo County offers free online developmental screening for children 0-5 in San Mateo County.

Figure 3: Detection Rates of Children with Delays: With and Without Screening Tools

DETECTION RATES OF CHILDREN WITH DELAYS: WITH AND WITHOUT SCREENING TOOLS		
	Without Screening Tools	With Screening Tools
Developmental Disabilities	30% identified Palfrey et al, 1994	70-80% identified Squires et al, 1996
Mental Health Problems	20% identified Lavigne et al, 1993	80-90% identified Sterner, 1991

REFERRAL TO EII: BRIDGING EARLY IDENTIFICATION AND EARLY INTERVENTION

Regardless of how developmental delays are noticed, a referral for further assessment is still needed to diagnose or evaluate the extent and nature of the delay.

Because IDEA services include assessment, a standard recommendation is to refer children 0-3 to GGRC and children 3-5 to their local school district. Pediatricians may also provide or prescribe diagnostic assessments or services for a child utilizing the child's health insurance.

After the referral has been made, IDEA regulates timelines for all the procedures leading up to and including the writing of the IFSP, which must be completed within a brief time window (45-days). In comparison, 50% more time (60 days) can elapse from the time a parent provides permission for their child to be evaluated for Part B special education services until the time the child's initial IEP is written. The Part C 45-day time clock starts running when GGRC receives a referral about an infant or toddler with a suspected disability or developmental delay, and within that 45-day timeframe, the early intervention system must complete the steps to prepare the child for early intervention services:

- Child Find
- screening
- initial evaluation of the child to determine eligibility
- initial assessments of the child and family, and
- writing the IFSP (if the child has been found eligible)

Pamphlets and materials describing how to access Early Start services are available on the GGRC website. The Pathway for Families to Access Regional Center Services for Children with Developmental Delays is a simplified version specific to San Mateo County.

The more detailed Map to Early Start Services describes timelines and tips for each step and Pathway for Professionals to Access Regional Center and/or Local Education Agency (LEA) provide descriptions of the steps involved and shed light on why some families and providers encounter barriers to accessing early intervention.

PART 2: BARRIERS TO EARLY IDENTIFICATION AND INTERVENTION

Barriers and challenges in access to EII for children and families, providers and mandated service providers include those that existed prior to the COVID-19 pandemic and those that persist or have been exacerbated as the pandemic continues as documented by the Help Me Grow Collaborative Roundtable, Help Me Grow San Mateo County and from interviews with key informants from GGRC, SELPA and the Health Plan of San Mateo (HPSM).

COVID-RELATED BARRIERS

The COVID-19 pandemic continues to create new barriers to access and magnify existing challenges for children with special needs and their families. While every family has experienced new challenges during COVID-19, there are heightened concerns for young children who are not receiving regular medical care, not attending early care, and learning programs and who are isolated and at higher risk for abuse and neglect. These concerns are reflected in the low rate of children seen at well-child visits and the reduced number of referrals to GGRC. For low-income families, the increased challenge of meeting their family's basic needs is magnified by crowded housing conditions, job loss, and economic instability during the stay-at-home order. School closures have caused delays in transitions, IEPs, and school district services. Reduced well-child visits and referrals to GGRC mean that fewer children are served. Finally, although services provided remotely work well and are even preferred by some families, they aren't working for others because of individual preferences or due to limited access or unfamiliarity with technology.

Communication issues are common including communication challenges between families and programs, interagency communication, and communications from public agencies. Since the beginning of the pandemic, public agencies have invested in efforts to provide current, clear information to reduce confusion about changes in recommended practices, policies, and procedures.

EXISTING AND PRE-COVID BARRIERS

FOR FAMILIES: Housing, economic instability and food insecurity are most frequently mentioned as negatively impacting families' ability to prioritize and participate in the referral process. Some families are reluctant to engage with GGRC due to their language, cultural preferences, status, or previous experience with the system of care. Some families require additional support to understand the importance of EII for their child and to complete the GGRC referral process, particularly those with limited organizational or cognitive skills or mental health issues. Some families are discouraged when attempting to reach their GGRC Service Coordinator by phone.

