

CHOC-UCI Early Developmental Services  
Evaluation Report  
July 2017 through June 2018

## Introduction

CHOC-UCI Early Developmental Services (EDS) provide a continuum of developmental services for children and families, from when a parent first has concerns about their child's development or behavior to full diagnosis and intervention for those children with developmental delays.

- Parents or professionals with a concern can contact **Help Me Grow (HMG)** at 1.866.GROW.025 or [helpmegrowoc.org](http://helpmegrowoc.org) for connection to a variety of developmental and behavioral services. Help Me Grow also works with primary health care providers to promote and offer training in developmental surveillance and screening.
- **Child Behavior Pathways (CBP)** provides a preventive and “intervention before diagnosis” approach for behavioral disorders through the use of 9-week COmmunity Parent Education (COPE) classes, social skills lessons for children, and teacher training services. CBP helps parents and teachers effectively manage challenging behaviors, improve family/classroom functioning, and encourage healthy relationships with infants, toddlers, and preschool age children.
- **The Early Developmental Assessment Center (EDAC)** provides comprehensive, multidisciplinary developmental and nutritional assessments, education, intervention strategies, care coordination and advocacy for high-risk infants and toddlers who have been referred from neonatal intensive care units (NICUs) and the community.
- When expert assessment and ongoing care are needed, **The Center for Autism & Neurodevelopmental Disorders (The Center)** provides comprehensive, multidisciplinary evaluations, diagnosis, treatment, and management of children of all ages who are suspected of having developmental, behavioral or learning problems. The Center also provides education and training for parents and professionals, participates in clinical research, and engages in community outreach and advocacy efforts.

Help Me Grow, Child Behavior Pathways, EDAC, and The Center also provide training and education to health care professionals and educators to help them recognize developmental delays, signs of autism and ADHD, when to refer children for assessment and intervention, and how to manage difficult behaviors in typical child care settings.

Major funding for EDS is provided by the Children and Families Commission of Orange County (CFCOC), which began supporting developmental services at CHOC and UCI in 2001. EDS grew

and evolved until 2005, when the last of the four programs, Help Me Grow, was established. In 2012, the CFCOC joined with the William and Nancy Thompson Family Foundation to make a catalytic funding award to expand services and build stronger connections among the four programs. The funding from the Thompson Family Foundation, along with a corresponding match, ended in June 2017.

For three years, from 2013/14 to 2015/16, HMG and CBP participated in the Child Signature Program (CSP), which was funded by First 5 California. CSP targeted children at greatest risk for school failure with the goal that they will enter school with the skills to be successful. HMG's role in CSP was to oversee Family Support Specialists (FSSs) who were assigned to classrooms where they built relationships with the families in the program, conducted home visits, provided care coordination, referred and connected families to needed services, and collaborated with program staff and specialists to coordinate services for children and parents. CBP offered play-based social skills lessons to children whose parents participated in COPE parenting classes and also provided a team of Mental Health Specialists to work with community partners to support children in the home and classroom.

This evaluation report describes the accomplishments of EDS in the 2017/18 fiscal year – July 1, 2017 to June 30, 2018. Its purpose is to show how EDS makes a difference in the lives of children and families in Orange County, tell its story to funders and families, and provide information for program improvement.

## Data Sources

Unless otherwise noted, data for this report come from the data system of the CFCOC, or from the programs themselves. The Commission's data system is the source of data for process measures, such as how many people received services and how many services were provided. Data describing the children and families who received services and program outcomes come directly from the programs.

## Process Measures

On a monthly basis, each program reports to the CFCOC how many new clients they served during the month and how many services they provided to all their clients. A count of only new clients provides an unduplicated count of the number of people served each year. For counting purposes, all clients are considered new at the beginning of each fiscal year. Each person may receive multiple services during a single encounter, so the number of services provided is typically much larger than the number of clients served.

The tables on the next page show the data by program for each of the past three years. In the graphs that follow, the total number of people served and the total number of services provided by all four EDS programs are shown for the past five years.

In this report, milestone data collected by CBP for the Child Signature Program (historical data for 2015/16) is included as a separate entry. This data was provided directly by the program.

HMG had contracts in 2015/16 to conduct developmental screening at sites in Garden Grove and Santa Ana, which accounts for the increased number of children served in that year. Those two sites accounted for 1225 children screened in 2015/16.

After several years of decline in the number of children served by EDAC (2700 in 2011/12, down to 924 in 2015/16), the numbers have stabilized over the last three years. The decline may be due to a decrease in multiple births (twins, triplets) and pregnancies utilizing reproductive technology, resulting in fewer babies that are discharged from a NICU. In addition, a number of other hospitals have established their own high-risk infant programs, which may reduce the number of children referred to EDAC at UCI and CHOC.

The Center reported serving more children ages 0-5 in 2017/18 than they had in the previous two years. In 2015/16 and 2016/17, they had fewer diagnostic providers than anticipated, and for some providers, data on the children they served was not captured in the data system that is used for reporting to the Commission. In 2017/18, The Center had more staff, had revamped its triage process to ensure that children under age 6 received priority, and improved its tracking system to more accurately capture data about who they served. In November 2016/17, about 3000 parents attended an International Conference sponsored by The Center, which explains the higher numbers of family members served in 2016/17.

### Children Ages 0-5

Program	Number of Children Served			Number of Services to Children		
	15/16	16/17	17/18	15/16	16/17	17/18
Help Me Grow	3355	1728	1839	13,067	9227	9580
CBP - original	NA	249	561	NA	995	1159
CBP – CSP	1977			3147		
EDAC	924	966	916	3593	8440	7984
The Center	522	544	836	2408	2602	4033
<b>TOTALS</b>	<b>6778</b>	<b>3487</b>	<b>4152</b>	<b>22,215</b>	<b>21,264</b>	<b>22,756</b>

### Family Members

Program	Number of Family Members Served			Number of Services to Family Members		
	15/16	16/17	17/18	15/16	16/17	17/18
Help Me Grow	3355	1728	1839	13,067	9227	9580
CBP - original	471	583	523	2158	2224	2026
CBP-CSP	530			1919		
EDAC	924	1507	2009	3439	5186	4020
The Center	2095	5416	2218	5555	9107	8968
<b>TOTALS</b>	<b>7375</b>	<b>9234</b>	<b>6589</b>	<b>26,138</b>	<b>25,744</b>	<b>24,594</b>

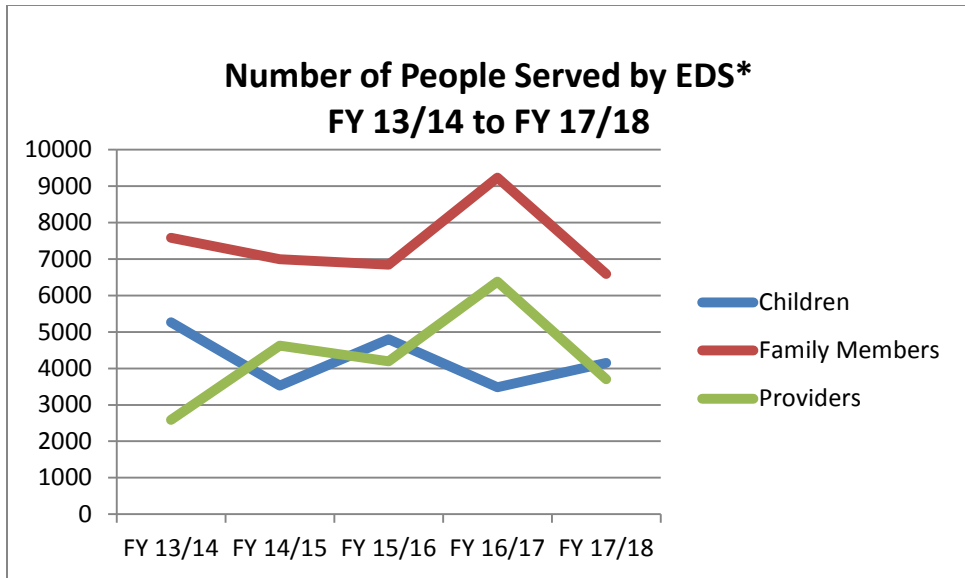
### Service Providers

Program	Number of Providers Served			Number of Services to Providers		
	15/16	16/17	17/18	15/16	16/17	17/18
Help Me Grow	772	233	218	3128	2139	2281
CBP - original	135	459	512	196	1044	608
CBP - CSP	778			1728		
EDAC	809	1055	989	1491	1477	1414
The Center	2481	4630	1969	2967	4820	2329
<b>TOTALS</b>	<b>4975</b>	<b>6377</b>	<b>3688</b>	<b>9510</b>	<b>9480</b>	<b>6632</b>

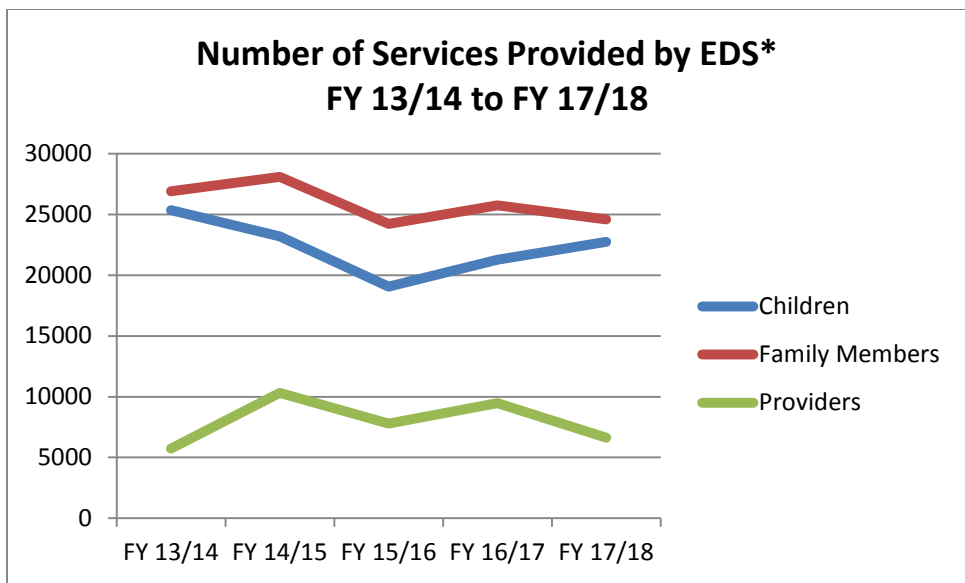
Data Source: Commission Data System

Note: The totals may include some duplication, because individuals served by more than one program are included in the counts of each program.

The next set of graphs show the number of people served, the number of services provided, and the budget for EDS over the past five years. The data for 2013/14 DOES NOT include the people served or services provided that were attributed to the catalytic funding that started in 2012/13. Similarly, the catalytic funding is NOT included in the budget figures for 2013/14. Catalytic funding and the people served by it are integrated into the figures for 2014/15 and subsequent years. Caution should be exercised in comparing data from 2013/14 with the years that follow.

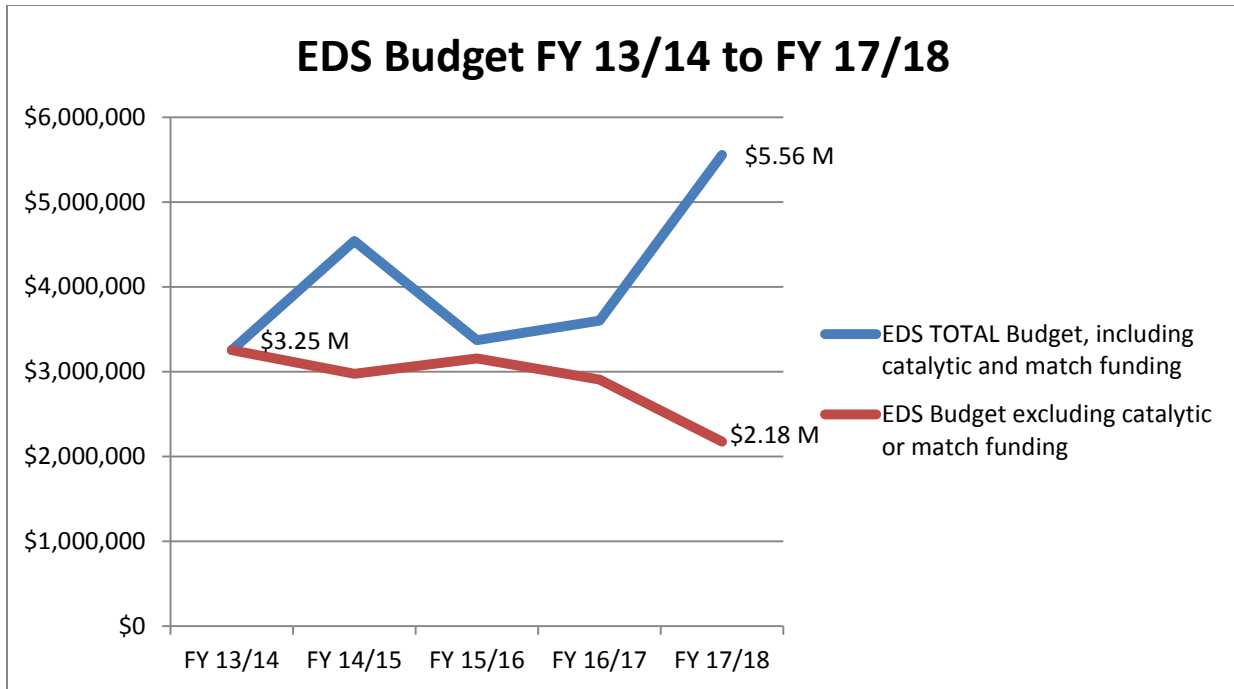


\*Data for 2013/14 excludes people who received services attributed to catalytic funds; Data for 2013/14 – 2015/16 excludes services attributed to CSP funds.



