

Developmental Screening Cohort

Landscape Analysis of Developmental Screening in Orange County

Report to the Children and Families Commission of Orange County

August 2016 – Updated January 2017

Introduction

In February 2016, the Children and Families Commission awarded support to the Developmental Screening Cohort to explore what it would take to increase the number of young children who are screened for developmental progress and connected to assessments and services. This year-long project will help the cohort learn more about what is currently happening in Orange County, where the gaps and barriers are to developmental screening and connection to service, and consider how it might make the case for additional funding to support projects that will help it achieve its vision that, “Collaborative partners ensure all Orange County children receive developmental screenings with evidence-based tools and identified concerns are addressed.”

This report fulfills the first requirement for this project, to describe the current state of developmental screening in Orange County. Subsequent reports will include a theory of change, a common agenda for the cohort, and evaluation framework, and the case for long-term sustainability of developmental screening efforts.

This report will attempt to address a number of questions about developmental screening in Orange County:

- What has taken place over the last 15 years to promote developmental screening and connection to services?
- Who is currently screening children?
- Where do screenings occur?
- How many children do we know are being screened?
- What screening tools are being used?
- What are the results of the screenings?
- Where do children get referred if their screening shows the possibility of a delay?
- What are the barriers to screening more children?
- What are the gaps in the screening and services system?
- What are the gaps in our knowledge about developmental screening?

A list of acronyms used in this report is provided in Appendix B – page 29.

What's happened in recent years

Before delving into the current state, it is worthwhile to take a look at past efforts, review what was learned, and see where progress has been made.

For over 15 years, the Children and Families Commission of Orange County (the Commission) has led efforts to increase the number of children in Orange County who are screened for developmental delays and connected to services. During this time, there has been considerable progress in improving awareness of developmental screening and there is every reason to believe that more children are being screened using evidence-based screening tools. However, there also is every reason to believe that not every child is screened for developmental delays at the recommended ages, and not every child whose screening shows the possibility of a delay is referred for assessment or services.

Since its inception in 1999, the Commission has funded a number of initiatives and projects that include developmental screening of young children. These include its Bridges for Newborns Initiative, Family Support Network, Pediatric Health Clinics at CHOC and UCI, and School Readiness Nurses. Some of these were among the first projects funded by the Commission and others were started later. Table 1 provides a timeline of key events, projects, and studies that have taken place to promote developmental screening using evidence-based tools. With each project or event, a brief overview and lessons learned and/or recommendations are provided. More detailed, narrative descriptions of the projects are provided in Appendix A on page 21 as well as links to reports that are available online (not all reports used to develop this timeline are available online).

Following the timeline, Table 2 shows the results of screenings from four of the projects described in Table 1.

Table 1. Orange County Developmental Screening Timeline, 2004-2016

Year(s)	Project/Event	Overview	Findings/ Lessons Learned/ Recommendations
1999	Children and Families Commission funds first projects	The Commission establishes Bridges for Newborns, which screens families for risk at birth and follows-up with families during the first year of the baby's life, including developmental screening.	NA
2004	Building a Model System of Developmental Services in Orange County	A study by the UCLA Center for Healthier Children, Families and Communities that examined the existing developmental/behavioral service delivery system.	Create an integrated system focusing on optimizing healthy child development through partnerships among families, primary care providers, and educators.
2004	School Readiness Nurse Initiative inaugurated	Facilitate early identification and treatment of health and development issues by conducting screenings and making referrals	NA
2005	Help Me Grow Orange County is established	Replicated HMG-Connecticut. It is a comprehensive, coordinated system designed to assist child health care providers, other professionals, and families in improving developmental outcomes for children.	NA
2007	CHIS – California Health Interview Survey	Adults with a child age 1 or older were asked whether they had completed a developmental or behavioral screen about their child.	25.1% of Orange County parents said they had completed a developmental or behavioral questionnaire about their child. This compares to 22.8% in California. This survey question was asked again in 2015.
2007	Pathways Leadership Committee convened	Guided a collaborative, community-focused planning effort intended to strengthen the pathway for young children receiving or in need of developmental and behavioral services in Orange County. Identified a primary outcome for the next five years: All children in Orange County will have recommended developmental/behavioral baseline screenings at milestone ages with linkage to appropriate services.	Established 4 goals: 1) Develop the infrastructure to ensure the effectiveness of the Orange County developmental/behavioral pathways system. 2) Develop relationships among community partners that serve children, birth through five, and their families ensuring the effectiveness of the developmental/behavioral pathways system through networking, linkages, collaborative projects and incentives. 3) Leverage opportunities to effect systematic change in practices and service coordination. 4) Raise public and professional awareness and understanding around optimizing early childhood development and encourage the implementation of developmental/behavioral screening for all children.
2005-2009	LEAPS – part of the First 5 California Special Needs Project	A pilot project designed to screen children at recommended intervals, provide pre-referral interventions, and support families with a higher level of need. The project took place at Pomona Elementary School in Costa Mesa.	<ul style="list-style-type: none"> • Screening results are presented in Table 2 • The most common concerns identified were communication, fine motor, and problem solving. • 99% of parents felt that screening was important. • Statewide, English speakers were more likely to report discussing the screening with program staff and being provided with activities to do at home than were Spanish-speakers. • Outgoing leadership, strong relationships among partners, and regular communication were key to building the service system to meet the needs of the children in the program.

Year(s)	Project/Event	Overview	Findings/ Lessons Learned/ Recommendations
2008-2009	Orange County Developmental Screening Pilot Project	Physician offices were supported to integrate developmental screening into well child visits.	<ul style="list-style-type: none"> • Even with support, only 44% of eligible children were screened. • Screening results are presented in Table 2 • The most common concerns were language or communication, social-emotional/behavior, and motor. • The project was most successful if the medical practice had a champion. • Physicians and office staff needed education about the importance of screening children with a validated tool, child development, and early intervention referrals. • It was feasible to implement screening without monetary incentives. • A data management system was needed to support follow-up on referrals. • Screening efforts need to be coordinated.
2010	Help Me Grow Physician Survey	123 physicians responded to a survey distributed by HMG-OC asking about their knowledge and opinion of HMG.	<ul style="list-style-type: none"> • Nearly all respondents said they had heard of HMG • Over 80% said they referred patients to HMG • Letters from HMG listing the referrals that HMG provided to their patients were helpful • Physicians who had received an in-office presentation from HMG-OC found it helpful and made more referrals to HMG as a result • Making the case for ongoing contact with physician offices, a few physicians said they stopped referring families to HMG when they ran out of information to hand out; some said that over time they forgot about HMG
2011	Help Me Grow Community Provider Survey	60 community providers who had been trained by HMG on how to administer the Ages and Stages Questionnaire (ASQ) responded to a survey distributed by HMG on the value of the training.	<ul style="list-style-type: none"> • Being trained on the ASQ led to greater ability to administer the screening tool, more children being screened, and greater confidence in making referrals based on the screening results. • Benefits of screening included early identification and referral for developmental delays; helping with parent communication and education; and sharing information with other professionals • Barriers to screening included parent factors, such as literacy or being a teen parent; having the resources (time, space) to conduct the screen; selecting the right interval; and concerns about whether parents can accurately answer the questions.
2009-2011	Physician's Developmental Screening Project	119 physicians were trained on how to use validated screening tools and offered 6 months of technical assistance to help them incorporate screening into their routines 71 physicians implemented screening in their practices and just under half of these completed a survey about their experience.	<ul style="list-style-type: none"> • Nearly 60% of age-eligible children in the practices were screened • Screening results are presented in Table 2 • The most common reasons for not screening all children included: the child was already known to have a developmental disability; the office was too busy or forgot to administer the screen; the parent declined to have their child screened; the child's age was not at the recommended interval for screening • 25% of children who scored in the monitoring zone received a referral; only 20% of children needing further assessment received a referral <p>Recommendations include:</p> <ul style="list-style-type: none"> • Educate parents about the value of developmental screening

Year(s)	Project/Event	Overview	Findings/ Lessons Learned/ Recommendations
			<ul style="list-style-type: none"> • support physicians as they implement business practices to make screenings more effective • continue to outreach to physicians about the value of connecting children at risk to further assessments and early intervention services • continue educating doctors about HMG-OC because when doctors know about HMG-OC, they tend to use it
2013	Engage Physicians, Ensure Screening, and Enhance Sustainability	HMG-OC conducted a one-year study with 4 physician offices to screen for developmental progress using evidence-based tools and bill insurance companies for the screening. 29 physicians and medical staff were trained on how to use the ASQ and nearly 600 children were screened by the 3 medical offices that fully participated.	<ul style="list-style-type: none"> • Screening results are presented in Table 2 • 9% of children who scored in the monitoring zone received a referral; 29% of children with at least one score in the Below Cutoff range received a referral • It was difficult to incorporate screening into the office's routine • Parents were not always able to complete the questionnaire correctly, which added time to the screening process • When the screen was completed correctly before the appointment and the child was Above Cutoff on all domains, it opened up time in the appointment to focus on other things, like safety or nutrition • Two practices said the screenings helped them identify delays they might otherwise have missed; one said it did not • Some children were not referred because parents were not concerned and did not want a referral • Some physicians relied on their own experience about when to make referrals rather than use the screening results • Using an evidence-based tool made it easier for physicians to talk to parents about possible developmental delays • Physicians did not receive payment for screens of children who had a capitated insurance plan, but for those in a fee-for-service plan, the average payment was around \$10.
2014	AAP Physician Survey	AAP-Chapter 4 surveyed pediatricians about their use of developmental screening tools. They received 54 responses, of which 38 were physicians and 16 were nurse practitioners or other health care providers.	<ul style="list-style-type: none"> • Most respondents said they use an evidence-based screening tool in their practice • They use a screening tool to ensure children with developmental delays are identified; to improve communication with families, to adopt evidence-based practices into their medical practice; and to improve the efficiency of their practice. A small number said they did it to receive compensation. • The respondents were confident in their ability to provide appropriate referrals • Five respondents who do not use evidence-based tools said they do not use them because they can gauge how children are doing without them; they didn't have the time or staff; or they didn't know how to implement the screening tools • The respondents acknowledged that more than 90% of their families want a developmental screen performed