FOR PROVIDERS: Providers noted frequent issues with the referral process, including lack of clarity on how to make a referral, technical issues for referrals submitted via fax and email, and referrals that could not be located by GGRC on follow-up and which need to be resubmitted. Providers have expressed a strong interest in receiving confirmation of referrals and being informed of the outcomes of referrals.

A recent survey of local pediatricians uncovered issues with the referral process to GGRC.

- Referral process: 60% indicated that the referral process was challenging for them. Comments were made on the need for an easier referral system.
- Follow up: 82% responded that additional follow-up was required to find out the outcomes of referrals made to GGRC.
- Comments were made on the needs for better communication between GGRC and the medical home including eligibility and sharing medical and developmental assessments.
- Comments included appreciation for improved communications with GGRC in recent years, that services are delivered effectively after evaluations are completed and understanding that GGRC and Early Start is under-resourced as a system.
- Responses indicated the need to improve communication between families and the physicians referring children for Early Start services, specifically regarding the value of early intervention services for their child.
- One provider commented that children in Spanish-speaking families are more likely to fall between the cracks and not be evaluated or have delays starting services.

SYSTEMS BARRIERS NOTED BY COMMUNITY PROVIDERS INCLUDE:

- The need for more regular and timely interagency communication with providers from GGRC and school districts about changes in policies, processes, eligibility, and availability of services, For example, because each of the 20 LEA/school districts have their own referral processes and procedures, families and the providers assisting with referrals may lack accurate information and experience challenges in the transition from Early Start to Preschool Special Education at age 3.
- Lack of coordination of services between medical and community systems
- Lack of care coordination for children with special needs and families served through multiple systems. Care coordination supports family-centered planning, eases access to and coordination among service providers, and reduces potential duplication and/or gaps in services.
- Wait lists for some EII services, e.g., feeding therapy, due to a limited number and availability of providers

SOME FAMILIES ARE RELUCTANT TO ENGAGE WITH GGRC DUE TO THEIR LANGUAGE, CULTURAL PREFERENCES, STATUS, OR PREVIOUS EXPERIENCE WITH THE SYSTEM OF CARE. SOME FAMILIES REQUIRE ADDITIONAL SUPPORT TO UNDERSTAND THE IMPORTANCE OF EII FOR THEIR CHILD AND TO COMPLETE THE GGRC REFERRAL PROCESS, PARTICULARLY THOSE WITH LIMITED ORGANIZATIONAL OR COGNITIVE SKILLS OR MENTAL HEALTH ISSUES.

SYSTEMS BARRIERS AND ISSUES FOR MANDATED SERVICE PROVIDERS

Even when referrals for early intervention are successful, the assessment process for early intervention often extends beyond the mandated 45-day timeline.

GGRC acknowledges that timely provision of services is challenging due to delays caused by incomplete referrals, cancelled appointments, and based on resources and availability of contracted specialized service providers. The table below illustrates how well regional centers in the greater Bay Area region met the timeline.

Transition from GGRC to school district services at age 3 is also noted as a barrier.

Each of the 20 LEA/school districts have their own process for Preschool Special Education which can be confusing for families and the providers assisting with referrals. SELPA and GGRC meet regularly to facilitate transitions from Early Start to School District services.

Transition services are difficult to provide when a child is referred too close to their third birthday with insufficient time to complete the IFSP.

Figure 4: How well regional centers in the greater Bay Area region met the 45-day timeline.