\*Data for 2013/14 excludes services attributed to catalytic funds. Data for 2013/14 – 2015/16 excludes services provided through CSP.

The annual budget for all four programs combined is presented in the next chart. Catalytic funding is included for the first time in 2014/15. From FY 13/14 to FY 17/18, the total budget, including catalytic and match funding, increased 71% while the base budget, excluding catalytic and match funding, declined 33%.



\* Budget amount for 2013/14 does NOT include catalytic funding. Catalytic funding is included in the TOTAL budget amounts starting in 2014/15. The TOTAL budget for 2016/17 includes nearly \$650,000 in matching funding from The Center and Help Me Grow, in addition to catalytic funding. The TOTAL budget for 2017/18 includes \$2,760,000 in matching funding from The Center and Help Me Grow.

#### Progress toward milestones:

EDS reports their progress toward specific milestones selected by the CFCOC based on the services each program provides. These milestones are standardized across all of the CFCOC's grantees. A one-year target quantity for each milestone is established in consultation with each program. The table below shows the target quantities for 2017/18, the number of clients served during the year, and when comparable numbers are available, the number of people served during the previous two years. Milestones for the CSP are included for HMG and CBP in 2015/16.

Milestone targets are an educated guess at the beginning of the year regarding what the program will be able to accomplish and there are many reasons programs may not achieve the targets. In addition, there are some milestones over which the programs have little control, such as milestones that rely on referrals from other institutions or the condition of the children who are receiving services. In 2017/18, the programs surpassed the targets for all milestones.

## Progress on Milestones

Milestone	Description	Program	Unit	# of Clients Served in 15/16	# of Clients Served in 16/17	# of Clients Served in 17/18	12-Month Target for 17/18
HC 2.1.1	Providers trained on how to screen, assess and /or identify child developmental milestones	HMG	New Providers	132	148	111	60
			Contacts	132	148	111	
HC 2.1.2	Providers educated on child development, recognizing key milestones and the importance of screening	HMG	New Providers	198	158	130	120
			Contacts	198	158	130	
		EDAC	New Providers	809	1055	989	400
			Contacts	1491	1477	1414	
		The Center	New Providers	2481	4630	2532	2500
			Contacts	2642	4820	2749	
HC 2.2.1 Previously HC 2.2.7 for CBP	Children receive developmental and/or behavioral screening using evidence-based screening tools (i.e., PEDS, ASQ, ASQ-SE, MCHAT, Child Behavior Checklist).	HMG	New Children	1464	259	238	100
			Screenings	1467	272	243	
		CBP	New Children	227	135	561	25
			Screenings	227	135	90	
HC 2.2.9	Children receive assessment (e.g., vision, hearing, speech/language, psychosocial issues (cognitive, emotional, behavioral), motor skills, health, special needs, and/or parent-	EDAC	New Children	924	966	916	700
			Assessments	8136	8440	7984	
		The Center	New Children	102	282	760	250

Milestone	Description	Program	Unit	# of Clients Served in 15/16	# of Clients Served in 16/17	# of Clients Served in 17/18	12-Month Target for 17/18
	child functioning)		Assessments	610	1605	2479	
HC 2.2.10a Previously 2.2.10 for EDAC	Parents receive referrals regarding their child's health and developmental concerns	EDAC	New Parents	1119	1298	1328	700
			Referrals	3386	3894	3984	
HC 4.4.1	Children receive specialty care clinic visits	The Center	New Children	522	544	800	750
			Visits	2408	2619	4047	
HC 4.4.3	Parents receive specialty care education, resources, referrals and support (includes care coordination)	EDAC	New Parents	984	1548	1963	750
			Contacts	1253	2061	2437	
		The Center	New Parents	2095	5416	2400	1500
			Contacts	5555	9186	10,520	
SF 3.1.1 Previously SF 2.2.1	Home visitors and/or program staff will assess and provide service plans to improve parent knowledge of healthy child development using a Commission-approved tool	HMG-CSP	Service Plans	271			
SF 3.1.4b Previously SF 2.2.4b	Parents participate in a parenting education class series on healthy child development	CBP	New Parents	416	583	561	50
			Services	NA	2489	2262	
		CBP – CSP	New Parents	231			
			Services				



Milestone	Description	Program	Unit	# of Clients Served in 15/16	# of Clients Served in 16/17	# of Clients Served in 17/18	12-Month Target for 17/18
		<b>CBP - TOTAL</b>	<b>New Parents</b>	<b>647</b>			
			<b>Services</b>				
SF 3.1.6 Previously SF 2.2.6	Children receive group interventions to improve healthy child development	<b>CBP – CSP</b>	<b>New Children</b>	<b>213</b>	<b>249</b>		
			<b>Services</b>		<b>995</b>		
		<b>The Center</b>	<b>New Children</b>	<b>33</b>	<b>137</b>	<b>134</b>	<b>75</b>
			<b>Services</b>	<b>24</b>	<b>187</b>	<b>1304</b>	
SF 4.1.2 Previously SF 3.1.2	Parents receive referrals to services	<b>HMG</b>	<b>New Parents</b>	<b>1930</b>	<b>1629</b>	<b>1839</b>	<b>1550</b>
			<b>Referrals</b>	<b>5912</b>	<b>4945</b>	<b>5063</b>	
SF 4.1.3 Previously SF 3.1.3	Providers receive referrals to services	<b>HMG</b>	<b>New Providers</b>	<b>298</b>	<b>230</b>	<b>218</b>	<b>200</b>
			<b>Referrals</b>	<b>538</b>	<b>468</b>	<b>343</b>	
SF 4.1.4 Previously SF 3.1.4	Parents receive follow up on referrals and services are accessed	<b>HMG</b>	<b>New Parents</b>	<b>945</b>	<b>790</b>	<b>833</b>	<b>600</b>
			<b>Referrals</b>	<b>1121</b>	<b>1051</b>	<b>923</b>	
		<b>HMG-CSP</b>	<b>New Parents</b>	<b>436</b>			
			<b>Referrals</b>	<b>673</b>			

Milestone	Description	Program	Unit	# of Clients Served in 15/16	# of Clients Served in 16/17	# of Clients Served in 17/18	12-Month Target for 17/18
SF 4.1.6 Previously 3.1.6	Family Support and child development teacher trainings	HMG-CSP	Trainings	12			
		CBP-CSP	Trainings	15			
SF 4.2.3 Previously SF 4.1.3	Providers receive training on behavioral health treatment services for children 0-5	CBP	New Providers	913	399	512	25
			Trainings	9	18	17	
		CBP – CSP	New Providers	Included in count above			
			Trainings	Included in count above			
		CBP - TOTAL	New Providers	913			
			Trainings	9			
SF 4.2.4 Previously SF 4.1.4	Parents receive education, resources, referrals, and support regarding their child's behavioral health issues	CBP – CSP	New Parents	4004			
			Support Services	1823			
SF 4.2.3	Staff participate in case management team meetings to support the needs of the families served	HMG-CSP	Meetings	12			
CB 2.2.1	Developing partnerships, coordinating and collaborating with other agencies to improve services	HMG	Partnerships	255	307	364	210

Milestone	Description	Program	Unit	# of Clients Served in 15/16	# of Clients Served in 16/17	# of Clients Served in 17/18	12-Month Target for 17/18
CB 3.1.4 Previously CB 2.3.4	Children with special needs served	HMG	New Children	686	626	447	250
		CBP	New Children	31	34	18	10
CB 3.1.8 Previously CB 2.3.8	Program staff will report the ongoing caseload for month reported	HMG-CSP	New Children	567			

Source: Commission Data System

## Child Demographics

Each program collects data that describes the children and families they serve. The tables that follow provide the demographic picture of the children served in 2017/18. Charts are used to show trend data of key demographic measures over five years, from 2013/14 through 2017/18.

Overall, the programs served more boys than girls. EDAC serves primarily children who are infants through age 3; over half of the children served by CBP were 4 or 5 years old. HMG and The Center serve children of all ages.

While CBP served a greater percentage of Hispanic children than they had in 2016/17, and EDAC served a smaller percentage, across all four programs, the percentage that were Hispanic was the same in 2016/17 and 2017/18, at 46%. The primary language of the majority of families served by HMG, EDAC, and The Center was English (ranging from 59-76%); 64% of families served by CBP have Spanish as their primary language.

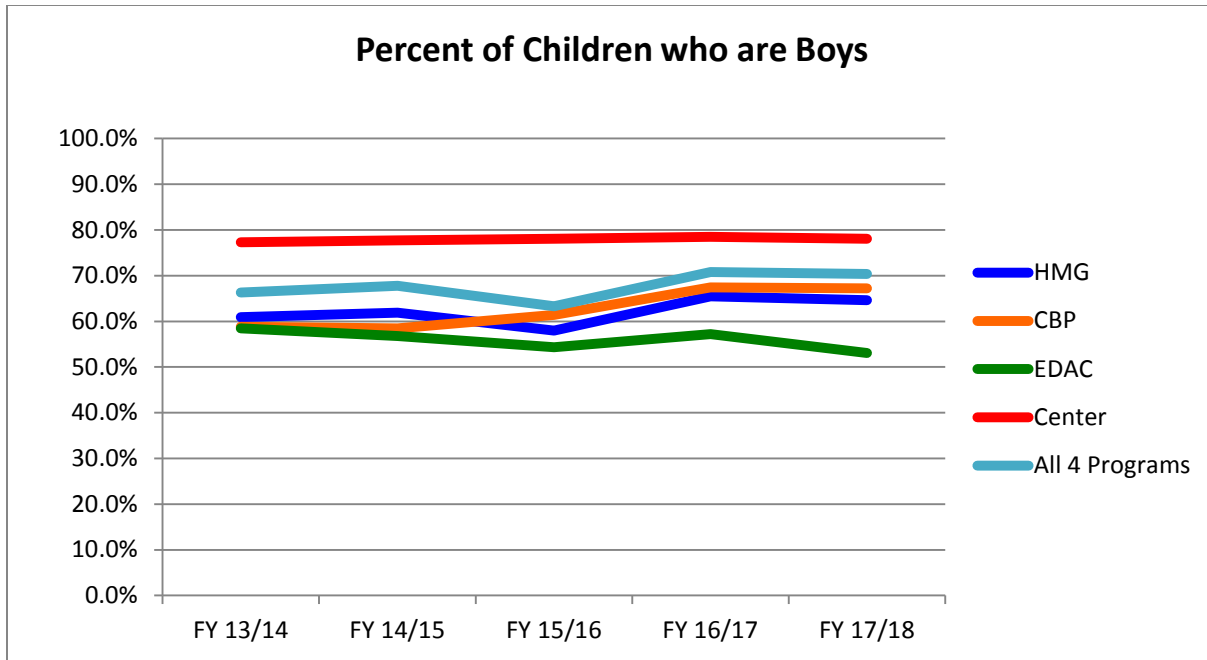
The programs served a large percentage of children with public insurance. Of the three programs that collect insurance information, 70-75% of the children served by HMG and EDAC had public insurance while just over half of the children served by The Center had public insurance.

Sex	HMG	Child Behavior Pathways	EDAC**	The Center
Boys	64.6%	67.2%	53.1%	78.1%
Girls	34.9%	32.8%	46.9%	21.9%
Unknown*	0.5%			
N=	2556	183	369	2808

\* Unknown because the mother is pregnant

\*\* EDAC data is of a cohort of children born in 2015 who qualified for service through CCS.