Year(s)	Project/Event	Overview	Findings/ Lessons Learned/ Recommendations
			<ul style="list-style-type: none"> Most of the 18 respondents who said they bill for the screening received less than \$15 per screen
2014	HRSA grant – funded HMG to establish the Developmental Screening Registry and Network	Healthy Tomorrows grant to establish a developmental screening network and registry. The OC Children’s Screening Registry is an online database designed to enable primary health care providers and community-based providers to enter developmental and behavioral screening data and share information on referrals and outcomes.	<p>The OC Children’s Screening Registry was pilot tested by three separate organizations in spring 2016. A Focus Group was held to gather feedback regarding the ease of use. Final infrastructure of the database is under development to ensure compliance with agreed upon security for shared access by Covered and Non-Covered entities.</p> <p>The Developmental Screening Network serves as the core group for the work on this Capacity Building Project (see 2016 entry below)</p>
2015	Developmental Pathways: Assessing Progress on Orange County’s Developmental & Behavioral Service Delivery System (2008-2015)	An assessment of progress toward achieving the goals and strategies set forward in 2007 by the Developmental Pathways Leadership Committee. The assessment included a review of key documents related to developmental/behavioral services, providers, and initiatives in OC and interviews with representatives from the Committee and other key stakeholders. 17 organizations participated in the assessment.	<ul style="list-style-type: none"> Interviewees felt there has been a positive, upward trend in the number of screenings done and in the quality and accuracy of referrals They believe more screenings are being conducted using validated screening tools and that children are being screened and referred at younger ages Interviewees indicated that convincing physicians to incorporate screening into their practices is an ongoing challenge, partly because of the time involved They believe some physicians still adopt a wait and see approach before they make referrals They recommended increased training on screening and early identification in residency programs There is no centralized, standardized data collection system for ongoing system monitoring Evaluation continues to be a challenge Even without a coordinated, countywide public information campaign, the interviewees thought that public awareness about the value of early identification and intervention has increased
2015	CHIS – California Health Interview Survey	Adults with a child age 1 or older were asked whether they had completed a developmental or behavioral screen about their child.	54.4% of Orange County parents said they had completed a developmental or behavioral questionnaire about their child. This compares to 42.3% in California.
2016	Capacity Building Project	The Children and Families Commission is providing support to a cohort of organizations focused on increasing the number of children screened for developmental delays and making sure they are referred for appropriate services.	The first deliverable is this Landscape Analysis

Table 2. Screening results from four of the projects described in Table 1

Project	Year	Number of screens	No concern/ no risk	No concern/ risk factors present/ Monitoring	Concern and/or risk/ need for further assessment
LEAPS	2005-2009	2135	62%	15%	24%
DSPP – HMG-OC	2008-2009	536	80%	7%	14%
DSPP – HCA-Family Health Department*	2008	801	69%	15%	17%
Physician’s Developmental Screening Project	2009-2011	5248	77%	9%	14%
Engage Physicians, Ensure Screening, and Enhance Sustainability	2013	Nearly 600	58%	29%	13%

*DSPP=Developmental Screening Pilot Project; HCA-Family Health Department serves a primarily low income, higher need population

What’s happening in 2016

To learn about the current state of developmental screening in Orange County, members of the Developmental Screening Cohort were asked to report on their organization’s screening efforts and provide their thoughts on the barriers to screening and connecting children to services. Responses to some questions were discussed at subsequent cohort meetings and additional explanation and suggestions made then are included in this report.

Responses were received from 16 members of the cohort:

- CalOptima
- Child Abuse Prevention Center
- Children’s Bureau
- CHOC Children’s
- Family Support Network
- Health Care Agency – Child Health Clinic
- Health Care Agency – Public Health Nursing
- Help Me Grow Orange County
- MOMS Orange County
- OCDE (Marc Lerner)
- Orange County Head Start
- Pretend City
- Rancho Santiago CCD
- Regional Center-Comfort Connection
- School Readiness Nurses
- Social Services Agency

In addition, information was received from Kaiser Permanente, which is not a cohort member. That information will be described later.

The information from the questionnaire will be presented in a sequence that starts with how the organization identifies children to be screened, including outreach to families, how many children were

screened in a 12-month time period, how many children were identified as needing further assessment or services, how many children were referred, where they were referred to, and what the barriers are with screening and referring.

Outreach and how children are identified for screening

Eleven respondents indicated that children were screened because they were enrolled in a program or were a patient at a clinic. In other words, there was no specific outreach related to developmental screening; the screening occurred because the child was receiving a particular service, such as a well-child checkup or was enrolled in a preschool. Other programs/agencies offer screening as a stand-alone service, meaning they screen and refer children but it is not necessarily connected with other services offered by the agency. Children are referred to these programs from preschools, health care providers, social services, and Help Me Grow. Sometimes the parent finds these organizations on their own because they have a concern about their child. These organizations also are more likely to conduct outreach in the community to encourage families to have their children screened. The outreach efforts of all the respondents include the following:

- ▶ Through routine/regular contacts with parents, including home visits
- ▶ Part of general outreach for the program
- ▶ Resource fairs
- ▶ Screening days and events
- ▶ Email to various agencies
- ▶ Parent newsletter
- ▶ Presentations to parents at community-based organizations (CBOs), preschools, etc.
- ▶ Trusted person at CBO promotes screenings to parents
- ▶ Table at Pretend City staffed by school readiness nurses (SRNs)
- ▶ Letter to foster parents
- ▶ School district family pages – online
- ▶ Quality Rating and Improvement System (QRIS) – rating early care and education (ECE) providers. Providers with a 5-star rating screen for developmental progress.
- ▶ Outreach to pediatricians, ECE providers, CBOs

All the organizations said they explain the importance of screening to parents either at the time the child is screened or as part of their outreach efforts. However, there does not appear to be a consistent, well-organized public information campaign to inform parents about the importance of developmental screening and how and where they can get their child screened.

Screening tools used

Organizations may use more than one screening tool. Twelve of the responding organizations use the Ages and Stages Questionnaire (ASQ); 7 use the Ages and Stages Questionnaire – Social Emotional (ASQ-SE); 5 use the PEDS; 3 use the M-CHAT; 2 use the Eyberg, and 1 each use the Edinburgh, Denver, or DP-3 (Developmental Profile-3).

Who conducts the screenings?

Screenings are conducted by a wide range of paraprofessionals and professionals. Five organizations reported using nurses and/or physicians; five use case workers or care coordinators; and five use teachers or early childhood educators. One reported that parents complete the screening on their own either online or by filling out a form they pick up at their location. Another said they either mail the screening tool to the parents or send a link so they can complete it online.

Where are screenings conducted?

Most of the organizations conduct screenings throughout Orange County or at a central location with children coming from throughout Orange County. Two organizations focus on children in Santa Ana and one of those also screens children from Orange. Another organization, for one of its programs, focuses on south Orange County.

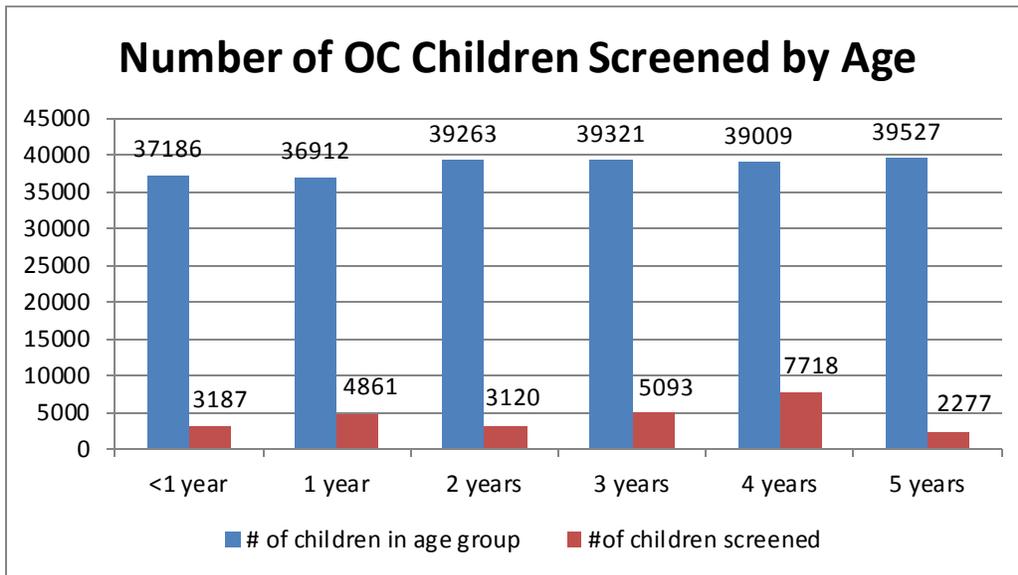
Eleven of the organizations conduct screenings in the child's home. Two offer parents the option to complete screens online. Two conduct screenings in a medical clinic and two at community-based locations. Other places and options include early education centers, social service agency offices, and by phone.

How many children were screened?