Data from CA Department of Developmental Services: Early Start Local Performance https://www.dds.ca.gov/services/early-start/state-performance-reports/

	2018-19	2017-18	2016-17	2015-16
LOCAL PROGRAMS	**TIMELY SERVICES (45 DAYS)** % of infants receiving IFSPs timely	**TIMELY SERVICES (45 DAYS)** % of infants receiving IFSPs timely	**TIMELY SERVICES (45 DAYS)** % of infants receiving IFSPs timely	**TIMELY SERVICES (45 DAYS)** % of infants receiving IFSPs timely
TARGETS	100%	100%	100%	100%
CALIFORNIA	82.44%	82.25%	88.84%	88.84%
GGRC	60.61%	60.61%	60.61%	75.9%
NBRC	66.67%	84%	84%	84%
RCEB	51.28%	51.28%	76.67%	77.1%
SARC	82.35%	82.35%	95%	92.5%

Timelines:

Within the 45-day timeline, GGRC is responsible for taking the child's history, evaluating a child's eligibility for services, conducting family and child assessment, including multidisciplinary assessments to describe a child's unique needs, functioning in each of the developmental areas, and completing an IFSP identifying interventions that will be provided based on the child's needs.

Regional centers rely on specialized service providers to complete the required assessments and services. These specialized service providers are independent contractors from a limited workforce available locally, therefore GGRC is at a disadvantage competing with health insurance, private and other payers for their services, which leads to delays completing assessments within the timeline and delays in providing some services.

Additional strains on the Regional Center system are the increased number of clients served, workforce turnover, and increased requirements from DDS. The combined factors contribute to the challenge of meeting the 45-day timeline for many Regional Centers.

In addition, GGRC describes delays in the referral process due to receiving referrals with incomplete information, cancelled and rescheduled appointments and families not interested in services for their child.

RESOURCES TO ADDRESS BARRIERS:

A wide range of resources are available to address gaps and barriers in the EII system including services included in mandated services, services and supports provided through participation in regional or statewide initiatives and resources developed in response to local gaps and barriers.

Some examples of resources for families include:

- The Family Resource Center at AbilityPath provides information, education, and peer-to-peer support to families of children with special needs.
- Help Me Grow San Mateo County offers a centralized access point for information, support, developmental and social emotional screenings, and linkage to services.
- Life Steps Foundation provides information, support, and inclusive services with expertise in serving young children with special needs and Asian families.
- Legal Aid Society assists families of children with disabilities with questions about GGRC, school district, CCS, and other services. They also provide a range of services for low-income families who encounter barriers to services.

Some examples of resources for providers and agencies include:

- Help Me Grow Child Health Provider Outreach offers information and training on screening tools and systems and referral pathways for pediatric providers.
- The Big Lift and the Quality Rating Improvement Scale (QRIS) support screenings in programs participating in targeted school districts and quality improvement initiatives.
- SELPA provides Alternate Dispute Resolution to mediate between families and school districts.

Some examples of systems level collaboration include:

- IHSD Head Start/Early Head Start collaborating with partners including school districts, County Office of Education, community agencies and advocacy groups to facilitate a continuity of services to meet children's developmental needs.
- DDS funding for Family Resource Center services, including grants to reduce disparities in access to services in East Palo Alto and Half Moon Bay.
- HPSM and GGRC coordinating services for Medi-Cal children to ensure continuity of services.
- SELPA, GGRC and school districts meet regularly to ensure smooth transitions for children from early intervention to special education.
- The Help Me Grow Collaborative Roundtable convening and facilitating multi agency, multidisciplinary case discussions of children with complex needs encountering barriers to service.
- The Help Me Grow Physician Advisory Group led by Dr. Neel Patel, HMG Physician Champion, includes representatives from the local health systems to promote screenings and to share information and resources on screening policies, practices, and innovations both locally and statewide.
- First 5 San Mateo County and Help Me Grow convene the Systems Change Group including agencies and programs serving young children with special needs to address systems level topics and issues for young children with special needs.

PART 3: OPPORTUNITIES TO REDUCE BARRIERS AND IMPROVE THE LOCAL EARLY IDENTIFICATION SYSTEM

Although beyond the scope of this section of the paper, it would be remiss to ignore the fact that the EII system exists within the context of federal and state mandates, IDEA, and Medicaid law for children with Medi-Cal insurance.