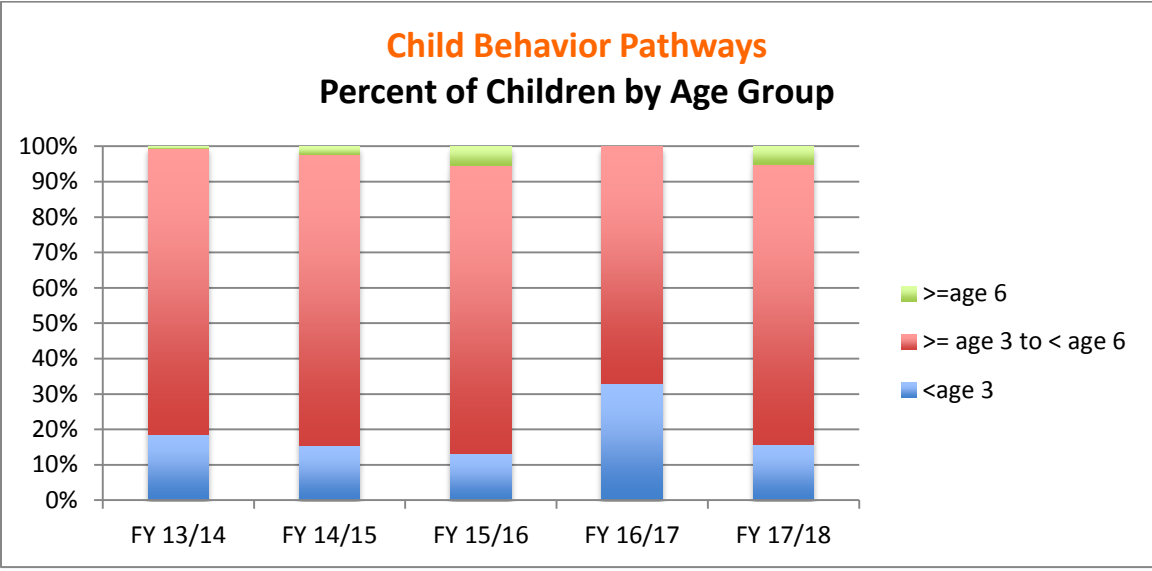
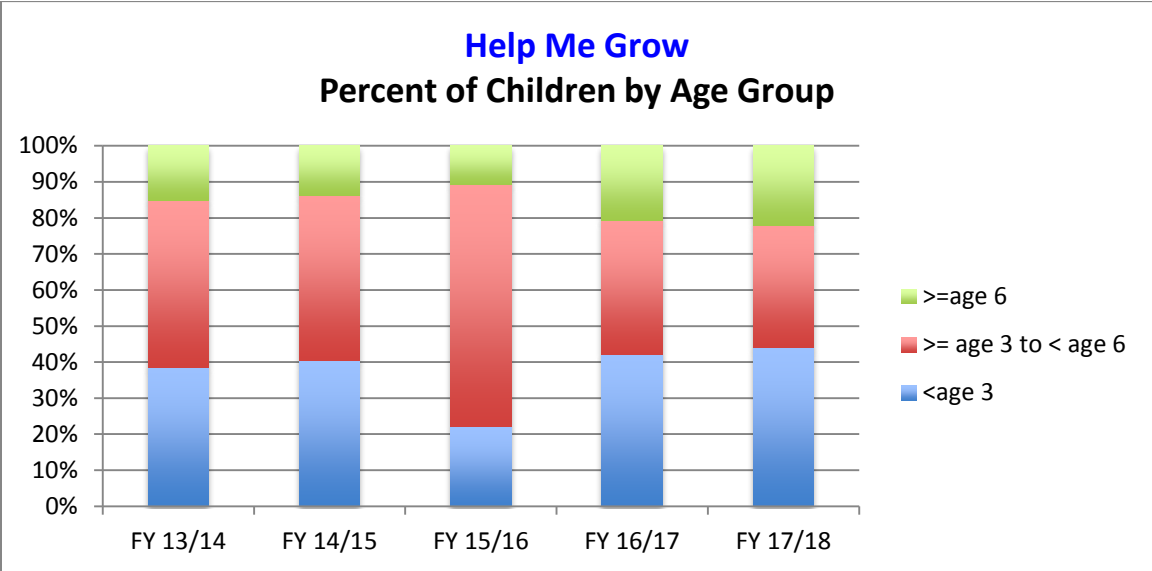
Across all four programs, 70.4% of the children served in 2017/18 were boys, similar to the rate in 2016/17 (70.8%), which was the highest in the past five years, and up from 63.3% in 2015/16. The biggest percentage point increases from 2015/16 to 2016/17 were at HMG and CBP, while the percentage of children served by The Center who were boys has remained constant over the past 5 years.



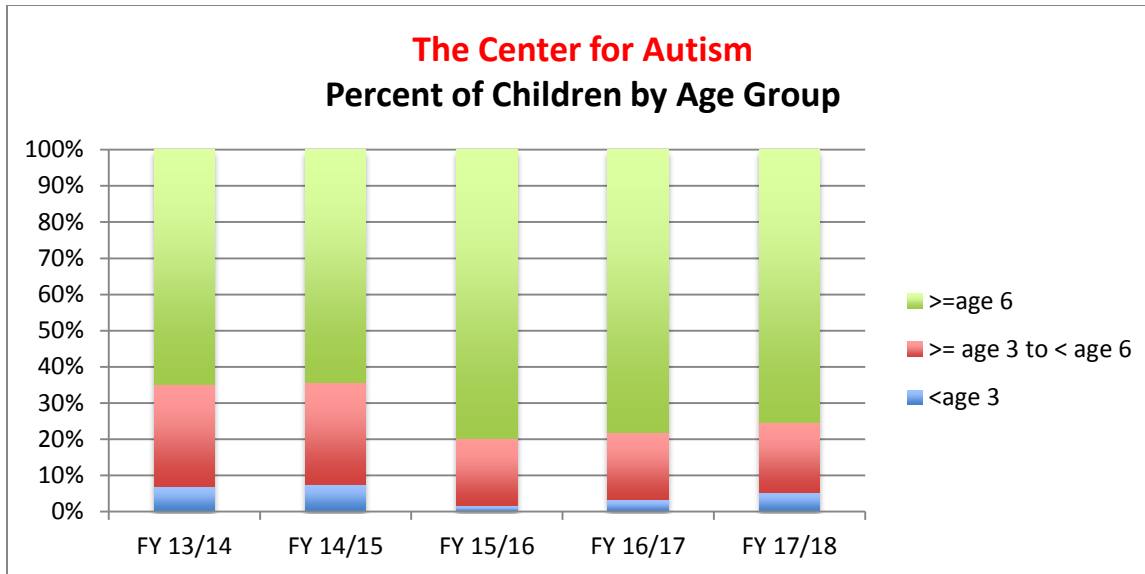
Child's Age	HMG	Child Behavior Pathways	EDAC*	The Center
<1 year	14.4%	3.8%	61.0%	0.0%
1 year	12.7%	7.1%	34.0%	1.5%
2 years	17.1%	4.9%	4.5%	3.9%
3 years	15.1%	15.3%	<0.5%	5.7%
4 years	11.5%	36.6%		6.2%
5 years	7.4%	27.3%		7.3%
>=6 years	22.0%	5.0%		75.5%
N=	2576	183	1097	2808

\*Age data for EDAC is from 2010/11; current data is unavailable but in the past these percentages were quite consistent from year to year.

Age trends are shown for each program with the exception of EDAC, which provides services only to children up to age 3. For the next three charts, the ages are combined into three groups, ages birth to under age three, ages three to under age six, and ages six and older. The higher percentages of children in the middle age group (3 to under 6) served by HMG and CBP in 2013/14, 2014/15, and 2015/16 reflect their participation in the Child Signature Program (CSP), which focused on services to preschool-age children. After a year when more children under age 3 were served, in 2018/19, CBP served more children in the 3-5 age group, which fits best with their mandate and curriculum.



The Center continues to provide services to children as they get older and therefore the percentage of children ages 6 and older is larger than the other programs that are focused primarily on children ages 0-5. Over the five years shown, the total number of children served by The Center has ranged from 2027 in 2015/16 to a high of 2808 in 2017/18; Since 2015/16, when the percentage of children served who were age 3 and younger was at a low of 1.6%, The Center has seen steady increases in the percentage served in that age group: 3.2% in 2016/17, and 5.4% in 2017/18. The Center credits improvements to their triage and tracking systems to ensure that more children under age 6 are served.



Race/Ethnicity	HMG	Child Behavior Pathways	EDAC*	The Center
American Indian	0.1%			0.1%
Asian/Pacific Islander	10.0%	5.8%	12.5%	8.9%
Black	1.5%		8.4%	0.7%
Hispanic	54.3%	68.4%	58.3%	36.7%
White	17.1%	14.0%	50.7%	39.4%
More than one	13.4%	8.8%	13.3%	**
Other	2.7%	1.2%	23.3%	10.4%
Don't Know/ Decline to answer	1.1%	1.8%	1.1%	4.0%
N=	1865	171	369	2808

\* EDAC data is of a cohort of children born in 2015 who qualified for service through CCS; percentages do not add up to 100% because there is a separate collection for “single race” vs. “multi-racial”; children who are “multi-racial” may also have been entered as “other” “don’t know” or some other race. The percent Hispanic cannot be separated out from the other race categories, so the other race categories include Hispanic and non-Hispanic.

\*\* The Center does not include a multiple race option when collecting race data.

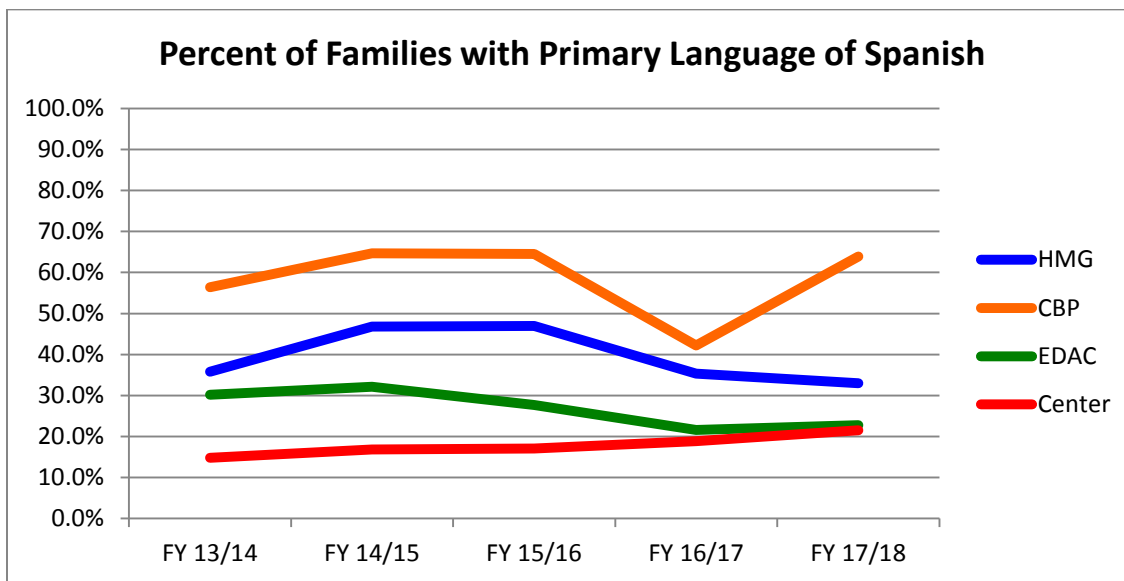
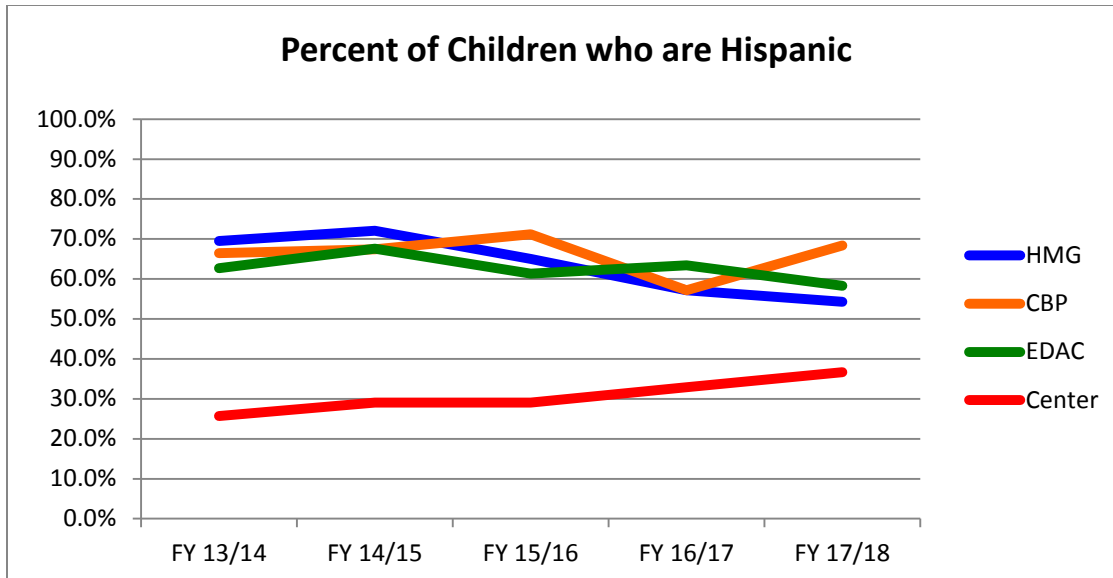
Primary Language	HMG	Child Behavior Pathways	EDAC*	The Center
Arabic				0.2%
Cantonese	0.1%		0.5%	
Chinese				0.1%
English	59.4%	36.1%	72.6%	76.4%
Farsi	1.0%		0.5%	<0.1%
Indian	0.1%			
Korean	0.5%		0.3%	0.3%
Mandarin	1.0%		1.4%	
Russian	0.1%			
Sign Language			0.3%	
Spanish	33.0%	63.9%	22.8%	21.5%
Tagalog	0.2%			
Vietnamese	2.3%		1.1%	1.3%
Other	2.3%		0.5%	0.3%
Unknown				
N=	2131	233	369	2808

\* EDAC data is of a cohort of children born in 2015 who qualified for service through CCS.