Fourteen respondents provided the number of children screened by their organization in a recent 12-month period. Respondents could choose whatever recent 12-month period was easiest for them to report on. All but two reported for the period from July 2014 to June 2015; two reported for January to December 2015. Collectively, the responding cohort members screened 26,661 children. While each respondent provided an unduplicated count of the children they screened, a child would be counted twice or more if they were screened by more than one organization. This may especially apply to the children reported by CalOptima and CHOC because both pulled their data from billing information. If CHOC billed CalOptima for a screening conducted at one of its clinics, it would have been reported by both organizations.

Thirteen of the respondents also reported the number of children screened by the age of the child – for a total of 26,256 children. In Figure 1, the number of children in Orange County for each age group (2010 Census) is compared to the number of children screened by cohort members. Two organizations reported screenings for children ages 0-17 months and 18-months to five years. These children were included with the age 1 and age 3 screenings respectively accounting for a total of 803 children in the age 1 group and 194 in the age 3 group.

Figure 1.



The two boxes below and the results of a recent physician survey (see page 17) provide some insights regarding physician practices and their use of evidence-based developmental screening tools. However, it is still difficult to know how many children are screened through physician practices. The American Academy of Pediatrics recommends screening children at 9-, 18-, and 24- or 30-month visits, as well as any other time concerns are raised during ongoing surveillance. If we had complete data from physicians, we would almost assuredly see greater numbers of children age 3 and under being screened.

Developmental Screening in Orange County Physician Offices

HMG’s EPIC Coordinator (Educating Providers in the Community) visits physician offices throughout the year to provide outreach about HMG services, training on how to use standardized developmental screening tools and advice on incorporating screening into their practice. At each visit, the EPIC coordinator has the practice complete a short feedback form that asks whether the office routinely conducts developmental screening at well-child visits, whether they use a standardized screening tool, such as the PEDS or ASQ, and whether they bill for screening.

During the 12-month period from February 2015 through January 2016, HMG received responses to these questions from 88 practices.

- 57% said they routinely screen AND use a standardized screening tool
- 23% said they routinely screen but DO NOT use a standardized screening tool
- 19% said they do not routinely screen (although 3 indicated they use standardized tools even though they don’t screen routinely)

Developmental screening at Kaiser Permanente

Based on an email exchange with Kaiser Permanente physicians.

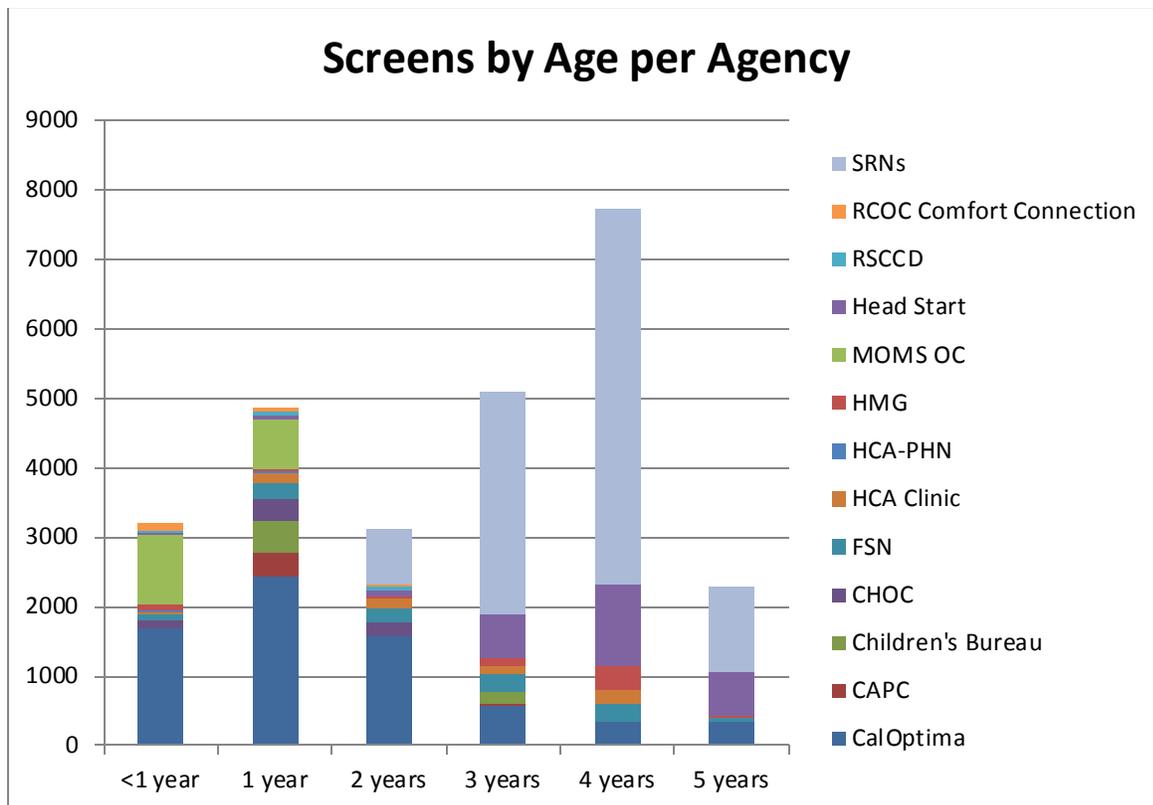
Kaiser Permanente has committed to screening children at all well-child visits. They use a tool that was developed for this purpose and is not an evidence-based tool. The parent is given a check list based on the child's chronologic age by the staff as they check in. The provider then reviews the screening tool with the parent during the visit. Based on review of the screening tool, children with parental and provider concerns are referred to a Developmental physician. In Orange County an M-CHAT is administered over the phone by a Developmental Coordinator to all appropriate patients referred for a Developmental physician consult.

All consults are completed within Kaiser Permanente except that some children are referred to Regional Center or their school district prior to assessment by a Developmental physician.

In Orange County, Kaiser Permanente screens nearly 100% of the 2-year-olds enrolled in its system, but that drops to 60-70% by age 5. A rough estimate is that Kaiser Permanente screens 20,000 to 25,000 Orange County children each year.

Figure 2 shows the number of children screened by age and by agency. While some organizations screen children of all ages, others focus on children within certain age groups. For example, school readiness nurses screen children ages 2-5, and primarily ages 3 and 4, while MOMS Orange County screens children age 1 or younger.

Figure 2.



Screening results

Eleven organizations were able to report the results of the screenings. This table shows the percentage of children whose screening results indicated the need for further evaluation, monitoring, or follow-up with the parent for each agency that uses the specified screening tool.

Table 3.

Ages and Stages Questionnaire		
Organization	Below Cutoff – further evaluation recommended	Percent “monitoring”
Orange County Head Start	6%	26%
Pretend City	8%	25%
Rancho Santiago CCD	9%	37%
Regional Center-Comfort Connection	10%	20%
MOMS Orange County	12%	NA
OC Child Abuse Prevention Center	13%	13%
HMG-OC	19%	24%
School Readiness Nurses	30%	10%
Early Childhood Services System of Care (Social Services Agency)	51%	NA
Ages and Stages Questionnaire – Social Emotional		
Organization	Above Cutoff – further evaluation recommended	Monitoring
Orange County Head Start	0.8%	NA
Rancho Santiago CCD	8%	NA
HMG-OC	22%	NA
School Readiness Nurses	30%	20%
Family Support Network	37%	NA
PEDS		
Organization	Path A – further evaluation recommended	Paths B,C, or D – further screening, referral, follow-up recommended
HCA-Child Health Clinic	2.5%	11.5%
School Readiness Nurses	15%	85%
Family Support Network	55%	29%

There is no information about outcomes of the M-CHAT or any of the other screening tools used by the responding organizations.

In a discussion about the screening results reported by the various organizations, it was noted that Head Start, Pretend City, Rancho Santiago CCD, MOMS-OC, and Prevention Center screen children who are enrolled in their programs and/or are representative of the general population, so it is expected that a relatively low percentage of the children would have a screen that led to further evaluation. HMG-OC often screens children about whom the parent already has a concern, so a higher rate of need for

further assessment is expected. Children in the Early Childhood Services System of Care are in the foster care system and at high risk for developmental delays. Regional Center – Comfort Connection refers some children to services without screening them, therefore, the percent of children screened who need further assessment is fairly low. Family Support Network conducts screening events in low-income neighborhoods and also screens children who are referred to them because there is already a concern, which may explain the high rate of identifying children who need further assessment.

When a screen identifies a potential problem, the organizations indicated they discuss the results with the parents, refer the child for further screening and/or assessment, and refer families to Help Me Grow, Regional Center, the child’s school district, or another organization/service. One organization said they provide education about stimulating activities if the screening result is “mild.”

Referrals

The percent of children referred for further assessment or for services is presented in Table 4.

Table 4.

Percent of all children screened who were referred for further assessment	Reporting Organization
6%	Rancho Santiago Community College District
8%	HCA – Child Health Clinic
8%	Pretend City
9%	Help Me Grow
26%	Orange County Head Start
30%	School Readiness Nurses
33%	MOMS Orange County
36%	Regional Center – Comfort Connection
51%	SSA-Early Childhood System of Care
85%	Family Support Network (includes referrals for all types of concerns, including vision, hearing, and dental)
Percent of children screened who were referred for services	Reporting Organization
6%	HCA – Child Health Clinic
20%	School Readiness Nurses
46%	Family Support Network
80%	Help Me Grow
99%	MOMS Orange County
100%	Orange County Head Start
100%	Regional Center – Comfort Connection

As noted above, Regional Center – Comfort Connection refers a larger percentage of children than it identifies as needing assessment through screening because some children are referred without being screened. The percentage of children referred for services may be high for some organizations because the regular service they provide may be considered a service to which the child was referred or the

organization makes a practice of referring families to parenting classes or other pre-intervention services regardless of screening results.