In addition to local county efforts, state and federal level policy changes in the Medi-Cal and Part C programs are needed to improve the EII system. State and federal action is necessary to expand the services Part C and Medi-Cal can provide, increase sustainable funding, and improve oversight. Medi-Cal in particular plays a significant role in the EII system and carries a lot of responsibility in ensuring children receive screening, care coordination, and treatment for developmental concerns. In addition, there is heightened attention on Medi-Cal's role in the EII system currently, given California's historic and pandemic-related low rates of pediatric preventive care access, including developmental screening.[42, 43]

Issues that can be addressed through advocacy at the state and federal levels include resource flows for increased reimbursement rates for services, effectively increasing regional center access to contracted service providers and improving service delivery including assessments and IFSPs completed within the 45-day timeline. These and other statewide EII systems issues and recommendations are described in *Early Identification and Intervention for California's Infants and Toddlers: 6 Key Takeaways,* a recent publication from the First 5 Center for Children's Policy.

STATE AND FEDERAL ACTION IS NECESSARY TO EXPAND THE SERVICES PART C AND MEDI-CAL CAN PROVIDE, INCREASE SUSTAINABLE FUNDING, AND IMPROVE OVERSIGHT. MEDI-CAL IN PARTICULAR PLAYS A SIGNIFICANT ROLE IN THE EII SYSTEM AND CARRIES A LOT OF RESPONSIBILITY IN ENSURING CHILDREN RECEIVE SCREENING, CARE COORDINATION, AND TREATMENT FOR DEVELOPMENTAL CONCERNS.

Addressing the documented barriers on a systemic, rather than individual case level will require a collaborative process to prioritize and target efforts. There are potential solutions to some barriers through leveraging existing efforts, such as community collaboration with GGRC to expand Child Find efforts, increased interagency communication or outreach to providers seeking clarity about the GGRC referral process. Other barriers might be resolved through technical solutions, e.g., lost, or incomplete referrals or tracking progress on the status of referrals.

Complex issues that are impacted by state and federal regulations and funding, such as the lack of compliance meeting the 45-day timeline for completing IFSPs, may require a different type of approach. Despite multiple perspectives on each of these issues, families, providers, mandated service providers and policy makers share the goal of ensuring that all children with delays and special needs and their families receive the services needed to support their optimal development.

The opportunities listed below include possible opportunities to address systemic barriers to early intervention services that were shared by key stakeholders. The list below is not intended to be exhaustive, but rather to serve as a starting point for community stakeholder discussion and action.

DESPITE MULTIPLE PERSPECTIVES ON EACH OF THESE ISSUES, FAMILIES, PROVIDERS, MANDATED SERVICE PROVIDERS AND POLICY MAKERS SHARE THE GOAL OF ENSURING THAT ALL CHILDREN WITH DELAYS AND SPECIAL NEEDS AND THEIR FAMILIES RECEIVE THE SERVICES NEEDED TO SUPPORT THEIR OPTIMAL DEVELOPMENT.

Opportunity 1: Expand and improve early identification through developmental screenings for all.

Developmental screening reliably identifies children with delays and the tools are readily available and easy to use in a variety of settings. Help Me Grow provides family and community outreach and access to online ASQs for any family in San Mateo County and numerous quality preschool and early learning programs successfully implement screenings. While continuing to promote screening in the medical home, we need to seek opportunities to create multiple points of access to screenings. For example, forming partnerships among community providers to expand outreach and make screenings available where families with young children gather and receive services, such as libraries, parks and recreation programs and faith-based organizations.

Opportunity 2: Shift our concept of EII from detect and refer to a focus on providing a continuum of services for children at-risk and matching to the unique needs of children and families.

The current model for EII relies exclusively on GGRC for services for children with developmental delays. Most barriers cited above pertain to the referral and assessment process for Early Start. The focus is on whether a child is eligible and receives Early Start services.

Making a shift in our way of thinking about access to the EII system from "eligible/not eligible" to a framework that describes a system of tiered interventions available to meet the needs of all young children and their families has the potential to serve many more children at risk, including those with mild to moderate delays, while continuing to serve children with significant delays. This is particularly important to consider with (1) our increasing recognition of the impact of Adverse Childhood Experiences (ACEs) on young children's development in the context of significant numbers of vulnerable children living in poverty or with multiple ACEs and (2) impacts of equity on how children and families can access EII.