After a drop in the percentage of Hispanic children served by CBP in 2016/17, the percentage returned to more typical levels in 2017/18. The same pattern is true for families whose primary language is Spanish. CBP has contracts with school districts to provide services to state preschools, which serve low-income families, of which a high percentage are Spanish speaking.

The decline in Hispanic children and Spanish-speaking families seen by HMG and CBP in 2016/17 is likely attributable to the closure of CSP at the end of 2015/16. Many of the families served by CSP were Spanish-speaking. CBP also provided more fee-based groups in 2016/17, which are less successful at enrolling low-income and/or Spanish-speaking families. EDAC noted that many bilingual families report that they speak English as their primary language, even when they speak both Spanish and English at home.

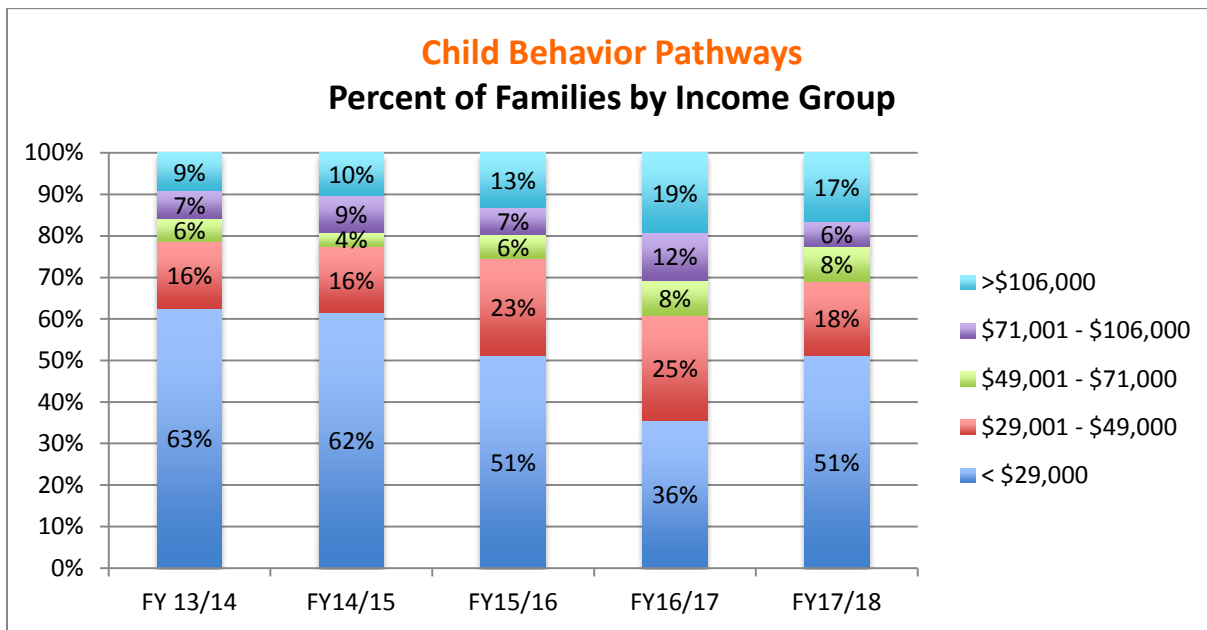




CBP is the only program that collects data on household income. While it was participating in CSP (2013/14 to 2015/16), the percentage of children in homes with income below \$49,000 ranged from 75-79%, compared to 61% in 2016/17 and 69% in 2017/18. The percent of families with income between \$49,000 and \$106,000 stayed fairly constant (around 13%) until 2016/17, when it was about 20%; in 2017/18, the percentage of families in this income range dropped back to 14%. The percent of families with income above \$106,000 was 9-13% during the CSP years. In 2016/17, the percentage increased to 19% and dropped slightly to 17% in 2017/18.

Household Income	Child Behavior Pathways*
Less than \$29,000	51.2%
\$29,001-\$49,000	18.0%
\$49,001-\$71,000	8.3%
\$71,001-\$106,000	6.1%
\$106,001 or more	16.5%
N=	133

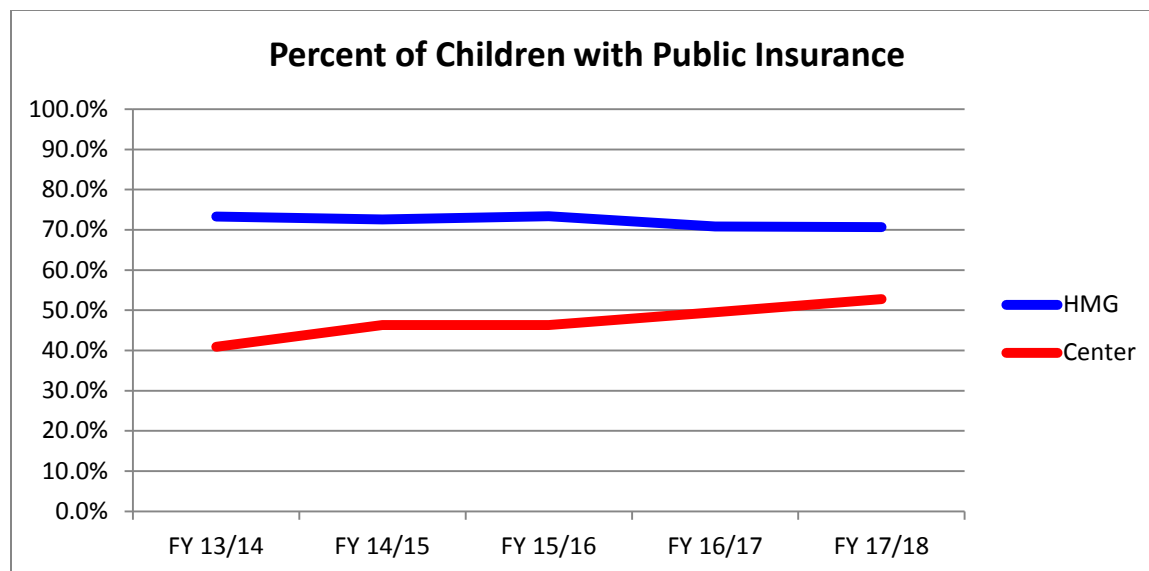
\* note for 2017/18: 50 Decline to Answer, Do Not Know and Missing responses are NOT included in the calculations of percents.



The percentage of children with public insurance served by HMG has remained fairly constant over the past five years, averaging around 73% during the CSP years of 2013/14 to 2015/16 and then dropping only slightly to around 71% in 2016/17 and 2017/18. The percent of children using public insurance at The Center has risen steadily from a low of 40.9% in 2013/14, to 52.8% in 2017/18.

Health Insurance Status	HMG	EDAC*	The Center
CalOptima (Medi-Cal assigned)	68.9%	67.2%	51.9%
Medi-Cal (Direct - unassigned)	1.1%		0.9%
Out-of-county Medi-Cal	0.7%		
California Children's Services (CCS)		75.6%	<0.1%
None/Self-Pay	0.4%	0.3%	1.3%
Private Insurance-HMO	11.7%	10.8%	8.2%
Private Insurance – POS/EPO		1.6%	3.6%
Private Insurance-PPO		18.7%	32.9%
Private Insurance-PPO/POS/EPO	14.5%		
<b>TOTAL Private Insurance</b>	<b>26.2%</b>		<b>44.7%</b>
Tri-Care (Military Insurance)	1.0%		1.1%
Other	1.7%	1.1%	0.1%
Missing			
N=	2044	369	2808

\* EDAC data is of a cohort of children born in 2015 who qualified for service through CCS; the percents add up to more than 100 because most of the children have more than one insurer, for example, 62.8% have both CCS and Medi-Cal

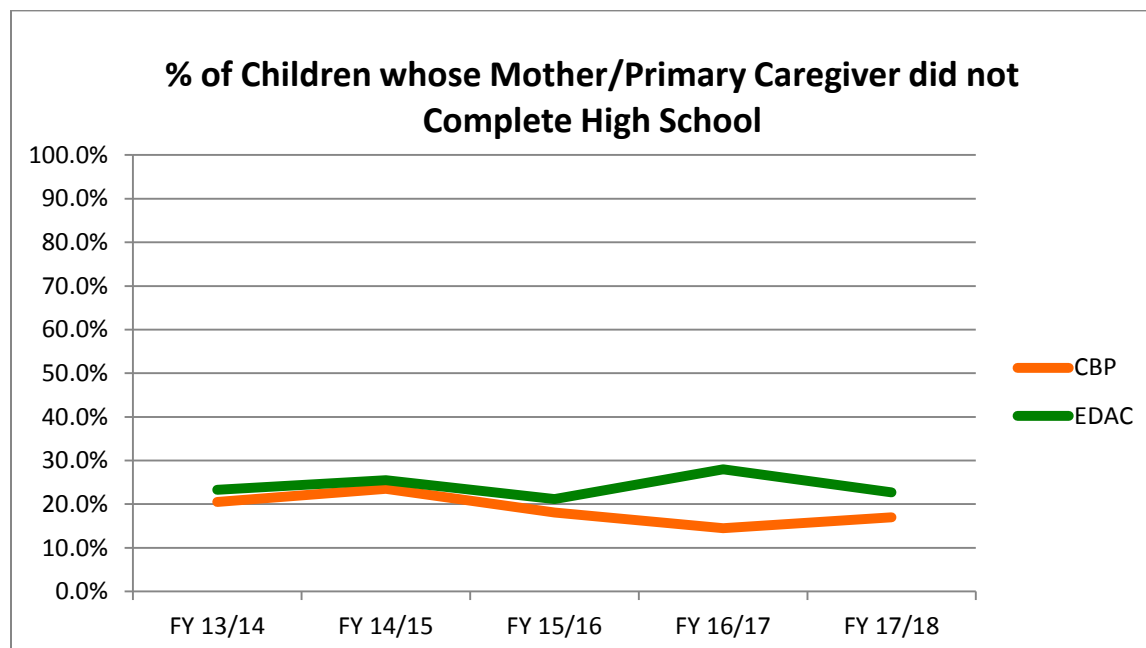


Mother's or Primary Care Giver's Education	Child Behavior Pathways	EDAC*
Did not complete High School	17.0%	22.7%
High School Diploma or GED	29.5%	28.8%
Some college or vocational school	21.6%	17.2%
Bachelors Degree	19.3%	19.4%
Graduate or Professional Degree	10.2%	10.0%
Other	2.3%	1.9%
N=	176	309

\* EDAC data is of a cohort of children born in 2015 who qualified for service through CCS. The percents were adjusted to exclude 60 clients who did not provide information about the primary caregiver's education.

The percentage of mothers participating in CBP services who did not complete high school was around 20% in the CSP years and then declined to 14.5% in 2016/17 before rising to 17.0% in 2017/18. The percentage with a Bachelors degree or higher hovered around 30% in in 2013/14 and 2014/15, dropped to 21% in 2015/16, and then rose to 36% in 2016/17. In 2017/18, it returned to 30%.

Over the last five years at EDAC, the percent of mothers who did not complete high school ranged from 21.2% for babies born in 2013 to 28.0% for the 2014 babies. The 2014 babies also had the highest percentage of mothers who had completed a bachelor's degree or higher, 33.9%, compared to the lowest among the 2011 babies, which was 26.1%.



## Why Families Use Early Developmental Services

The reasons families use EDS vary by program. Some families are referred from a neonatal intensive care unit or by their child’s pediatrician; others are referred by a childcare provider or a family friend. Children present with a wide variety of concerns, as described below.

**Help Me Grow** – The most common reasons families contact HMG are shown below. Behavioral concerns have consistently been the top reason families call HMG, with communication concerns second the last two years. The top four reasons (behavioral, communication, parental support, and general development) have consistently accounted for over half of the concerns parents have when they call HMG. In 2016/17, the percentage of calls with behavioral concerns was at an all-time high and the percentage with communication concerns was the highest it had been since 2012/13. Both concerns remained high in 2017/18. The percentage of callers with developmental concerns was at an all-time high in 2017/18 and the percentage with a concern about mental health continued to slowly rise from a low of 1.1% in 2012/13.

Percent of All Concerns*			Reason for Call
15/16	16/17	17/18	
16.8	20.3	20.4	Behavioral
11.8	15.4	15.0	Communication
13.0	11.2	10.5	Parental Support
11.1	9.4	9.4	General Development
6.0	6.4	8.5	Developmental concerns
5.4	7.1	6.4	Hearing
5.0	5.5	5.4	Diagnosis
3.2	3.8	4.3	Mental Health
4.7	5.8	3.8	Education
2.5	2.4	2.5	Childcare
1.4	1.9	2.5	Health Insurance
3.4	1.5	2.3	Basic Need
4.0	1.1	1.9	Health/Medical
1.5	1.9	1.6	Cognitive (Learning)
0.8	1.2	1.5	Adaptive
4.0	1.9	1.0	Family Functioning (Family Issues)
1.9	1.4	1.0	Social Interactions (Social/Emotional)
1.2	0.8	1.0	Gross Motor
0.7	0.2	0.4	Vision
0.5	0.3	0.2	Fine Motor
0.9	0.6	0.1	General Information
0.2	0.0	0.1	Living Condition
0.0	0.0	0.2	Other
4953	4048	3897	N = total number of concerns

\* Callers may have more than one concern per child, so the totals are greater than the number of children served.