The most common referral resources used by the reporting organizations (with the number of organizations reporting that they use the resource preceding the name) were:

- 10 – Regional Center
- 9 – school districts
- 6 – Parent support/parent education services
- 5 – Help Me Grow
- 4 – Pediatrician/Primary care provider
- 4 – Head Start; Learning Links; educational/enrichment programs; Childhood Language Center
- 3 – Early Development Assessment Center (EDAC)
- 3 – Children’s Bureau/Prevention Center
- 3 – Behavioral health services
- 2 – Family Support Network
- 1 each – Center for Autism and Neurodevelopmental Disorders; WIC; Healthy Smiles; car seats; California Youth Services; Providence Speech and Hearing; Expressions; Riverview

Ten responding organizations said they follow-up with the parents to find out if the child was connected to services; two said they do this sometimes; and one does not follow-up with the parents because they refer families to Help Me Grow for connection to service and follow-up. The organizations use a multitude of strategies for following up on referrals. Most common are phone calls to the parents and face-to-face contact during home visits or return appointments. Other methods include contacting providers, email and regular mail.

There was little consensus among the respondents about which services are the most challenging for parents to obtain. Four mentioned behavioral health services, but no other service was mentioned by more than one respondent. The services mentioned by only one respondent included: fine and gross motor; speech; developmental evaluation for children not eligible for Regional Center or school district services; Regional Center because of the eligibility requirements; inclusion support; parenting classes because of the cost; car seats; school district preschool; Head Start; and social skills/socialization support for children with behavioral/developmental problems and without autism. A few other responses were more general, just mentioning long wait lists, location, cost, and time of day, without referencing a particular service type.

Barriers to screening

The respondents were asked for their opinions about barriers to screening young children and barriers to connecting children to further assessment and/or services. The initial responses were discussed at a cohort meeting and additions to the list were made based on that conversation. The barriers to screening could be grouped into four categories as shown below:

- ▶ Parent Issues
 - Insufficient knowledge of child growth and development
 - Do not understand the importance/value of developmental screening
 - Do not cooperate
 - Do not follow through
 - Missed appointments
 - Denial; afraid to find out if there is a problem
 - Stigma; cultural barriers
 - Parent literacy too low to read and comprehend the questions
- ▶ Provider Issues (both medical and ECE providers)
 - Dismissive
 - Not enough time
 - Not required; not a HEDIS measure
 - Lack of awareness about the value of developmental screening and early intervention
 - Unwilling to screen as part of well-child visit
 - Can't bill separately for screening
 - Do not value evidence-based tools
 - Use tools incorrectly – wrong interval; score incorrectly; misinterpret
 - Do not understand that a screen is not a diagnostic tool and that further evaluation may be needed
- ▶ Access Issues
 - Language – there are so many languages spoken in Orange County – can't be prepared for all at screening events
 - Transportation
 - Lack of funding
- ▶ Child Issues
 - Child cooperation
 - Foster child too new to home to result in accurate screening

There was a general sense that parents don't demand or expect screening by their health care provider because they don't understand its importance and they often don't know enough about age-appropriate child growth and development to know if their child is on target or behind. Some may not want their child screened because of stigma associated with developmental delays and they don't want their child labeled. Parents are busy and may not have time to complete a questionnaire or even take their child to their well-child appointment. Some parents do not read and comprehend well enough to answer the questions on a developmental screening tool.

Providers (both medical and early care and education professionals) present their own set of concerns. Physicians, in particular, may not be able to bill for the costs of screening (especially if the child is in an HMO) or may not feel that the meager compensation is worth the effort. If screening with an evidence-based tool is not required or monitored, they may believe they can do just as well without it. There also

was concern that some providers administer the tool incorrectly and misinterpret the results. Providers are very busy and may not budget or prioritize the time for developmental screening.

A set of access barriers were identified as well, related to the many languages spoken in Orange County, transportation, and lack of funding to conduct developmental screening.

Barriers to children being connected to service

Barriers to children being connected to service also fell into four categories that were similar yet slightly different from the barriers to screening:

- ▶ **Parent Issues**
 - Not ready to face the problem; believe their child will grow out of it
 - Don't want their child labeled
 - Don't follow through with referrals
 - Don't understand the value of early intervention
 - Don't understand the value of participating in ALL sessions
 - Gender issues – case workers have a difficult time connecting with fathers
 - Cultural issues – even when caseworker speaks the same language
- ▶ **Provider Issues**
 - Refuse to authorize evaluation
 - Time
 - Lack of awareness of available resources or value of early intervention
- ▶ **System Issues**
 - Difficult to navigate system
 - Need care coordination
 - Lack of parent friendly procedures
 - Too few OT, PT, speech, and language services
- ▶ **Access Issues**
 - Transportation (mentioned by 5 respondents)
 - Language/culture – there are so many languages spoken in Orange County
 - Wait lists
 - Work schedules
 - Evaluation resource is not in insurance network
 - Cost

Parent barriers to connecting the child to services were similar to barriers to screening the child, with the addition of a few more – parents may not understand the benefit of early intervention, thinking their child will just grow out of it; there also can be gender/cultural issues that occur when, for example,

the mother is willing to obtain the recommended services but the father (in some cultures more than others) is not, perhaps because of stigma and/or pride.

Providers may not authorize further evaluation, preferring to wait and see; may not have or take the time to make referrals; or may not be aware of all the resources available for children with developmental delays.

In addition, the service system can be difficult for parents to navigate, especially with regards to eligibility and insurance coverage. Care coordination can assist with making sure children are connected to needed services, and some organizations, like HMG, provide this. The respondents also felt there are too few occupational therapy, physical therapy, and speech and language services in the county.

Transportation was mentioned by 5 respondents as a potential barrier to connecting children to services, along with language and cultural barriers, work schedules making it difficult for parents to take their children to appointments, wait lists for some services, insurance coverage (or lack of coverage), and costs.

Physician Survey conducted in September/October 2016

In September and October of 2016, 56 Orange County pediatric and family medicine practices responded to a survey asking for their experiences with and opinions about developmental screening using evidence-based tools. The full report of the survey results is in Appendix C, starting on page 30.

Respondents were asked to complete the survey for their practice, regardless of whether they were a solo practitioner or part of a group practice. However, they were not asked whether they were responding for just themselves or a group practice. This makes responses on practice size and numbers of children screened difficult to interpret. There also is no way to know what percentage of Orange County medical practices were represented by the survey respondents. Even so, the responses provide valuable insights into physician practices and opinions about developmental screening.

Details of some of the key findings are provided below, but to summarize, they show that many, but not all, physicians (at least among the survey respondents) routinely screen young children using evidence-based tools during well-child checkups. This is especially true at the 18 and 24-month checkups. Most of the physicians said they inform the parents of potential problems identified in a screen, provide activities the parents can do with their child, and refer the parents to resources to address the potential problem.

Physicians acknowledge that using an evidence-based tool makes it easier to identify developmental delays and talk to the family about possible developmental problems. However, time constraints, the lack of reimbursement, and the shortage of referral resources remain barriers to routine screening. More detail about these findings is provided below.

Among the 53 respondents who provided detailed information about their screening process,

- 57% used the ASQ-3, PEDS, or PSC to screen for developmental delays in 95% of the children they see
- 15% used one of these tools with more than half but fewer than 95% of the children they see
- 11% used one of these tools with about half of the children they see
- 11% used one of these tools with fewer than half the children they see
- 17% did not use any of these tools at all

The AAP recommends that children be routinely screened using an evidence-based tool at their 9, 18, and 24 or 30-month well child checkups. Respondents were asked about their screening practices at each of these milestones.

Well-child checkup	Percent of respondents who said they screen 95% or more of the children they see at this interval	Percent of respondents who said they screen none of the children they see at this interval
9-months	52.2%	30.4%
18-months	76.1%	15.2%
24-months*	65.2%	17.4%

*Respondents were asked about their practices at the 30-month checkups. Those who screened 95% or more at 30 months also screened 95% or more at 24 months; those who did not screen at 24 months also did not screen at 30 months.

About half of the respondents estimated that fewer than 10% of the children they screen are found to be at risk for developmental delays or social-emotional/behavioral concerns.

Most respondents (91%) said fewer than half of the children who are identified at risk for developmental delays or social-emotional/behavioral concerns are referred for further assessment.

However, there are other actions the respondents always or usually take when a screening indicates a potential problem.

Action taken when a screening indicates a potential problem	Percent who do this all or most of the time
Inform the parents about the potential problem	97.8%
Provide the parents with some activities they can do with the child	91.3%
Refer the parents to resources to address the potential problem	91.3%
Make a note in the child's record to rescreen at the next visit	87.0%
Refer the child to the Regional Center (for children under age 3)	76.1%
Refer the child to speech/audiology services	67.4%
Refer the child to his/her school district (for school-age children)	67.4%
Refer the parent to other supports for connection to services, such as Help Me Grow	58.7%
Refer the child to a clinical specialist for an assessment	50.0%
Refer the family to a Family Resource Center	32.6%
Refer the parents to parenting classes/support, such as COPE or Triple P	28.2%

Over 90% of the respondents agreed with each of three statements about the value of using an evidence-based tool:

- It is important to use an evidence-based screening tool at the recommended intervals
- Using an evidence-based tool makes it easier to identify developmental delays
- Using an evidence-based tool makes it easier to talk to the family about possible developmental problems

Other survey questions explored the barriers pediatricians faced to screening all of their patients. While 64% AGREED that “there is adequate time to perform developmental screening during a typical well-care visit,” 80.4% said that “inadequate time to perform developmental screening during a typical well-care visit” is a barrier for primary care providers to screen.

70% DISAGREED that reimbursement for well-child visits is sufficient to cover time spent on developmental screening and 70% AGREED that inadequate reimbursement for conducting a formal screening using a tool is a barrier for primary care providers to screen.