Community based early childhood services are widely available throughout the county. Many children at-risk for developmental delays and children not identified with delays are served in community programs which provide important preventive services, These programs often go unrecognized and are only briefly referenced in IDEA as "generic resources" for children who are not eligible.

Head Start and Early Head Start are national models of providing a continuum of services for young children and their families in community-based settings and in collaboration with GGRC and school districts to serve children with a wide range of developmental needs, including children identified with developmental delays and disabilities.

Palabritas y Padres is an example of a local community-based intervention developed to address gaps in services for children with communication concerns. This short-term intervention for Spanish-speaking families provided 8-week parent-child groups where families learned to encourage their child's speech and language, to participate in everyday conversations and to gain confidence in their role as their child's teacher. Most parents and the therapist reported noticeable progress and increased enjoyment of their child. Several children previously referred for EII services made sufficient progress and no longer required additional services; one child was diagnosed with autism soon afterwards.

Similar groups could be offered with a focus on selected developmental areas to promote gross motor, adaptive self-help, or social-emotional development.

Alternative paths to services for children with special needs also exist through health insurance, quality early care and learning, and parent-participation programs. Services provided through health insurance may provide a limited number of services based on progress towards goals. In comparison, IFSP goals are reviewed and updated at minimum every 6 months, and services are provided until the child transitions at age 3. While limited data is available on the relative value and impact of short and long-term services for children with developmental delays, maximizing utilization of health insurance to provide EII services is recommended.

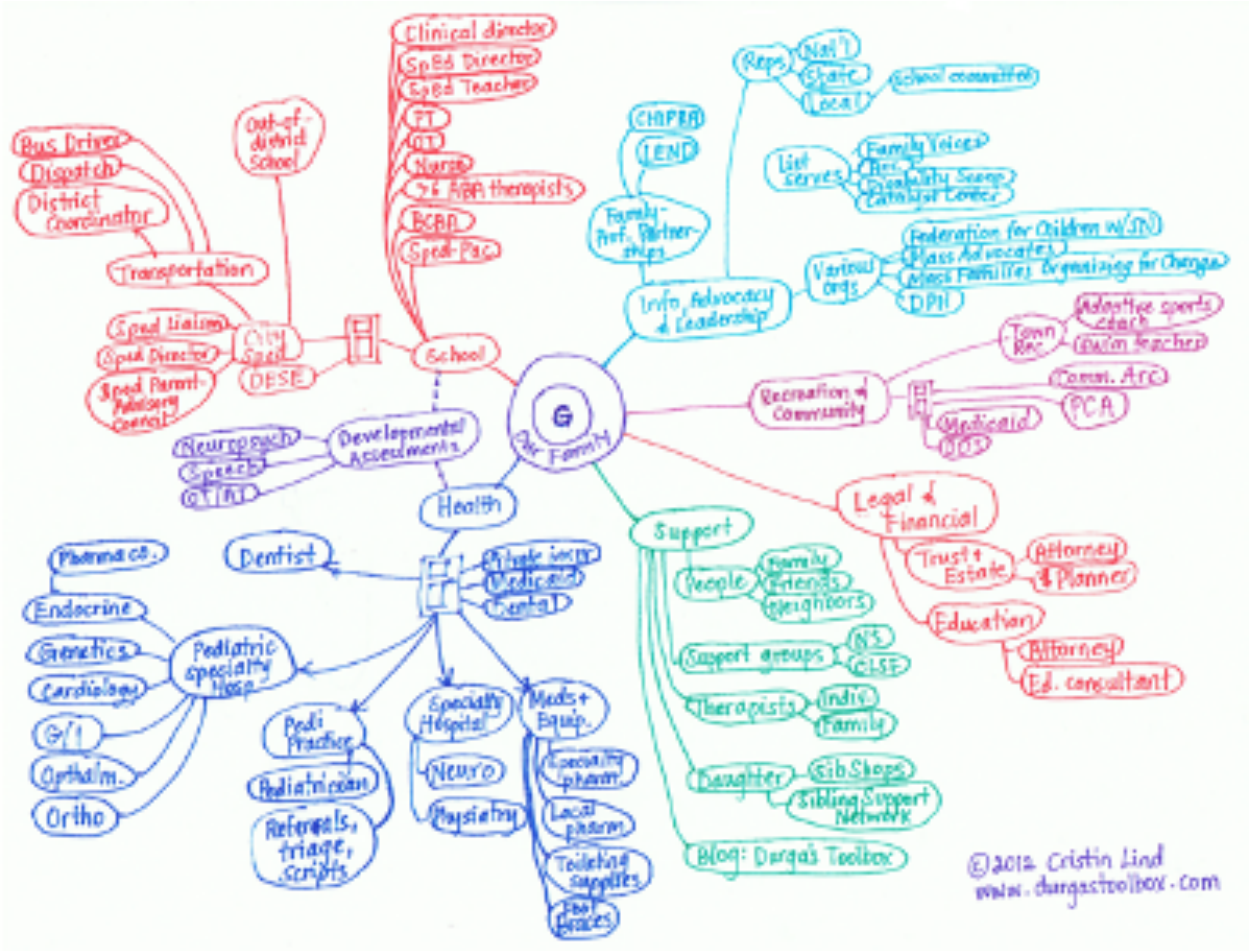
Opportunity 3: Make high-quality care coordination available for all children with special needs to support seamless and appropriate services