**Child Behavior Pathways** – CBP serves families who are concerned that their child may have attention or behavior difficulties and are looking for parenting strategies to help them cope with these challenging behaviors.

Families receive referrals to CBP from a variety of sources. When it was active, the Family Support Specialists of the CSP program were the largest source of referrals. Since then, most referrals have come from preschool teachers and childcare providers, and through brochures and flyers. In 2017/18, a larger percentage of referrals were from friends or by word-of-mouth, and fewer were from Help Me Grow, compared to 2016/17.

Percent of all Referrals			Referral Source
2015/16	2016/17	2017/18	
15.2%	22.6%	30.9%	Preschool teacher/childcare provider
11.6%	31.6%	24.2%	Brochure/flyer
4.0%	7.6%	9.0%	Physician
1.9%	3.7%	7.3%	Friend/word of mouth
0.8%	2.0%	3.9%	Social Services/social worker
7.8%	9.0%	3.4%	Help Me Grow
1.9%	5.6%	3.4%	Website
11.8%	3.0%	3.4%	Presentation/school meeting
1.0%	0.3%	2.8%	The Center for Autism & Neurodevelopmental Disorders
0.6%	1.0%	2.2%	Family Resource Center
1.7%	1.7%	1.7%	Psychologist/specialist
	2.0%	1.1%	School Readiness Nurse
	1.0%	0.6%	Health Fair
	1.3%	0.0%	CBP staff
	1.0%	0.0%	Email
27.4%	0.7%	0.0%	Family support specialist (HMG-CSP)
0.8%	0.0%	0.0%	Library
13.5%	6.0%	6.2%	Other
474	301	178	Total number of referrals for the year

The COPE parenting classes help families recognize when their child has special needs. When families enroll, they are asked if their child currently receives services related to his/her behavioral and/or physical needs. In 2017/18, about 20% responded yes and those children are considered “special needs.” This was about double the rate in previous years. About midway through the COPE series, the parents are provided an opportunity to rate their child’s behaviors using the Child Behavior Check List (CBCL). While the CBCL is not a stand-alone diagnostic measure, it can be used to identify behaviors that flag the child as a greater risk for special needs services, pending further assessment. For the specific purposes of CBP, a child who scores in the “clinical range” (at or above the 92<sup>nd</sup> percentile) on any of the subscales is classified in a general category of special needs. Based on the use of the CBCL in this way, just

over 21% of the children were identified as having special needs in 2017/18, down from 39% in 2013/14 but up from 14% in 2015/16.

Special Needs	Before COPE Group (reported by parents)	During COPE Group (Scores on Child Behavior Check List)
2013/14	12.8% of 264 children	39.0% of 122 children
2014/15	13.4% of 446 children	21.6% of 450 children
2015/16	9.2% of 385 children	13.7% of 227 children
2016/17	10.5% of 237 children	25.2% of 135 children
2017/18	19.9% of 171 children	21.4% of 84 children

## EDAC

One way families qualify for services from EDAC is to meet the eligibility requirements for California Children’s Services (CCS). Children eligible for CCS typically receive three comprehensive assessments from EDAC in the first 36 months of their lives; Visit 1 occurs when children are 6-8 months old, Visit 2 at 14-16 months of age, and Visit 3 when they are 24 months or older. This report looks at data of all the children born in one calendar year (2015) who should have completed 3 visits to EDAC by the end of June three years later (2018). By looking at the children across all three visits, it is possible to develop a picture of the children’s needs and their progress over time. The 2015 cohort started with 369 children, served either at CHOC EDAC (256 children) or UCI EDAC (113 children).

The babies served by EDAC have multiple risk factors, including those related to being preterm and low birth weight. More of the babies registered in 2015 had severe risk factors compared to the babies registered in 2014: 45% were very low birth weight and just over 50% were very preterm. Thirteen percent were a twin, triplet, etc. Babies served by UCI EDAC were more likely to be low birth weight (76.1%) or preterm (74.3%) compared to the babies served by CHOC EDAC (62.1% low birth weight and 59.4% preterm).

2011 Babies	2012 Babies	2013 Babies	2014 Babies	2015 Babies	Birth Weight, Gestational Age, Multiple Births
77.7%	68.9%	73.9%	61.0%	66.4%	Low Birth Weight (<=2500 grams)
54.8%	48.1%	55.9%	39.8%	45.0%	Very Low Birth Weight (<=1500 grams)
76.6%	65.9%	72.4%	60.6%	64.0%	Preterm (<36 weeks gestation)
62.2%	55.3%	61.2%	51.1%	51.5%	Very Preterm (<32 weeks gestation)
16.8%	20.1%	18.9%	15.5%	12.7%	Multiple birth (twin, triplet, etc.)
376	264	376	264	369	N=number of babies

Listed below are the percent of children who met the various criteria to qualify for CCS. Because children could meet more than one criterion, the percentages add up to more than 100%. While babies served by CHOC EDAC were less likely to be low birth weight or preterm,

they were more likely to have received nitric oxide for more than 4 hours (15.2%) and/or to have documented seizure activity (8.2%) compared to UCI EDAC (4.4% and 2.7% respectively).

Across both programs, EDAC has seen changes over time in the CCS medical eligibility criteria of the babies who enroll in HRIF. Compared to 2011, fewer of the 2015 infants were preterm, low birth weight, and/or had persistent apnea. A much larger percentage of the 2014 and 2015 babies were reported as receiving nitric oxide for more than 4 hours for persistent pulmonary hypertension and/or had documented seizure activity. This is likely due to changes in the eligibility criteria.

At Registration					
2011 Babies	2012 Babies	2013 Babies	2014 Babies	2015 Babies	CCS Medical Eligibility Criteria
62.5%	54.9%	61.2%	51.1%	51.5%	Gestational age at birth was less than 32 weeks (Very Preterm)
54.8%	48.5%	55.9%	39.8%	45.0%	Birth weight was less than or equal to 1500 grams (Very Low Birth Weight)
11.4%	11.7%	12.2%	8.0%	11.4%	Used oxygen for more than 28 days and have chronic lung disease (CLD)
9.0%	8.7%	8.8%	12.1%	11.9%	Received iNO (nitric oxide) for more than 4 hours for Persistent Pulmonary Hypertension (PPHN)
6.6%	8.0%	6.1%	10.2%	6.5%	Documented seizure activity
4.0%	0.8%	1.9%	0.8%	0.8%	Persistent apnea
1.6%	1.1%	0.5%	1.5%	1.4%	Extracorporeal Membrane Oxygenation (ECMO)
NA	NA	NA	0.4%	2.2%	Neonatal encephalopathy
376	264	376	264	369	N=number of babies

Two things contribute to the changes seen over time. 1) Over the last 5-7 years, other local hospitals have developed their own High-Risk Infant Follow-up (HRIF) programs, and they are likely to enroll the preterm and low birth weight babies from their NICU that do not have other complications. Infants with persistent pulmonary hypertension (PPHN) or suffering from seizures are often transferred to the CHOC NICU, where they can receive specialty care, and then can choose to enroll in CHOC's HRIF program rather than going back to their original hospital's HRIF program. 2) In 2013, changes in the eligibility definitions in two eligibility categories led to more infants being counted in those categories. a) The eligibility criteria for "received iNO for more than 4 hours for PPHN" was expanded to include infants who were treated during hospitalization with sildenafil or other pulmonary vasodilatory medications for pulmonary hypertension. The criteria for "documented seizure activity" was expanded to include "observed clinical" seizure activity.



## **The Center for Autism & Neurodevelopmental Disorders (The Center)**

The Center is dedicated to the earliest diagnosis and treatment of autism, ADHD and other developmental disorders. They see children who have any type of developmental, behavioral or learning problem.

Children referred to The Center have many issues requiring evaluation and diagnosis including language delays, communication deficits, global developmental delays, motor delays, learning issues, and behavior problems of all types (including ADHD, oppositionality and defiance, hyperactivity/impulsivity, anxiety, OCD, disruptive, aggressive, noncompliant, destructive and self injurious components). For many children, the major presenting concern is possible autism. Some children already have other known diagnoses, but need to be assessed for co-morbid autism or other issues needing clarification or treatment recommendations (eg., Down Syndrome, Rett, Fragile X, etc.). The Center also sees children with possible delays or who are at risk for delays, such as infants of substance abusing mothers and children in foster care or being adopted.

## Outcome Measures

Each program collects outcome measures to demonstrate how their program is meeting the needs of the community and making a difference for the clients they serve. For 2015/16, the program data used for outcome measures by HMG and CBP includes data about children and families in the Child Signature Program.

### Help Me Grow

#### *Where HMG's Clients Live*

City	Percent of HMG clients by city			Percent of Orange County births by city
	2015/16*	2016/17*	2017/18*	2015**
Santa Ana	36.7	21.4	20.0	13.8
Anaheim	10.9	15.6	15.9	13.3
Irvine	2.6	6.3	7.2	10.6
Garden Grove	10.4	6.2	5.5	5.6
Orange	4.2	5.2	5.3	4.9
Fullerton	3.8	3.4	4.3	4.3
Tustin	3.3	4.5	3.7	3.0
Costa Mesa	2.7	3.4	3.4	4.1
Mission Viejo	1.6	2.6	3.1	2.2
Huntington Beach	5.4	3.5	2.8	4.9
Buena Park	1.3	2.8	2.7	2.6
Lake Forest	0.8	2.3	2.7	2.0
Westminster	1.3	2.2	2.2	2.6
Rancho Santa Margarita	1.1	1.4	2.1	1.4
San Clemente	1.0	2.1	1.8	2.0
Aliso Viejo	0.9	1.4	1.7	1.8
La Habra	0.7	1.4	1.7	2.1
Stanton	2.6	1.3	1.4	1.1
Fountain Valley	0.8	1.4	1.3	1.2
Placentia	0.7	1.6	1.2	1.4
San Juan Capistrano	2.1	1.4	1.2	1.0
Laguna Niguel	1.1	1.4	1.2	1.5
Brea	0.7	0.7	1.1	1.4
Cypress	0.5	1.1	1.0	1.1
Cumulative percent	97.1	94.6	94.3	89.9
N=	4693	2435	2473	37,621

\* percentages are calculated among only Orange County cities; in 2017/18, HMG received calls about another 70 children who lived outside Orange County.

\*\*Birth data is for 2015 as reported in the 23<sup>rd</sup> Annual Report on the Conditions of Children in Orange County.

Help Me Grow provides a free service that is available to all Orange County residents regardless of income. Residents from every city in Orange County, and a number of cities outside Orange County, contacted Help Me Grow seeking referrals because they have concerns about a child’s development. The table above shows the Orange County cities that accounted for at least one percent of HMG clients in 2017/18, and compares the percent of HMG clients to the percent of all Orange County births represented by each of those cities. In 2017/18, these 24 cities accounted for 94% of HMG’s clients and 90% of all Orange County births. HMG also received calls about 70 children who lived outside Orange County.

The higher percentages of clients from Santa Ana and Garden Grove in 2015/16 are the result of two contracts HMG had with state-funded preschools in the school districts that serve those cities.

*How callers heard about HMG*

The next table shows how callers learned about HMG from 2015/16 to 2017/18. Health care providers and community agencies, such as The Center for Autism, WIC, MOMS Orange County and the Social Services Agency, have consistently been among the primary ways callers heard about HMG. Because of HMG’s participation in CSP, early care and education providers were a large source in 2015/16.