Having places to refer children for further assessment and early intervention services is important if physicians are to routinely conduct screenings. Just under half (48.9%) AGREED with the statement, “There are sufficient resources in my community to provide services to children with developmental problems.” And, 63.0% AGREED that a “lack of available programs to refer children with developmental and social emotional/behavioral problems” is a barrier for primary care providers to screen young children.

Among a list of barriers presented on the survey, 78% of the respondents said wait lists/capacity issues for service providers were a medium or big problem (56% said it was a BIG problem). Over half also said that affordability, parent follow through, and the amount of time it takes to make a referral were medium or big problems.

Summary

Over the past 15 years, there has been considerable progress in raising awareness of the need to screen young children for developmental progress using evidence-based screening tools and connect children to assessments and services as indicated. The number of children age 5 and under who are screened is believed to have increased, and this assumption is supported by newly released data from the California Health Interview Survey that shows the percent of Orange County parents who said they had filled out a checklist about their child’s learning, development, or behavior rose from 25.1% in 2007 to 54.4% in 2015. Yet, it still falls short of the goal for universal screening in Orange County.

The lack of a centralized data system for developmental screening makes it difficult to establish a baseline or track progress over time. While many of the cohort members were able to quickly produce data on the children their organization screens, not all could do this. The Orange County Children’s Screening Registry was pilot tested in the spring of 2016. Once it is fully implemented, it will be a data

resource about the number of children screened, the ages and locations at which children are screened, and the results of the screenings.

Another concern is reports that not all children who score in the “needs further assessment” category are referred for assessment and/or services. While the organizations that provided information for this report appear to have a good track record for making referrals, there is evidence from recent physician studies that some physicians still prefer to rely on their own expertise or “wait and see” rather than make a referral based on screening results. In the recently completed physician survey, most respondents (91%) said fewer than half of the children who are identified at risk for developmental delays or social-emotional/behavioral concerns were referred for further assessment.

The challenges to achieving universal screening and connection to services emanate from various sources, starting with the two main actors – parents and providers. There was broad agreement about these challenges, and while there have been concerted efforts to address the challenges with providers, there has not been a consistent, well-organized campaign to educate parents about the value of developmental screening and early intervention to address developmental delays in their children. Stigma and a lack of knowledge about typical development and the benefits of early intervention contribute to this continued challenge. Few parents have come to expect or demand a developmental screen as part of their child’s well-child checkup.

The efforts to get physicians to incorporate developmental screening into their routine practices have served to show how difficult it can be to change routines, especially when there are a number of factors working against it, including the amount of time physicians have with patients, the inability to receive additional payment for screenings if the child’s insurance is capitated, and a shortage of referral resources. Previous efforts also point out that it takes ongoing, consistent communication with physician offices to establish and maintain developmental screening routines.

Next Steps

The Cohort may want to consider methods to gain more input from parents. With the exception of the parent survey that was part of the LEAPS evaluation, there have been very few opportunities to learn directly from parents about their views of developmental screening and early intervention. If parents contribute to the challenges in making sure every child is screened, it would be helpful to hear their voice on why this is the case.

The information from this review will be used in the development of a Theory of Change for expanding developmental screening in Orange County and ensuring that children are referred for service as needed.

Appendix A

2004 – Building a Model System of Developmental Services in Orange County

In 2004, the Commission sponsored a study by the UCLA Center for Healthier Children, Families and Communities that examined the existing developmental /behavioral service delivery system and presented recommendations to support a model system of developmental services. A core recommendation of this report, “Building a Model System of Developmental Services in Orange County,” was the creation of an integrated system focusing on optimizing healthy child development through partnerships among families, primary care providers, and educators.

2004 – School Readiness Nurse Initiative

The Commission funded School Readiness Nurses (SRNs) in Orange County’s elementary school districts. The SRNs provide health-related support by conducting health education classes to parents and connecting children to health insurance and a medical home. They also facilitate early identification and treatment of health and development issues by screening preschool-age children for developmental delays and providing referrals to meet the health and social service needs of children and their families.

2005 – Help Me Grow established

One year later, Help Me Grow Orange County (HMG-OC) was launched and was the first site to replicate Help Me Grow- Connecticut, which was started in 1998. Help Me Grow is a comprehensive, coordinated system designed to assist child health care providers, other professionals, and families in improving developmental outcomes for children, birth through five. One of the core components of the system is a centralized call center staffed by care coordinators who assist families and professionals in connecting children to appropriate programs and services. In addition, Help Me Grow Orange County has played an important role in promoting the use of evidence-based screening tools by training physicians, nurses, and early childhood educators on how to properly administer and score the tools.

2007 – Pathways Leadership Committee

In May 2007, the Commission convened the Pathways Leadership Committee to guide a collaborative, community-focused planning effort intended to strengthen the pathway for young children receiving or in need of developmental and behavioral services in Orange County. This Committee identified a primary outcome for the next three to five years (2008-2013) - **All children in Orange County will have recommended developmental/behavioral baseline screenings at milestone ages with linkage to appropriate services.**

The plan prepared by the Pathways Leadership Committee was designed to 1) Significantly increase the number of children screened and referred; 2) Ensure all services are family centered; 3) Manage the referral process through Help Me Grow as the system coordinator and 4) Provide ongoing management and measurement of the overall system of care to stimulate improvement and innovation.

The Committee also developed four primary goals to achieve the targeted outcome:

GOAL 1: Develop the infrastructure to ensure the effectiveness of the Orange County developmental/behavioral pathways system.

GOAL 2: Develop relationships among community partners that serve children, birth through five, and their families ensuring the effectiveness of the developmental/behavioral pathways system through networking, linkages, collaborative projects and incentives.

GOAL 3: Leverage opportunities to effect systematic change in practices and service coordination.

GOAL 4: Raise public and professional awareness and understanding around optimizing early childhood development and encourage the implementation of developmental/behavioral screening for all children.

The plan included specific goals and strategies, and can be found at this web address:

<http://www.helpmegrowoc.org/files/PHS%20Pathways%20Presentation.pdf>

2007 – California Health Interview Survey (CHIS) in 2007

The 2007 California Health Interview Survey included questions about whether parents had completed a checklist regarding their child's development. These questions were asked of adults who had a child age 1 or older: "Did they ever have you fill out a checklist about concerns you have about {his/her} learning, development, or behavior?" and "Did they ever have you fill out a checklist of activities that (child) can do, such as certain physical tasks, whether {her/she} can draw certain objects, or ways {he/she} can communicate with you?"

25.1% of Orange County parents said they had completed a developmental or behavioral questionnaire about their child. This compared to 22.8% in California.

2005-2009 – First 5 California Special Needs Project (SNP): LEAPS (Learning, Early Intervention, and Parent Support)

The SNP was designed to ensure early identification of children with disabilities and other special needs and provide early intervention services through coordinated delivery of community-based services. LEAPS was one of 10 demonstration sites throughout California, and was carried out at Pomona Elementary School in the Newport-Mesa Unified School District (NMUSD). Children ages 0-5 in the Pomona Elementary School catchment area and their families were eligible for screening, preschool, parent education, and parent/child activities. Over 500 children were screened each of the four years of the project. Children who screened at risk were offered pre-referral interventions and, if needed, support obtaining special education services. The program led to the development of a protocol for developmental screening, referral, and follow-up that has been implemented in all of the NMUSD school-based preschools.

Over four years, on average, 62% of the children screened as having no concerns and no risks; 15% had no concerns but risk factors were present; and 24% were found to need further assessment. By age group, 1- and 2-year olds were most likely to be recommended for assessment, at around 30%. The three most common domains for which children were recommended follow-up were communication, fine motor, and problem solving.

A family satisfaction survey was conducted at all 10 sites throughout California. Ninety-nine percent of all respondents believed that early developmental screening is important for their child, primarily because it allowed them to find help for delays or problems as well as prevent illnesses. Statewide, there were differences in how English-speakers interacted with staff as compared to Spanish-speakers. English speakers were more likely to report discussing the screening with program staff than Spanish-speakers (82% compared to 69%). English-speakers were also more likely to report that program staff provided them with activities to do at home (70% compared to 58%). These results were not broken out by county/project, so it is not known to what extent these results applied to Orange County, where 86% of the survey and 85% of interview respondents spoke Spanish.

Another aspect of the SNP was to coordinate resources so there would be services available to children and families with needs. Interviews with site coordinators and First 5 staff found that the sites engaged with existing partners and brought in new partners. Regular communication was key to maintaining and building these relationships as well as commitment to a shared vision and understanding of roles. Having outgoing leadership and strong relationships among the partners led to greater success in ensuring appropriate referrals and development new services to fill critical gaps.

Sources:

Orange County Developmental Screening Pilot Project report, Limor Zimskind, Brandy Miller, and Alyce Mastrianni, October 2009.

PowerPoint to the Community Action Planning Team; June 2009; received from Limor Zimskind

2008 Special Needs Project Evaluation,

Special Needs Project: Perceptions and Beliefs on Coordinating Resources and Inclusion of children with Special Needs, WestEd Center for Prevention & Early Intervention,

2007-2009 Orange County Developmental Screening Pilot Project (DSPP)

After the report of the Developmental Pathways Leadership Committee, the Commission embarked on the OC Developmental Screening Pilot Project. Four organizations participated by working with physician practices to screen children during well child checkups using either the PEDS or the ASQ. The practices were expected to report the results of the screenings and participate in evaluation of the project. In addition, four private preschools participated but did not report screening results.

Over the course of the project, it was estimated that 2229 children were eligible for a screening, of which 985 children were screened, or 44% of eligible children were screened. Screening results are

shown for two of the participating organizations (one did not report screening results and the other's results included duplication of children who were screened using two different tools resulting in a distortion of the results). The most common concerns identified were language or communication, social-emotional/behavior, and motor.