The complexity of the EII system is well described in Navigating the Early Identification and Intervention Maze: A Flowchart from the First 5 Center for Children's Policy. 44

In a graphic depiction of the EII system from a parent's perspective, the care map below shows one' mother's illustration of the complexity of her son's care. While most children's needs are less complex, it is important to understand the many different service sectors and types of services involved in the system of care.

Figure 5: My Son's Care Map

Used with permission from Cristin Lind, http://www.cristinlind.com



The process of developmental screening, referral for further evaluation, and ongoing interventions and services requires coordination among primary care providers, specialists, early care and education providers, early intervention and special education programs, and families to ensure that children and families receive appropriate services and do not fall through the cracks. Referral and care coordination require appropriate tools, such as referral forms, feedback mechanisms, and methods of communication among the providers and agencies serving children and families.[40]

Care coordination addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs of families. Effective care coordination connects children to services, facilitates provider communication, and supports families as primary caregivers. While care coordination may be available to families of children with complex medical conditions (CMCs), funding for care coordination outside the medical system is difficult to access for most children with special health care needs.

Locally, HPSM and CCS provide care coordination for CMCs but most children with special health care needs who would benefit never receive care coordination services and their families do the best they can to coordinate their child's services. EPSDT requires coordination of care for children with MediCal and is a promising opportunity to expand care coordination for children with special health care needs.

A local example of successful care coordination is Help Me Grow which provides screenings, and care coordination that includes family support for referrals to EII, and follow-up to support linkage to services. For greater impact, Help Me Grow services could be maximized through countywide scale and spread to support increased family access to GGRC and school district services and community-based resources. Without systematic care coordination, the most vulnerable children can easily go undetected and slip between the cracks in the system. With care coordination, children are linked to and receive the EII services needed to optimize their health and development, families are supported while learning to navigate the system, and providers have confidence in making referrals for EII services.

Opportunity 4: Support families to receive timely access to assessment through 1) targeted care coordination to support linkage to services, 2) an alternative dispute resolution process, and 3) increased collaboration with GGRC to better understand the mechanisms to address systemic barriers such as timelines more expediently and partner on solutions.

Due to their rapid growth and brain development from 0-3 years, timely access to EII services is of critical importance for young children. While parents have rights to pursue legal action for delays and disagreements, enhanced care coordination and access to a transparent alternative dispute resolution process could provide quicker resolution and access to services.