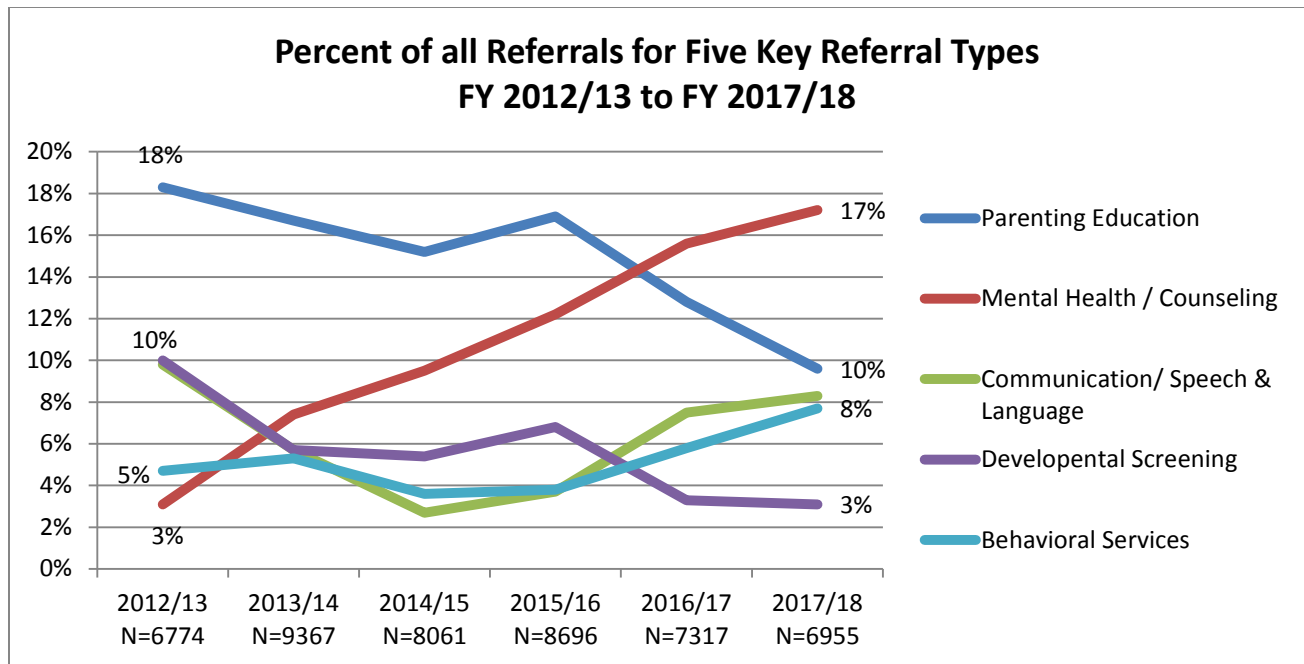
Source	Percent of Callers by Source		
	2015/16	2016/17	2017/18
Health Care Provider/Health Insurance	28.7	37.9	38.2
Community Agency	17.0	24.1	21.2
HMG Outreach	4.0	8.6	9.3
Previous Caller	6.0	6.4	7.3
Early Care and Education Provider	27.2	5.0	6.4
Friend or Family	4.3	4.1	4.5
School	6.2	4.5	3.7
2-1-1 Orange County	2.2	2.6	2.6
Developmental Screening Activity or Event	2.3	1.1	2.6
Regional Center of Orange County (IDEA Part C)	1.4	1.5	2.2
Mental Health Provider	0.2	0.3	1.0
Hospital	0.2	3.8	0.9
Media	0.2	0.2	0.0
Other			0.2
N=	2880	2313	2313

*The types of referrals families receive from HMG*

Families can receive a wide variety of referrals from HMG, depending on their concerns about the child and their needs. The most frequent types of referrals made by HMG (each accounting for at least 1% of referrals in one of the three years) are shown in the next table. Services with the least referrals (less than 1.0% of all referrals) included respite/ caregiving services, social skills, psycho-educational testing, and health/medical subspecialists. Only 0.9% of referrals in 2017/18 were for services outside of Orange County.

Percent of all Referrals			Type of Referral
2015/16	2016/17	2017/18	
12.2	15.6	17.2	Mental Health/Counseling
16.9	12.8	9.6	Parenting/Education
3.7	7.5	8.3	Communication/Speech & Language
7.2	7.5	7.8	Parent/Child Participation
3.8	5.8	7.7	Behavioral Services
7.5	9.2	4.8	Educational/Enrichment
2.9	4.2	4.6	Part C: Regional Center of Orange County
4.1	4.4	4.1	Parent/Caregiver (Family) Support
5.8	5.1	3.8	Health/Primary Care
1.7	2.2	3.8	Occupational/Physical Therapy
3.7	2.7	3.3	Recreation/Sports/After School/Camps
6.8	3.3	3.1	Developmental Screening
2.4	3.3	3.0	School District
2.8	3.1	3.0	Childcare
2.7	2.6	3.0	Advocacy
2.2	1.6	2.8	Allied Health Professionals
4.0	1.6	2.4	Basic Needs
1.6	1.6	1.9	Early Literacy
1.9	1.2	1.6	Health/Neurodevelopmental Subspecialists
0.9	0.7	1.5	Access to Health Insurance
1.3	1.2	0.8	Social Skills
1.1	0.4	0.3	Legal Assistance
8696	7317	6955	Total Number of Referrals for the Year

Since 2012/13, there has been an increase in the percent of referrals for mental health/counseling services, behavioral services, and communication services, and a decline in the percentage of referrals for parenting education and developmental screenings, as seen in the next chart.



#### *Follow-up to ensure families are connected to care*

If callers agree to receive a follow-up phone call, HMG can check to make sure the child is connected to the referrals provided. The table below shows the number of callers who agreed to receive a follow-up call from 2015/16 to 2017/18, followed by the number and percent of those who were reached when the follow-up attempts were made. The percent of callers who were reached declined from 84% in 2015/16 to 77% in 2017/18. Starting in 2016/17, HMG no longer offered follow-up calls to families with children above age 8 years, which accounts for some of the decline in the number of callers who agreed to a follow-up call.

	2015/16	2016/17	2017/18
Total number of callers who agreed to a follow-up call	2037	1500	1416
Total number of callers who were reached on a follow-up call and received care coordination	1716	1199	1091
Percent of callers who agreed to a follow-up call who were actually reached	84.2%	79.9%	77%

#### *Children are connected to care*

Callers to HMG may call about more than one child and may receive multiple referrals regardless of the number of children about which they are calling. The multiple referrals offer families a choice and it is not expected that families would connect with every referral they receive. When HMG follows up with families, they track the status of the referrals for each child

and the family as a whole (the case). When a family or child has completed an appointment for at least one referral, the case or child is considered “connected.” If a family or child has not yet completed an appointment, but has an appointment scheduled, they are considered “pending.” The next table shows the number of cases and children that had connected with a referral or had an appointment pending at the time of follow-up.

Of the three years shown, the rate at which cases and children were connected was highest in 2015/16, declined in 2016/17 and declined a little further in 2017/18. The rate at which cases and children were connected or pending (combined) was highest in 2015/16, and the dropped to about the same levels in 2016/17 and 2017/18.

	2015/16	2016/17	2017/18
<b>CASE (Entire Family)</b>			
Connected	71.3%	60.5%	56.7%
Pending	9.7%	15.4%	19.1%
<b>TOTAL Connected or Pending</b>	<b>81.0%</b>	<b>75.9%</b>	<b>75.8%</b>
Not Connected	18.6%	23.6%	23.6%
Number of Cases	1719	1204	1096
<b>CHILD</b>			
Connected	71.8%	61.1%	57.6%
Pending	9.5%	14.5%	18.9%
<b>TOTAL Connected or Pending</b>	<b>81.3%</b>	<b>75.6%</b>	<b>76.5%</b>
Not Connected	18.3%	23.9%	23.0%
Number of Children	2029	1399	1285

The changes in rates correspond to participation in CSP (2013/14 – 2015/16) when Family Services Care Coordinators each worked with 30 families at school sites where they had in-person interactions and were able to follow and support the families much more closely.

### *Barriers to service*

When callers are not connected to service, HMG endeavors to find out why the connection was not made. By far, the most common reason was that the caregiver did not use the referral information. Unreturned phone calls (at an all-time high), eligibility issues and difficulty completing the application were the next most common reasons. Scheduling conflicts continued to be a declining reason for not connecting to service. Waitlists, program capacity, health insurance, location, cost, transportation, language, and childcare each accounted for less than 1.5% of the reasons why the connection was not made.

2015/16	2016/17	2017/18	Barrier
67.2%	78.3%	69.4%	Caregiver did not use referral information
1.9%	1.9%	6.3%	Agency did not return call
3.9%	4.2%	6.0%	Eligibility issues - due to age, income, Regional Center criteria, school district criteria, etc.
6.1%	3.9%	5.8%	Application too difficult
6.2%	2.9%	2.6%	Scheduling conflict (date/time)
1.9%	0.9%	1.3%	Waitlist
3.6%	1.3%	1.2%	Capacity issue – program not accepting new clients/full
1.6%	1.2%	1.2%	Health insurance issues – pending approval, service not covered, uninsured
0.4%	0.4%	0.9%	Unable to acquire the required auth/referral for service
0.5%	0.2%	0.9%	Location is difficult to access
1.0%	0.6%	0.8%	Cost prohibitive to family
0.9%	1.2%	0.7%	Transportation not available
1.1%	0.2%	0.4%	Language barriers at intake or during service provision
1.6%	0.2%	0.3%	Connected to alternate service in other category
0.3%	0.5%	0.1%	Childcare
1.9%	2.0%	2.8%	Other
1709	1292	764	N

## Child Behavior Pathways

### *Outreach Efforts*

Outreach efforts are made to increase awareness of Child Behavior Pathways and ensure that families have every opportunity to enroll in the classes. The outreach efforts include contact with families at community workshops, presentations, resource fairs, and school events. CBP staff also attend workshops and make presentations for the professional community to emphasize that CBP is the “go to” program for parents seeking social, emotional, and strategic behavior support services. The table below lists the types of outreach efforts undertaken in 2017/18, the number of events attended, the number of attendees for each type, and the number of hours spent attending the outreach events. Compared to the three previous years, CBP participated in fewer events in 2017/18; still, it reached about the same number of people as it had in 2016/17. The total number of hours spent on outreach decreased 38% from 2015/16 to 2016/17 and another 29% from 2016/17 to 2017/18. Two changes at CBP explain the reduction in outreach efforts: 1) the end of the Child Signature Program (CSP) meant there was less funding and staff to conduct outreach, and 2) direct contracting with schools to provide mental health services reduced the need to promote the COPE groups in the same way and to the same extent.

Over the past two years, CBP has invested more time on sustainability activities, attending meetings and reaching out to organizations and entities that may help their long-term sustainability efforts. Recent efforts have focused on developing contracted fee-based services for state and private preschool programs.

2017/18	Example of Type of Event	# of Events	# of Attendees	# of Hours
Community Collaboration / Consultation	Cal Optima Community Alliance Committee	2	8	23.5
Community Event	Connection Cafés, CalOptima Community Alliance Forums	8	680	4.5
Promotion of Project	SCAN monthly meeting, health fairs, CHOC Ask the Expert	32	1240	64
TOTALS	2017/18	42	1928	92
TOTALS	2016/17	52	1899	129
TOTALS	2015/16	83	2766	208.5
TOTALS	2014/15	85	2462	193.5

*Serving low-performing school districts*

One goal of the Child Behavior Pathways program is to serve families who live in school districts with low overall academic performance. After a high point in 2014/15 (the peak of participation in CSP), when 90% of the COPE classes were in low-performing school districts, there was a decline in the subsequent years, with about two thirds of classes offered in low-performing school districts in 2017/18.

COPE Classes in Low-performing Schools	2014/15	2015/16	2016/17	2017/18
Number of COPE Classes in school districts with low academic performance	28	24	14	16
Total number of COPE Classes	31	31	24	24
Percent of COPE Classes in low-performing school districts	90.3%	77.4%	58.3%	66.7%

*Outcomes for children and families*

Data collected from parents who attended COPE classes demonstrate that parents use and value the strategies they are taught and see improvements in their child’s behavior as a result of the classes. Parents also indicated they found CBP’s parent support services to be extremely useful.

**The Parenting Scale (PS)** is a self-report measure of dysfunctional discipline practices by parents. The PS assesses three discipline styles: laxness (permissive, inconsistent discipline),



over-reactivity (harsh, emotional, authoritarian discipline and irritability), and hostility (use of verbal or physical force). In 2016/17, parents completed the PS at the first and last sessions. Results show that following participation in the COPE parenting class, parents (N=147) were significantly less likely to endorse using each of the three dysfunctional discipline styles (laxness,  $p<.01$ ; over-reactivity,  $p<.01$ ; hostility,  $p<.01$ ). After years of consistent results with the PS, it was not collected in 2017/18.

Parents felt strongly that Child Behavior Pathways was beneficial to them in a number of ways. Rating a series of statements on a six-point scale, with 1 being strongly disagree and 6 being strongly agree, each of the five statements scored a mean rating of 5.3 or better in 2017/18. The ratings were slightly lower than those reported in 2016/17.

COPE Group Evaluations Statement	Mean Rating (highest rating possible is 6)		
	2015/16	2016/17	2017/18
I have been able to apply many of the parenting strategies.	5.5	5.6	5.4
I feel more confident in my parenting skills.	5.3	5.5	5.3
I have noticed improvements in my child's behavior.	5.2	5.4	5.4
I feel that the relationship with my child has improved.	5.3	5.5	5.4
I feel that I am a better parent as a result of this course.	5.3	5.6	5.4
N=	248	167	139

In 2017/18, 100% of parents who completed the Group evaluation said they would recommend the class to others. When asked to rate the 9-week COPE Group using a 6-point scale, with 1 meaning "not useful at all" and 6 meaning "extremely useful," parents gave it an average rating of 5.9, meaning nearly all parents found the class extremely useful. In 2016/17, the average rating was 5.8.

*Social skills classes.*

Social skills classes are offered to the children while their parents participate in select COPE classes. Parents were asked to indicate how much they disagreed or agreed (using a 6-point scale) with a set of statements about the social skills class. In the table below, the percent who agreed with each statement at any level is presented for the past three years.

2015/16	2016/17	2017/18	Parents Feedback about Social Skills Classes
96.5%	98.5%	100.0%	I would recommend the social skills class to other parents
95.3%	87.7%	96.3%	My child looked forward to going to the social skills class
99.0%	100.0%	100.0%	My family benefited from the social skills class
85	65	60	Number of respondents

Respondents were asked to indicate which aspects of the social skills class their family found helpful. There have been some changes from year to year, but a high percentage of parents have consistently indicated that having the opportunity for their child to become familiar with the techniques taught in the COPE class was helpful. In 2017/18, there was a decline in the percentage of parents who found the techniques useful compared to previous years. The percentage of parents who said it was helpful to have their child experience a sit out decreased to under 20% in 2017/18.