Across the three organizations, the percent of screenings that showed no concern but risk factors present and resulted in a referral for further assessment or for services ranged from 21% to 75%. The percent of screenings that showed a concern or recommended assessment that resulted in a referral ranged from 59% to 91%.

Lessons learned through the Developmental Screening Pilot Project included:

- The need to identify a champion at physician offices to advocate for conducting developmental screening as part of well-child checkups
- Educate physicians and medical office staff about child development, the importance of screening with a validated tool, and early intervention referrals
- It is feasible to implement developmental screening without the use of monetary incentives (the project included incentives for some, but not all, of the medical practices to participate). Some practices indicated that being provided the screening tools, referral resources, and technical assistance was sufficient incentive to participate.

Recommendations from the project included:

- Explore ways to follow-up on referrals, including data systems to support tracking the child after a referral is made
- Coordinate developmental screening efforts, including increased communication between a child's early care and education program and their medical home. This would reduce duplication of screening and help ensure children are connected to service.

HMG surveys and projects

Between 2010 and 2013, HMG-OC conducted two surveys and participated in two projects that yielded some information that speaks to the progress and the challenges of meeting the targeted outcome that all children are screened with linkage to appropriate services.

2010 – Physician survey

In 2010, 123 physicians responded to a survey distributed by HMG-OC asking about their knowledge and opinion of HMG. Nearly all respondents said they had heard of HMG and over 80% said they referred patients there. Most physicians said the letters they received from HMG listing the referrals that HMG provided to their patients were helpful. Physicians who had received an in-office presentation from HMG-OC found it helpful and made more referrals to HMG as a result. A number of offices said they stopped referring when they ran out of information or that they forgot about HMG. One commented, "I refer to HMG when I think of it." The full report is available at this web address:

<http://www.helpmegrowoc.org/files/Help%20Me%20Grow%20Physician%20Survey-2010-Final.pdf>

2011 – Community provider survey

A survey in 2011 of community providers who had been trained by HMG on how to administer the Ages and Stages Questionnaire (ASQ) showed that being trained on the ASQ led to greater ability to administer the screening tool, more children being screened, and greater confidence in making referrals based on the screening results. Respondents said benefits of screening included early identification and referral for developmental delays; helping with parent communication and education; and sharing information with other professionals. Barriers to screening included parent factors, such as literacy or teen parent; having the resources (time, space) to conduct the screen; selecting the right interval; and concerns about whether parents can accurately answer the questions. The full report is located here: <http://www.helpmegrowoc.org/files/Help%20Me%20Grow%20Orange%20County%20ASQ%20Participant%20Survey-Spring%202011%20Final%208-2.pdf>

2009-2011 – Physician’s Developmental Screening Project

Over a three-year period (2009-2011), HMG-OC trained 119 physicians on how to use validated screening tools and offered 6-months of technical assistance to help them incorporate screening into their routines. Seventy-one of the physicians (60%) actually implemented developmental screening in their practices. Just under half of these physicians completed a survey and said they screened nearly 60% of the children in their practice. The most common reasons they gave for not screening all children included: the child was already known to have a developmental disability; the office was too busy or forgot to administer the screen; the parent declined to have their child screened; the child’s age was not at the recommended interval for screening.

More than three-fourths of the children who were screened had no concerns; 9% were in the monitoring range on the ASQ; and 14% were found to need further assessment. Despite these results, only 25% of those in the monitoring zone received a referral and 20% of children whose results showed a need for further assessment were referred.

The report included a number of recommendations, several of which were especially relevant to the efforts to increase the number of children screened and connected to service. These were 1) educate parents about the value of developmental screening; 2) support physicians as they implement business practices to make screenings more effective; 3) continue to outreach to physicians about the value of connecting children at risk to further assessments and early intervention services; and 4) continue educating doctors about HMG-OC because when doctors know about HMG-OC, they tend to use it.

The full report can be found at this web address: <http://www.helpmegrowoc.org/files/PDS%20Report-Final.pdf>

2013 – Engage Physicians, Ensure Screening, and Enhance Sustainability

In 2013, HMG-OC conducted a one-year study to recruit physician offices to conduct routine developmental screening using evidence-based tools and bill insurance companies for the screening. An effort was made to choose practices that did not routinely screen children for developmental delays and

whose patients had a variety of insurers. Sixteen physician offices were invited to participate and four agreed to do so. Each participating practice was trained on how to administer and score the ASQ. After the training, one of the four decided not to implement routine screening using an evidence-based tool, although they did participate in the evaluation of the project.

Twenty-nine physicians and medical staff were trained on how to use the ASQ. Nearly 600 children were screened by the three medical offices, most at just one of the three. For two practices, the screening results and information about referrals made were provided to HMG-OC. For the other practice, HMG-OC scored the screens and contacted the families directly to make referrals. Fifty-eight percent of the children scored Above Cutoff in all five areas of the ASQ; 29% were in the Monitoring range in at least one domain; and 13% had at least one area that scored Below Cutoff, indicating a need for referral for assessment and/or services.

A total of 39 children received a referral – 29% of those with at least one score in the Below Cutoff range received a referral and 9% of those in the Monitoring zone were referred.

Physicians at all four practices participated in an end-of-project interview. The three practices that administered the ASQ found it challenging to fit the screening into their routine. They also had problems with parents not completing the questionnaire properly, which meant scoring and interpreting the results took more time. However, when the ASQ was completed properly before the appointment and the child was Above Cutoff on all domains, it actually opened up more time in the appointment to talk about other things, like nutrition and safety.

The practice that did most of the screenings did not think the screening identified any problems they didn't already know about. The other two practices said they identified a few new cases due to the screening.

Children were not always referred on the basis of the screening results because some physicians relied more on their own experience about when to refer. Another reason children were not referred was that parents were not concerned and did not want a referral.

Physicians received about \$10 for each screen in fee-for-service insurance plans but did not receive any additional payment for screening children in capitated plans, like an HMO. The problem with capitated plans was summed up well by one physician: "The well-child checkup is paid the same amount whether the screening is done or not – and the screening is not required. There's no pay for performance; no bonus for doing developmental screening. And if you generate more referrals, you risk looking like you are referring too much."

One positive that physicians noted about using an evidence-based tool was that it made it easier to talk with the parents when a problem was identified.

The full report can be found at this web address:

<http://www.helpmegrowoc.org/files/Engage%20Physicians,%20Ensure%20Screening,%20Enhance%20Sustainability.%20HMG%20Orange%20County%202013%20.pdf>

2014 – AAP survey of physicians

In 2014, Chapter 4 of the American Academy of Pediatrics surveyed Orange County pediatricians about their use of developmental screening tools. Thirty-eight of the 54 respondents were physicians and another 16 were nurse practitioners or other health care providers. Most of the respondents said they use a developmental screening tool in their practice, and most used either the ASQ or the PEDS (Parent Evaluation of Developmental Status). Those who use a screening tool said the primary reasons they use a screening tool is to ensure children with developmental delays are identified; to improve communication with families; adopt evidence-based practices into their medical practice; and to improve the efficiency of their practice. A small number said they did it to receive compensation.

Respondents said they were confident in their ability to provide appropriate referrals when children were identified with a concern. More than half of the respondents said they had made referrals to Regional Center; speech/audiology; a school district; pediatric neurology or for a developmental pediatric evaluation; or Help Me Grow Orange County.

Five respondents answered a question asking why they do not use a developmental screening tool and three said it is because they can gauge how children are doing developmentally without using a screening tool. One respondent said they didn't have the time or the staff, and one said they didn't know how to implement the screening tools.

Most respondents estimated that fewer than 10% of their families would NOT want a developmental screen performed. Eighteen respondents said they bill for the screening (using CPT Code 96110) and most receive less than \$15 per screen. Nineteen respondents who didn't bill said they were unaware that compensation was available (6 respondents), that compensation was not allowed (5), or it was not worth the effort (4).

2015 – Developmental Pathways: Assessing Progress on Orange County's Developmental & Behavioral Service Delivery System (2008-2015)

The Commission assessed progress toward the goals and strategies set forth in the 2007 report from the Pathways Leadership Committee. They found that some strategies were completed while others had seen progress or were initiated but not completed. The findings were based on a review of key documents related to developmental/behavioral services, providers, and initiatives in Orange County and interviews of representatives of the Pathways Leadership Committee and other key stakeholders.

Interviewees who either conduct screenings or receive referrals reported that there has been a positive, upward trend in the number of developmental screenings and there has been an improvement in the quality and accuracy of the referrals coming from early childhood education providers and others. They inferred that this was the result of increased use of validated screening tools and stronger referral linkages among community-based providers, schools, and Regional Center. They also felt that children are being screened and referred at earlier ages.

Those interviewed also indicated that increasing the number of physicians conducting screenings using validated tools at the AAP-recommended intervals is an ongoing challenge. They noted that the “wait and see” approach employed by physicians continues to be an entrenched issue with some physicians; there should be increased training on screening and early identification in residency programs; the limited time physicians have at each patient visit makes it challenging to incorporate screening; and that education, awareness, and sustainability efforts should be ongoing in order to embed changes.

The assessment also found that data collection for ongoing system monitoring and evaluation continues to be a challenge. Consistent, standardized data would help with care coordination, systems improvement, and efforts to focus on prevention and wellness.

One of the strategies of the Developmental Pathways was to raise public and professional awareness and understanding around early childhood development and encourage implementation of developmental/behavioral screening for all children. Even without a coordinated, countywide public information campaign, the interviewees thought that public awareness has increased about the value of early identification and intervention. This increase was attributed to information sharing about these topics by Pretend City, Help Me Grow, the schools and early childhood programs, among others.