1. Targeted care coordination to support linkage to services

While many families successfully navigate through the referral process, others encounter more barriers completing the required steps in the referral process to obtain services for their child. Bolstering support for these families could help to address issues such as delays, miscommunication, and complaints requiring further advocacy.

For parents and providers, a natural sense of protectiveness for their baby or toddler with special needs is coupled with the hope that services are available to support their child's development in the early years. When the child or family has complex medical or psychosocial needs, there is a heightened sense of urgency to connect them to services. However, some families are additionally challenged by other factors based on cultural background, previous experience with the system, immigration status or may lack awareness of their child's rights to EII services. These families may be reluctant to question delays or be challenged by requirements to provide additional information and participate in the assessment or evaluation and are unlikely to complain when services are delayed or denied. For these families, care coordination services can support their understanding of how their child might benefit from early intervention services, support their access to early intervention services in a family centered manner and support their ability to navigate the system.

2. Alternate Dispute Resolution Process

IDEA requires the timely resolution of complaints through: (1) mediation; (2) minimum complaint procedures; and (3) due process hearing procedures.[45] While parents have rights to pursue legal action, it could be less costly and contentious to create an alternate, more transparent process to address issues in a way that produces the best results for all in a more expedient manner. In many cases, access to an alternative process might offer swifter resolution and save the time and emotional and financial cost to families and of going through the formal process of mediation, complaint, and due process.

An innovative local example of alternative dispute resolution is the SELPA Appropriate Dispute Resolution (ADR)41 process for conflict resolution with the goal of avoiding conflict at the family and district level. Through parent

SOME FAMILIES ARE ADDITIONALLY CHALLENGED BY OTHER FACTORS BASED ON CULTURAL BACKGROUND, PREVIOUS EXPERIENCE WITH THE SYSTEM, IMMIGRATION STATUS OR MAY LACK AWARENESS OF THEIR CHILD'S RIGHTS TO EII SERVICES. THESE FAMILIES MAY BE RELUCTANT TO QUESTION DELAYS OR BE CHALLENGED BY REQUIREMENTS TO PROVIDE ADDITIONAL INFORMATION AND PARTICIPATE IN THE ASSESSMENT OR EVALUATION AND ARE UNLIKELY TO COMPLAIN WHEN SERVICES ARE DELAYED OR DENIED.

engagement, parent training and staff training, conflict is preempted by building capacity through prevention, interventions for disagreements, more intensive interventions when members are "stuck", and facilitated resolution to resolve conflicts. The process is rapid, responsive, free of charge, confidential, protective of legal rights and focused on desired outcomes.

In another local example, the Help Me Grow Collaborative Roundtable is convened by Developmental Behavioral Pediatrics at Stanford Children's Health, for case discussion of young children with complex medical or psycho-social needs who encounter barriers to service. The members include representation from a range of programs serving children with special needs including SELPA, HPSM and GGRC. Through facilitated case discussion, providers familiar with the child and family identify resources or strategies to address gaps or barriers, develop a plan and designate a provider responsible for follow-up with the family who closes the loop by updating the group at a future meeting. Legal Aid Society participates in the Roundtable and assists families of children with disabilities with questions about GGRC, school district, CCS, and other services. They also provide a range of services for low-income families who encounter barriers to accessing services. A similar model of care coordination collaborative to discuss complex cases of children with special health care needs and systems level issues has successfully addressed barriers in other counties.

3. Increased collaboration with GGRC to better understand the mechanisms to address systemic barriers such as timelines more expediently and partner on solutions.

Some barriers are persistent, have been noted by many families and reported by multiple providers, such as children not receiving an IFSP within the 45-day timeline. For barriers that are documented repeatedly, a closer examination of the root causes and data would help to understand if some families or populations are more likely to experience a particular barrier to services or whether the source of the barrier is rooted in an institutional process, practice, or policy. Establishing a consistent format to address systems level barriers with relevant stakeholders

could promote the adoption of equitable and systemic solutions through a collaborative approach with the shared goal of ensuring that young children with delays receive appropriate and timely support and services.