Percent who said it was helpful			Aspects of the Social Skills Class that Parents Found Helpful
2015/16	2016/17	2017/18	
75.3%	70.8%	68.3%	Opportunity for my child to become familiar with the techniques taught in COPE class
77.6%	60.0%	56.7%	The opportunities my child had to practice social skills with other children
69.4%	72.3%	50.0%	Being able to use class materials to talk to my child about social skills during the week
75.3%	58.5%	46.7%	Having the providers teach my child social skills
67.1%	50.8%	46.7%	Getting to practice the social skill at home with my child using the recommended weekly activity
78.8%	69.2%	45.0%	Relaxation techniques (breathing bottles, etc.)
42.4%	47.7%	36.7%	Feedback from the providers
42.4%	35.4%	18.3%	Having my child experience a sit out
85	65	60	Number of respondents

## EDAC

Data collected on all children born in 2015 across their three visits to EDAC provide some insights to how these high-risk infants and their need for services change over time. It is important to keep in mind that this is not a true cohort because more children are seen for the first visit than for either of the subsequent visits. Among the reasons children do not receive all three visits include 1) children are found to be doing well on neurodevelopmental examination and testing and High Risk Infant Follow-Up (HRIF) services are no longer required; 2) parents/caregivers of children who are well-connected to therapies and resources may not return to the program; 3) sometimes parents feel their child is receiving the services he/she needs and the EDAC visit is duplicative; 4) some children are in protective custody and move out of the area after they are adopted. Other reasons a child may not receive all three visits include inability to pay out-of-pocket insurance bills; and the families have competing priorities or lack transportation.

A total of 369 babies born in 2015 registered with either the CHOC HRIF (256 babies) or the UCI HRIF (113 babies). The number of children who attended Visit 1 was 294; by Visit 2 it was 231;

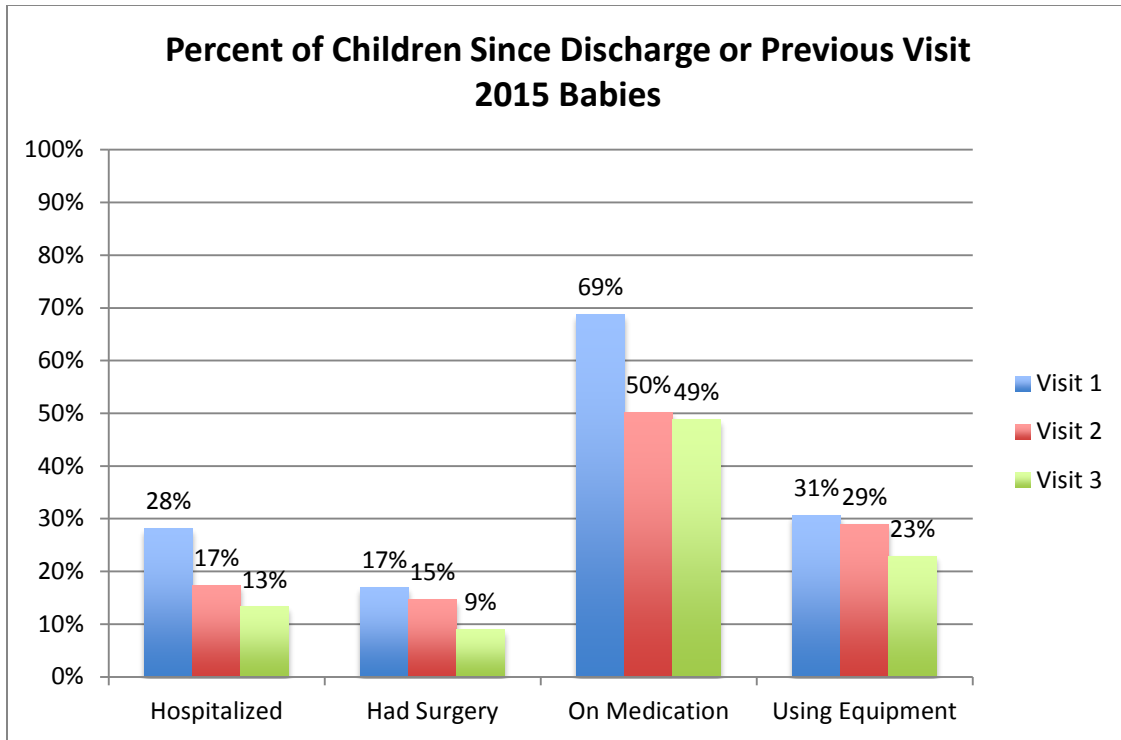
and 166 children returned for Visit 3. During this period four children died, and 179 cases were closed.

Eligibility for California Children’s Services (CCS) is determined when a child is registered for the HRIF program and this initial determination carries through to each visit. In the table below, the percent of children born in 2015 who met each CCS medical eligibility criteria at each visit is shown. The children who came for Visit 3 were more likely to have been preterm, low birth weight, and/or have used oxygen for more than 28 days and have CLD. Preterm babies often have multiple issues that put them at high risk for delays and the data support the expectation that the babies who returned for Visit 3 were more likely to have met multiple criteria and have more severe problems.

Regis- tration	Visit 1	Visit 2	Visit 3	CCS Medical Eligibility Criteria
51.5%	54.1%	54.5%	57.2%	Gestational age at birth was less than 32 weeks
45.0%	46.6%	47.2%	50.6%	Birth weight was less than or equal to 1500 grams (considered Very Low Birth Weight)
11.4%	12.6%	13.0%	13.9%	Used oxygen for more than 28 days and have chronic lung disease (CLD)
11.9%	12.2%	12.6%	10.8%	Received iNO (nitric oxide) for more than 4 hours for Persistent Pulmonary Hypertension (PPHN)
6.5%	7.1%	7.4%	6.0%	Documented seizure activity
0.8%	0.7%	0.9%	1.2%	Persistent apnea
1.4%	1.0%	1.3%	0.6%	Extracorporeal Membrane Oxygenation (ECMO)
2.2%	2.0%	2.2%	1.8%	Neonatal encephalopathy
369	294	231	166	N=number of babies

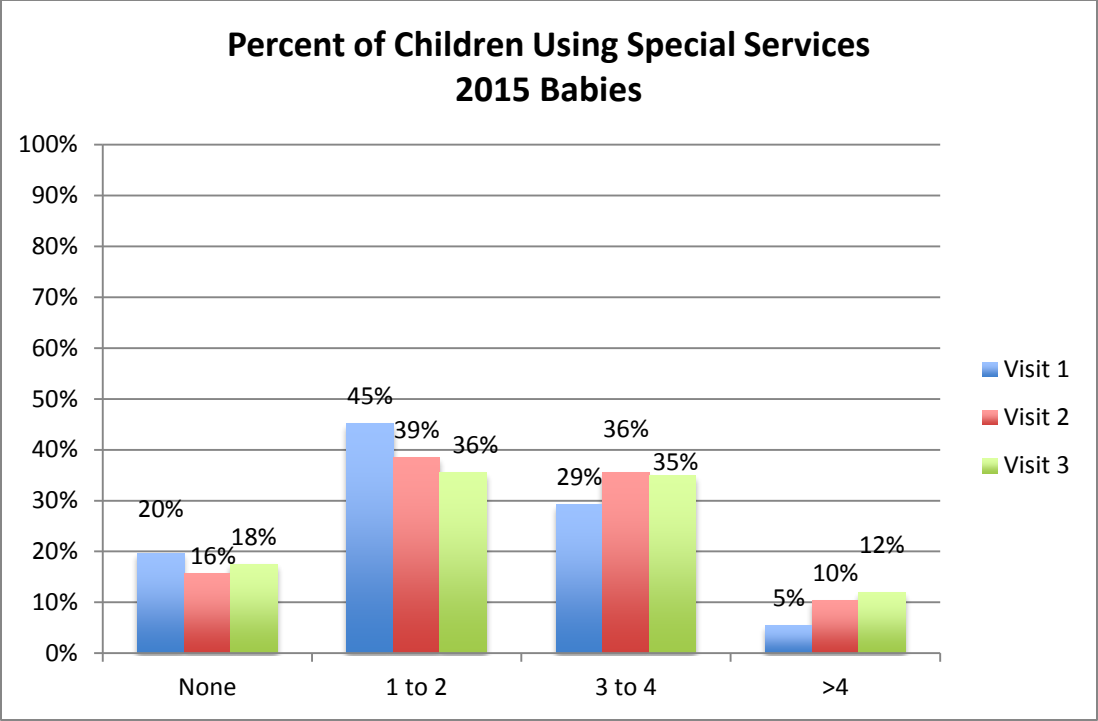
At each visit, the child’s medical history is recorded to show what happened between discharge from the NICU or the previous visit and the current visit (shown in chart below). The percent of children hospitalized, having surgeries, on medication, or using equipment declined from Visit 1 to Visit 3.

Overall, similar values and trends between visits were seen among the 2014 babies. The percentage of infants using equipment, such as a nebulizer, apnea monitor, feeding equipment, orthotics, etc. at Visit 3 has declined over the last four years, from 35% among 2012 babies, 30% among 2013 babies, 25% among the 2014 babies, and 23% among the 2015 babies. The percent of 2015 babies on medication at Visit 1 (69%) was lower than any of the previous three years, when it was around 75%. By Visit 3, the percentage using medication was about the same among the 2013, 2014, and 2015 babies.

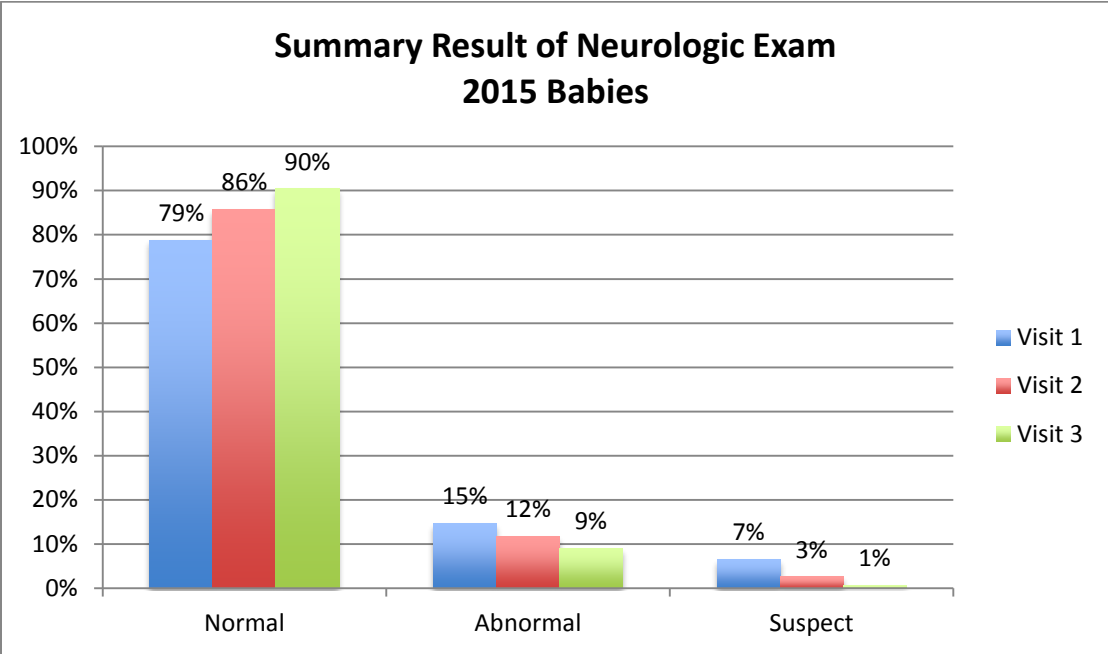


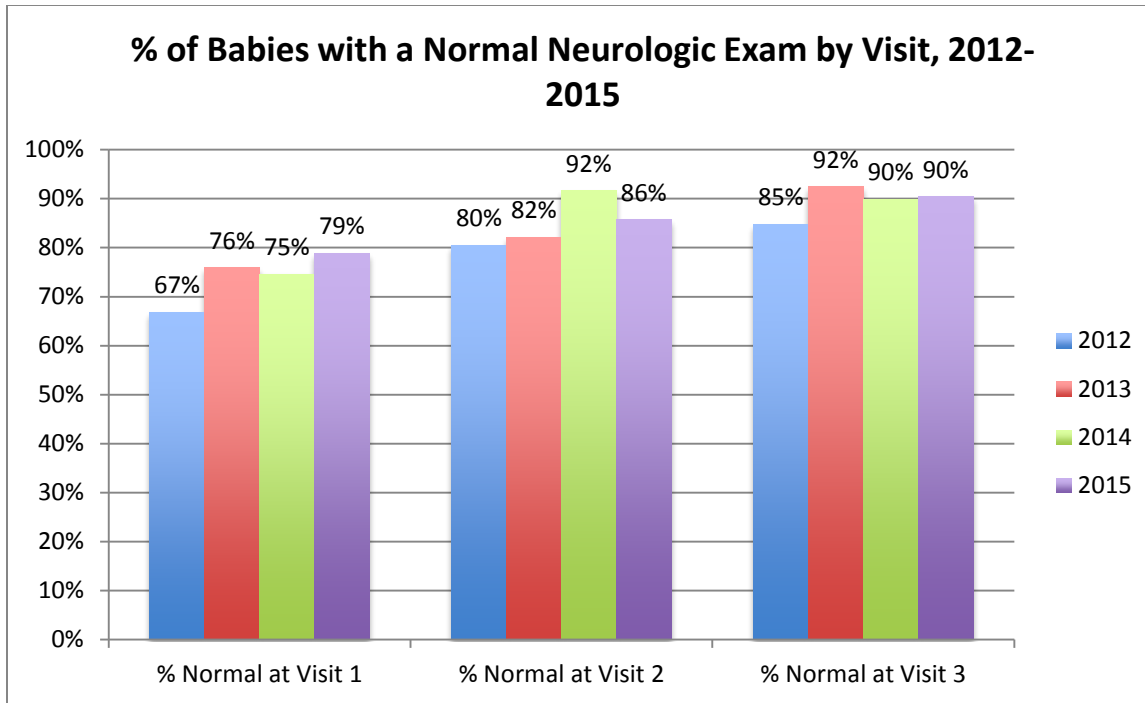
The percent of children using special services, such as physical therapy, occupational therapy, speech/language communication, behavior intervention, feeding therapy, etc., increased slightly from Visit 1 (79.9%) to Visit 3 (82.5%) (shown on chart below). The percentage of children using 4 or more special services increased at the second and again at the third visits. This could indicate that the children who returned for subsequent visits had more complex problems, or just reflect that children are ready for additional services (such as speech/language and behavior intervention) as they get older. EDAC also helped parents connect to existing referrals that they may initially have been reluctant or too overwhelmed to receive.