Appendix B

List of Acronyms Used in this Report

Acronym	Full Name
AAP	American Academy of Pediatrics
ASQ	Ages and Stages Questionnaire
ASQ-SE	Ages and Stages Questionnaire-Social Emotional
CAPC	Orange County Child Abuse Prevention Center
CBO	Community-based Organization
CHIS	California Health Interview Survey
CHOC	CHOC Children’s Hospital
DP-3	Developmental Profile-3
DSPP	Developmental Screening Pilot Project
ECE	Early Care and Education
EDAC	Early Development Assessment Center
EPIC	Educating Providers in the Community
FSN	Family Support Network
HCA	Health Care Agency
HEDIS	Healthcare Effectiveness Data and Information Set
HMG-OC	Help Me Grow-Orange County
HRSA	Health Resources and Services Administration (Federal agency)
LEAPS	Learning, Early Intervention, and Parent Support
M-CHAT	Modified Checklist for Autism in Toddlers
OC	Orange County
OCDE	Orange County Department of Education
OT	Occupational Therapy
PEDS	Parents Evaluation of Developmental Status
PHN	Public Health Nurse
PSC	Pediatric Symptom Checklist
PT	Physical Therapy
QRIS	Quality Rating and Improvement System
RCOC	Regional Center of Orange County
RSCCD	Rancho Santiago Community College District
SNP	Special Needs Project
SRN	School Readiness Nurse
SSA	Social Services Agency
UCI	University of California, Irvine
UCLA	University of California, Los Angeles
WIC	Women, Infants and Children (supplemental nutrition program for WIC)

Appendix C

Physician Survey

January 2017

Methodology

A survey of physician practices that serve children under the age of 6 was conducted in September and October of 2016. The survey was conducted by the Silicon Valley Community Foundation with input on the survey questions from members of the Developmental Screening Cohort. A link to the questionnaire in SurveyMonkey was distributed to pediatricians and family medicine practitioners via email by the American Academy of Pediatrics, Chapter 4, the Coalition of Community Clinics, CHOC Children's Hospital, and members of the Developmental Screening Cohort.

Respondents were asked to complete the survey for their practice, regardless of whether they were a solo practitioner or part of a group practice. However, the survey did not ask whether the respondent was answering the questions for just their own practice or for a group practice, and if a group practice, how many physicians are in the group.

About the responding practices

A total of 56 Orange County physicians, nurse practitioners, and physician assistants completed some or all of the survey. Most of the respondents were pediatricians. The 48 respondents who reported how many children their practice serves collectively serve about 58,000 children under the age of six – an average of 1200 children per practice and a median of 700. The number of children served ranged from 3 to over 10,000. Eight respondents did not answer this question.

A pediatrician or physician had primary responsibility for developmental surveillance at 82% of the practices. A nurse practitioner or physician assistant had this role at 11% of the practices. (N=56)

Developmental screening practices

Developmental screening was defined as "screening children's development and/or behavior through the use of validated or evidence-based tools for the purposes of identifying children who may need more comprehensive evaluation." Nearly all the respondents (91%) said their practice routinely screens children for developmental delays; 7% said they screen only when there is a concern; 2% said they do not screen children for developmental delays. (N=56)

85% said they use a validated or evidence-based screening tool such as the ASQ-3, PSC, or PEDS to screen children for developmental delays. 15% said they do not use an evidence-based tool. (N=55)

47 respondents provided an estimate of the number of children their practice screens in a typical month. The numbers ranged from 1 to 3500, with an average of 172. These numbers cannot be related

to the numbers of children in the practices, because some respondents provided the number of children in the practice but not the number screened per month and vice versa.

The respondent's sites have a variety of ways to have the developmental screening completed and they may employ more than one method (N=55):

- 83.6% - A questionnaire is completed by parents during the well-child visit
- 60.0% - Questions are asked of parents orally during the well-child visit
- 18.2% - A questionnaire is completed by parents in advance of the well-child visit

Only 5 respondents answered a follow-up question for those that ask developmental questions orally – all 5 said in their practice, the questions were asked by a pediatrician or physician. Two also indicated that the questions could be asked by a nurse practitioner in their office.

Who interprets screening results

The person in the office primarily responsible for the interpretation of developmental screenings (n=55):

- 78.2% physician or pediatrician
- 12.7% nurse practitioner
- 1.8% physician assistant
- 7.3% other – (2) whoever is seeing the patient (could be physician, NP, PA, etc.), (1) psychologist, (1) social worker

Providers were trained to interpret developmental screenings through a variety of mechanisms (n=55) (respondents selected all that applied, so the percentages do not add up to 100):

- 65.5% residency/clinical training
- 38.2% attended a training that offered CMEs
- 27.3% self-taught (e.g. manual, video)
- 16.4% in-service training
- 16.4% attended a class/training (no CMEs)
- 1.8% not trained
- 1.8% unsure
- 1.8% other – MOC project

Which screening tools are used

Respondents were asked to consider a list of screening methods and estimate what percent of children in their practice are screened using that method. The screening methods included both evidence-based (e.g., ASQ-3 or PEDS) and non-evidence-based methods (e.g., a checklist developed by the practice).

53 respondents said they use at least one mechanism, including non-evidence based screening tools, to screen at least some children for developmental delays (several respondents indicated that their practice uses more than one of the options 95% of the time or more).

Screening Tools - Full Names

ASQ-3 – Ages and Stages Questionnaire
 ASQ-SE – Ages and States Questionnaire – Social Emotional
 PEDS – Parents Evaluation of Developmental Status
 PSC – Pediatric Symptom Checklist
 Bayley Infant Neurodevelopmental Screener (BINS)
 Brigance Screens and Inventories
 Denver II Developmental Screening Test (DDST)
 M-CHAT – Modified Checklist for Autism in Toddlers

The table below shows how frequently the most commonly accepted evidence-based developmental screening tools are used.

The percentage of children who are screened	ASQ-3	ASQ-SE	PEDS	Pediatric Symptom Checklist (PSC)	M-CHAT (for Autism)
95% or more	35.8%	7.5%	22.6%	3.8%	43.4%
More than half but less than 95%	1.9%	0.0	5.7%	1.9%	7.5%
About half	11.3%	5.7%	1.9%	1.9%	9.4%
Less than half but more than 10%	3.8%	1.9%	3.8%	9.4%	3.8%
10% or fewer	13.2%	11.3%	9.4%	3.8%	11.3%
None/missing	34.0%	73.6%	56.6%	79.2%	24.5%

Of the 19 respondents who said they use the ASQ-3 with 95% of their patients or more, 4 said they also use the ASQ-SE with 95% or more of the children they see; 1 said they use the ASQ-SE with 10% or fewer of the children they see; 11 said they do not use the ASQ-SE with any children.

This table shows the frequency with which other screening methods are used.

The percentage of children who are screened	Clinical Assessment	Informal checklist filled out by parents	Informal checklist filled out by staff	Denver II	Bayley (BINS)	Brigance
95% or more	52.8%	7.5%	17.0%	9.4%*	1.9%**	0.0%
More than half but less than 95%	7.5%	3.8%	1.9%	0.0%	0.0%	0.0%
About half	1.9%	1.9%	0.0%	3.8%	0.0%	0.0%
Less than half but more than 10%	1.9%	0.0%	0.0%	1.9%	0.0%	1.9%
10% or fewer	7.5%	3.8%	1.9%	7.5%	9.4%	5.7%
None/missing	28.3%	83.0%	79.3%	77.4%	88.7%	92.5%

*3 of the 5 respondents who said they use the Denver II with 95% or more of their patients said they also use either the ASQ-3 or the PEDS with 95% or more of their patients. The other 2 respondents indicated they rely primarily on the Denver II, which is NOT considered an evidence-based screening tool for developmental delays.

**this respondent also said they use the ASQ-3 and ASQ-SE with 95% or more of their patients.

30 out of 53 respondents (56.6%) said they use the ASQ, PEDS, or PSC with 95% of the children they see.

Of these 30 respondents:

- 19 (63%) use the ASQ with 95% or more of the children they see.
- 12 (40%) use the PEDS with 95% or more of the children they see.
- 2 (6.7%) use the PSC with 95% or more of the children they see.

The percentage that use at least one of these three evidence-based tools and how often:

The percentage of children who are screened	Using the ASQ-3, PEDS and/or PSC
95% or more	56.6%
More than half but less than 95%	3.8%
About half	11.3%
Less than half but more than 10%	3.8%
10% or fewer	7.5%
None/missing	17.0%
N=53	100.00%

When children are screened

The American Academy of Pediatrics (AAP) recommends that children be screened using an evidence-based tool at their 9, 18, and 24 or 30-month well child checkups. The table below shows the percentage of children respondents indicated their practice screens using evidence-based tools at these intervals. A large majority of the respondents indicated they screen 95% or more of the children they see at the 18 and 24-month well child visits. All of the respondents who said they screen 95% or more at the 30-month visit also indicated they screen 95% or more at the 24-month visit. Just over half screen 95% or more at the 9-month visit. Five of the 46 respondents (10.9%) said they screen none of the children at any of the 6 intervals provided.

The percentage of children who are screened	6-month visit	9-month visit	12-month visit	18-month visit	24-month visit	30-month visit
95% or more	30.4%	52.2%	43.5%	76.1%	65.2%	33.3%
More than half but less than 95%	6.5%	6.5%	4.3%	2.2%	8.7%	2.2%
About half	4.3%	2.2%	2.2%	2.2%	4.3%	6.7%
Less than half but more than 10%	10.9%	4.3%	4.3%	4.3%	0.0%	4.4%
10% or fewer	8.7%	4.3%	10.9%	0.0%	4.3%	6.7%
None/missing	39.1%	30.4%	34.7%	15.2%	17.4%	46.7%
N=	46	46	46	46	46	45

How screenings are documented

Respondents could select from several options to indicate how they record completed screenings in the child's health record (n=47). Most said they scan the summary sheet and attach it to the child's health record.