Opportunity 5: Promote transparency and interagency data sharing to fully understand the current landscape of EII services, make informed decisions where to target systems improvement efforts and to ensure that children with special needs are being connected to services.

Data is fundamental to understanding the current landscape of EII including gaps and barriers, to targeting systems improvement efforts, and to evaluate progress towards the goal of a system of seamless services supporting the development of young children with special needs. In complex systems such as the EII system, transparency of metrics and sharing of data across agencies is needed to accurately describe how well the system is doing in meeting goals, to plan improvements, and to measure their effectiveness and continue to adjust.

An example of the need for data sharing is incomplete screening data countywide. Because screenings are conducted in multiple programs across service sectors with different funding streams, outcome measures and data systems and metrics, there is no reliable baseline data for the number of screenings, or the number of children screened countywide. There are examples of agencies that include developmental screenings in performance measures and reporting such as HPSM for children with Medi-Cal, The Big Lift and QRIS for children in selected preschools and early care and learning programs, and Head Start/ Early Head Start for children who are eligible based on age, income, homelessness, as a foster child or as a child with disabilities.

A CENTRALIZED SCREENING REGISTRY OR DATABASE AVAILABLE TO PRIMARY CARE AND COMMUNITY PROVIDERS HAS THE POTENTIAL TO PREVENT DUPLICATION AND PROACTIVELY IDENTIFY CHILDREN.

A centralized screening registry or database available to primary care and community providers has the potential to prevent duplication and proactively identify children. The OC Children's Screening Registry is an example of how it is possible to communicate screening data between organizations and providers and link children to services and referrals.

A local, though more limited, example of centralized screening data is the ASQ Hub at SMCOE developed for The Big Lift, All participating programs have access to an online ASQ database to track screenings and screening results of children in their program and SMCOE can monitor linked programs and generate reports with aggregate data.

A local example of a more comprehensive client data system for tracking screenings, referrals and referral outcomes is the Help Me Grow STAR database. Care coordinators use the database to gather individual client information for intake, link automatically to the ASQ online screenings completed by families, and enter referrals made matched to concerns, and referral follow-up reminders to ensure that care coordinator contacts the family or referral for the outcome of the and ensure that children and families are connected to services.

To address the issues related to providers who want to be informed of the outcomes of referrals but who have limited capacity and resources to follow up, a centralized referral database tracking the status of referrals to GGRC would provide visibility into whether referrals were received, the status of the referral and whether the IFSP has been completed and the child is receiving services. Despite significant resource, data sharing and privacy issues related to building a shared referral database, there are clear benefits for children, families, and the providers and organizations serving them in expediting and tracking referrals, coordination of services, and improved communication and relationships.

NEXT STEPS: DEVELOPING SHARED PRIORITIES FOR SYSTEMS CHANGE EFFORTS AND ACTION

In conclusion, while there is widespread agreement among families, providers and agencies serving young children with special needs of the need to improve access to the EII system, the next steps will require collaborative development of shared priorities for local system change efforts.

The next steps in addressing systemic barriers will require collaborative development of shared priorities for local system change efforts with all partners and agencies invested in improving the local EII system. This includes families, health care, family support services, San Mateo County Health, Health Plan of San Mateo, San Mateo County Office of Education, SELPA, Help Me Grow San Mateo County, First 5 San Mateo County and GGRC.

To actualize the vision for family-centered, trauma informed, equitable systems it is imperative to look to families for their lived wisdom and experience.

Aligning our local efforts with organizations advocating for policy and legislative change addressing systemic barriers with transparency and accountability at the state level, such as the First 5 Center for Children's Policy is highly recommended.

"CHILDREN DESERVE OUR COLLECTIVE ATTENTION AND ACTION. WE LOOK FORWARD TO CO-CREATING SOLUTIONS THAT MOVE THE EII SYSTEM TO A MORE ROBUST AND SUSTAINABLE REALITY FOR CHILDREN, FAMILIES, AND PROVIDERS."

—MICHELLE BLAKELY,
FIRST 5 SAN MATEO COUNTY

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