- 63.8% - The completed tools and/or summary sheet is scanned and attached to the child's health record
- 12.8% - The summary score and each domain score is entered into the child's health record
- 6.4% - Only the summary score is entered into the child's health record
- 4.2% - We record that a screening was completed, but no results are entered in the child's record
- 12.8% - Other
 - Record in electronic health record with totals in each section and scan in
 - Summary score is entered to child's health record thru our electronic medical record system
 - I screen personally and record in chart

How many children screen at risk

Respondents were asked to write in the percentage of children their practice identifies as being at risk for developmental delays or social-emotional/behavioral concerns. Nearly half of the respondents (48.9%) said that fewer than 10% of the children they screen have a concern. Three respondents (6.7%) said half or more of the children they screen are at risk for developmental delays or social-emotional/behavioral concerns.

Percentage of children under age 6 identified as being at risk for developmental delays or social-emotional/behavioral concerns (n=45)	Percentage of practices indicating the specified range
0-4%	15.6%
5-9%	33.3%
10-14%	13.3%
15-19%	8.9%
20-24%	13.3%
25-49%	8.9%
50% or more	6.7%

Respondents were then asked to estimate 1) what percentage of the children were identified through the use of an evidence-based screening tool, with no previous indications of a delay and 2) what percent were identified without the use of an evidence-based tool, because they were previously diagnosed, the parent had indicated a concern, or the child presented with signs that were obvious enough to detect without a screening tool. The survey required that the percentages for the two options add up to 100%.

On average, respondents identified 49% of developmental concerns through the use of an evidence-based screening tool and 51% without the use of an evidence-based tool.

Percentage range	Percent who indicated this range for “identified through the use of an evidence-based screening tool” (n=43)	Percent who indicated this range for “identified without the use of an evidence-based tool” (n=43)
0-24%	27.9%	25.6%
25-49%	7.0%	13.9%
50-75%	30.2%	23.2%
75-100%	34.9%	37.2%
Mean	49%	51%
Median	50%	50%

The percent of children identified at risk who are referred

Respondents selected from 6 frequency options to indicate the percentage of children at-risk who are referred for further assessment. Most respondents (90.7%) said their practice refers fewer than half of the children who are identified as at-risk.

Percentage of children identified at-risk for developmental delays or social-emotional/behavioral concerns who are referred for further assessment	Percent of respondents who selected this response (n=43)
95% or more	2.3%
More than half but less than 95%	0.0
About half	7.0%
Less than half but more than 10%	34.9%
10% or fewer	53.5%
None	2.3%
N=	46

Actions providers take when a potential problem is identified

Respondents were asked to indicate how often they take each of a list of possible actions when a child’s screening indicates a potential problem. Over 90% said they always inform the parents about the potential problem and 78% said they always make a note in the child’s record to rescreen at the next visit. Nearly two thirds said they always provide the parents with some activities they can do with their child. None of the respondents said they never do these things.

However, 26% said they never refer the family to a Family Resource Center and 20% said they never refer families to parenting classes/support.

Action taken when a potential problem is found	All of the time	Most of the time	Some of the time	Never
Inform the parents about the potential problem	91.3%	6.5%	2.2%	0.0
Make a note in the child’s record to rescreen at the next visit	78.3%	8.7%	13.0%	0.0
Provide the parents with some activities they can do with the child	63.0%	28.3%	8.7%	0.0
Refer the parents to resources to address the potential problem	43.5%	47.8%	8.7%	0.0
Refer the child to the Regional Center (for children under age 3)	34.8%	41.3%	21.7%	2.2%
Refer the child to speech/audiology services	30.4%	37.0%	32.6%	0.0
Refer the child to his/her school district (for school age children)	28.3%	39.1%	32.6%	0.0
Refer the child to a clinical specialist for an assessment	26.1%	23.9%	50.0%	0.0
Refer the parent to other supports for connection to services, such as Help Me Grow	17.4%	41.3%	37.0%	4.3%
Refer the family to a Family Resource Center	17.4%	15.2%	41.3%	26.1%
Refer the parents to parenting classes/support, such as COPE or Triple P	6.5%	21.7%	52.2%	19.6%
N=46				

Opinions about Developmental Screening

Respondents were asked to rate how strongly they disagreed or agreed with a series of statements about developmental screening. Nearly all of the respondents agreed with three statements – that it is important to use an evidence-based screening tool at the recommended intervals, that using an evidence-based tool makes it easier to identify developmental delays, and using a standardized tool makes it easier to talk to the family about possible developmental problems. Three-quarters agreed that parents expect their child’s pediatrician to screen their child for developmental delays using evidence-based tools.

While 64% feel there is adequate time during a well-child checkup to complete a developmental screen, 70% do not feel that there is adequate reimbursement for screening.

Statement about Developmental Screening	AGREE at any level	DISAGREE at any level
It is important to use a validated or evidence-based screening tool at the recommended intervals	95.7%	4.3%
Using a validated or evidence-based tool makes it easier to identify developmental delays	93.6%	6.4%*
Using a standardized tool makes it easier to talk to the family about possible developmental problems	93.6%	6.4%
Once I identify developmental delays in a child, I feel confident in how to care for the child, including managing consultations for referrals for therapy	87.2%	12.8%**

Statement about Developmental Screening	AGREE at any level	DISAGREE at any level
Parents expect their child's pediatrician to screen their child for developmental delays using validated or evidence-based screening tools	76.6%	23.4%
I have the clinical expertise to identify most children with developmental delays in my site setting without the use of a formal screening instrument	72.3%	27.6%
During a typical well-care visit, there is adequate time to perform developmental screening	63.8%	36.2%
There are sufficient resources in my community to provide services to children with developmental problems	48.9%	51.1%
Using parental concern about a child's developmental is a good substitute for formal developmental screening	44.7%	55.3%
Reimbursement for well-child visits is sufficient to cover time spent on developmental screening	29.8%	70.2%
N=47		

*all s strongly disagree; **none s strongly disagree

Barriers to Screening

Respondents were asked how strongly they agreed or disagreed that a set of statements are barriers for primary care providers to conduct developmental screening of children under age 6. Unlike the previous question, when 64% agreed there is adequate time to screen, for this question, 80% agreed that inadequate time to perform screenings during a typical well-care visit is a barrier. Like the response to the previous question, 70% felt inadequate reimbursement is a barrier to screening.

Responses to the previous question showed that only 49% felt there are sufficient resources in the community to provide services to children with developmental problems; here, 63% agreed that a lack of available programs to refer children with developmental concerns is a barrier to screening.

Barriers for Primary Care Providers to Screening	AGREE at any level	DISAGREE at any level
Inadequate time to perform developmental screenings during a typical well-care visit	80.4%	19.6%
Inadequate reimbursement for conducting a formal screening using a tool	69.6%	30.4%
Unfamiliarity with validated or evidence-based screening instruments designed for the pediatric office	65.2%	34.8%
Lack of available programs to refer children with developmental and social-emotional/behavior problems	63.0%	37.0%
Lack of training in surveillance and screening for developmental problems	54.3%	45.6%
Lack of knowledge regarding referral options for children whose screens indicate risk for developmental delay	50.0%	50.0%
Validated or evidence-based screening tools are too expensive to use routinely	43.5%	56.5%
Primary health care providers do not believe that formal screening is an appropriate role for them	34.8%	65.2%
N=46		

Five respondents wrote in other barriers to developmental screening:

- Belief the child will grow out of it; prefer to watch and wait
- Cost; insurance won't cover referral resources
- Language/culture (2)
- Long waits for neurologist or developmental pediatricians
- Literacy level of parents

Respondents rated a set of potential barriers to referring and connecting families to developmental assessments and services to indicate how large a problem they thought each barrier is. Over 78% of respondents thought wait lists and capacity issues for service providers are a medium to large problem. Over half also indicated that affordability of the services, parent follow-through, and the amount of time it takes to make a referral are medium to large problems. Over half felt that the family's language, transportation, and the parents' perception of the necessity for the referral were either small problems or not problems at all.

How big a problem is each of the following barriers to referring and connecting families to developmental assessments and services	A big problem	A medium problem	A small problem	Not a problem
Wait lists/capacity issues for service providers	56.5%	21.7%	15.2%	6.5%
Parents cannot afford the services to which they are referred (n=45)	20.0%	37.8%	24.4%	17.8%
Parents do not follow through with referrals	15.2%	41.3%	37.0%	6.5%
The amount of time it takes to make a referral	15.2%	39.1%	28.3%	17.4%
Services are not available in the language spoken by the family	15.2%	17.4%	41.3%	26.1%
Parents cannot get transportation to the services	8.7%	39.1%	34.8%	17.4%
Parents do not think the referral is necessary	4.3%	28.3%	50.0%	17.4%
N=46 except where noted				

The last three questions asked about the respondent's knowledge and use of a centralized telephone access point or call center to connect children with developmental concerns and their families to services and care coordination. Orange County's centralized telephone access point is called Help Me Grow, but this name was not mentioned in the question. Of the 46 respondents who answered this question, 56.5% said yes, Orange County has a centralized telephone access point; 30.4% were unsure; and 13.0% said no.

Of the 26 respondents who said yes, there is a centralized telephone access point, 11.5% said they refer families to it very often and 46.1% said they refer often; 30.8% sometimes refer to it and 11.5% never refer to it.

The 20 respondents who said they were unsure or that there is no centralized telephone access point or call center, 50% said they were very likely to use it and 50% were likely if there was one.