Compared to the previous years, the percentage of 2015 babies using special services at Visit 1 (80%) was lower than among the 2014 babies (86%) but higher than the 2013 babies (76%) and the 2012 babies (71%). By Visit 3, the differences were less pronounced – 82% of 2015 babies were receiving special services compared to 84% of 2014 babies, 80% of 2013 babies, and 82% of 2012 babies.

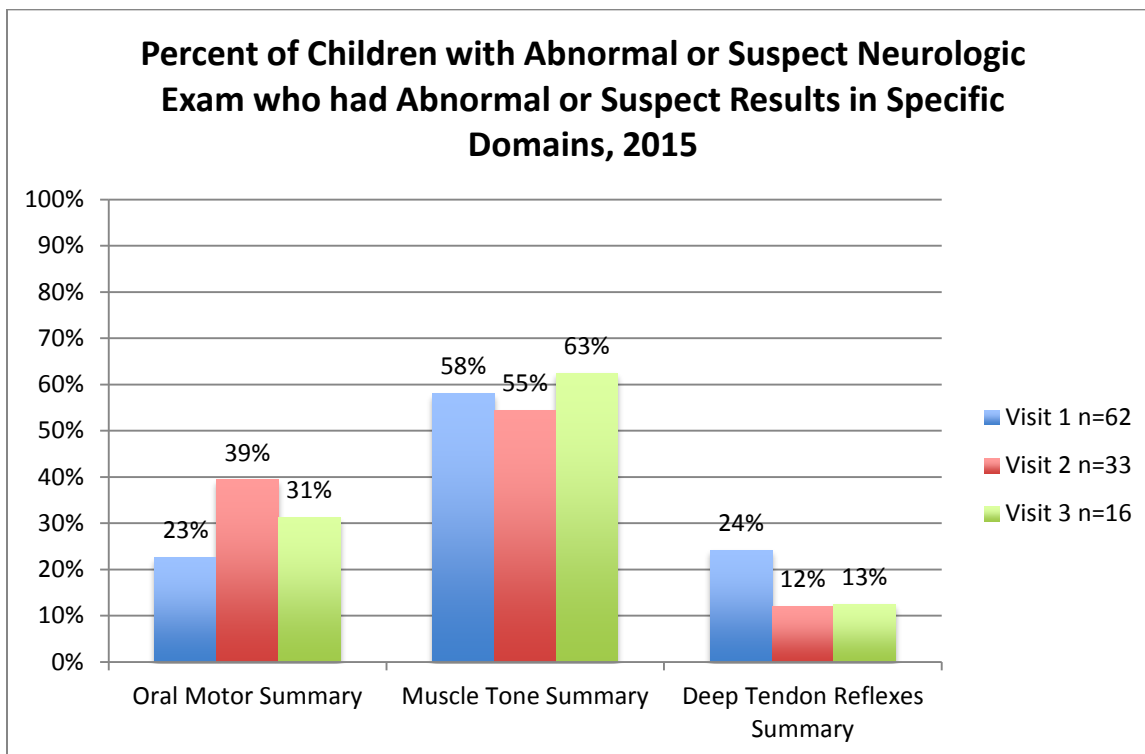


All children received a neurologic exam at each visit. The percent of children with a normal exam was 79% at Visit 1 and rose to 86% at Visit 2 and 90% at Visit 3. The percent of babies with a normal neurologic exam at each visit over the past four years is shown in the second table below.



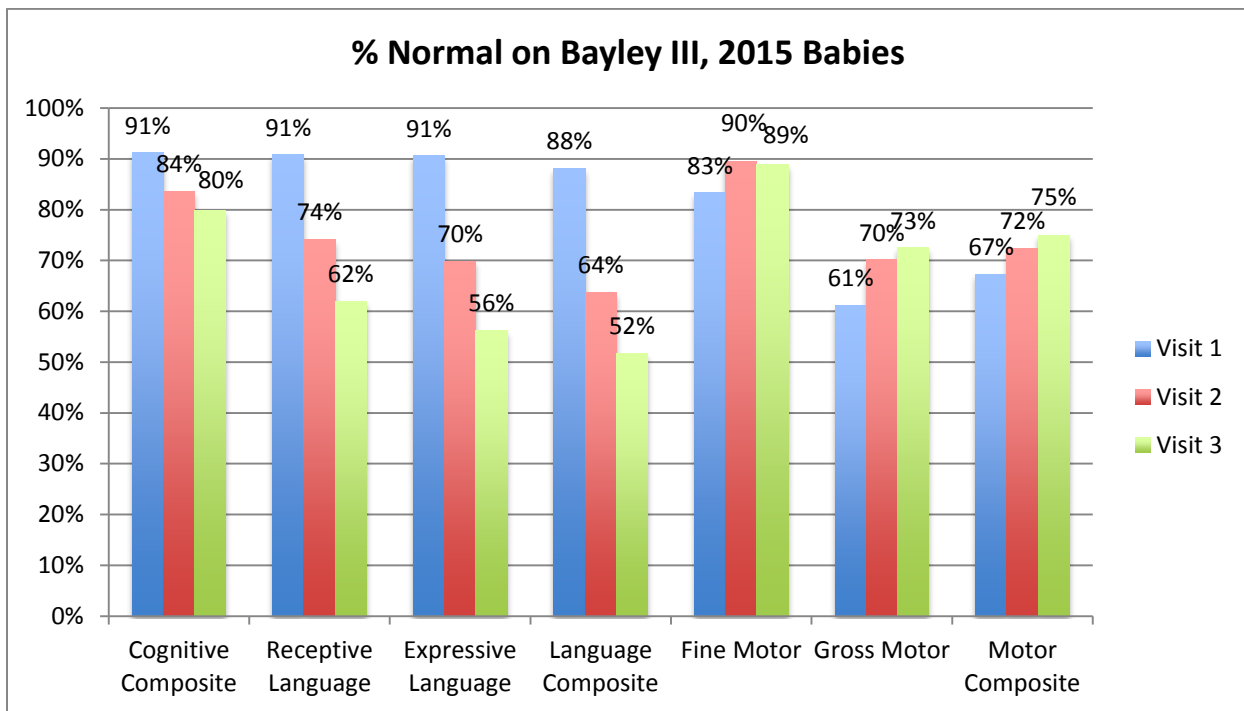


Among children with an abnormal neurologic exam, over half had a muscle tone abnormality and about a quarter to a third had an oral motor function abnormality. At Visit 3, only 13% had an abnormality of the deep tendon reflexes, which is much lower than seen in previous birth groups: 31% among 2014 babies and 23% among 2013 babies.

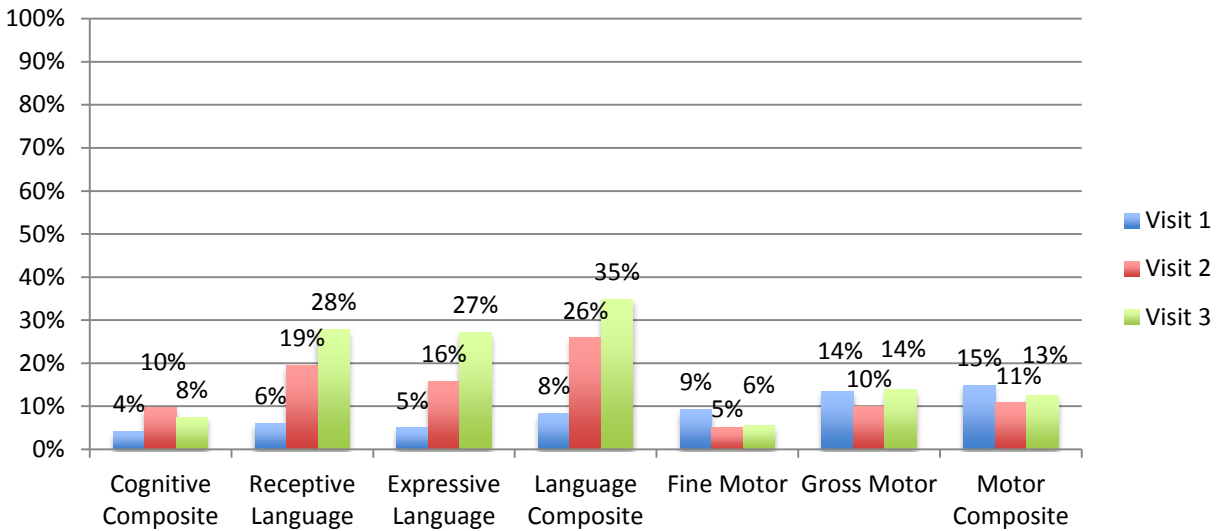


Nearly every child is assessed for developmental progress at every visit. Out of 691 possible assessments, only six (less than 1%) were not done. Four were not performed due to the known severe developmental disability of the child; one because of a medical condition of the child; and one because an examiner was not available. Assessments were done using the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley III). In the charts that follow, the percent of children who scored “normal,” “mild/moderate delay,” or “significant delay” for each domain are shown for each visit.

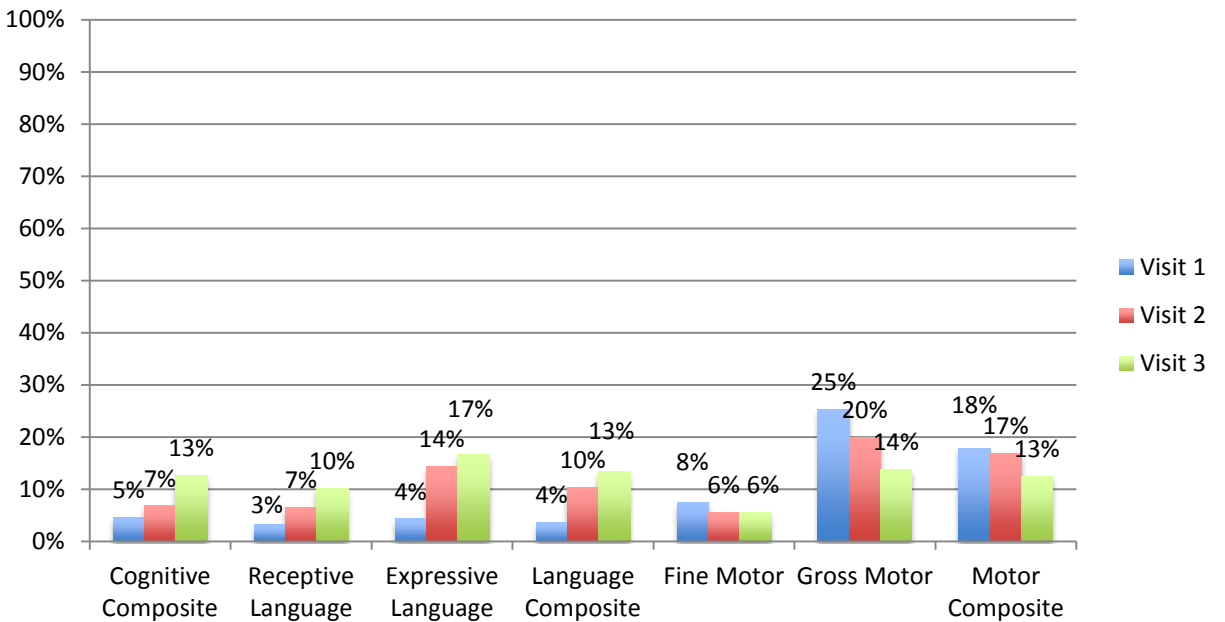
The values and patterns of change from Visit 1 to Visit 3 have been consistent for the past four years, with a smaller percentage of babies assessed as “normal” by Visit 3 in cognitive and language domains and more babies in the “normal” range on motor skills.



### Percent with Mild/Moderate Delay on Bayley III, 2015 Babies

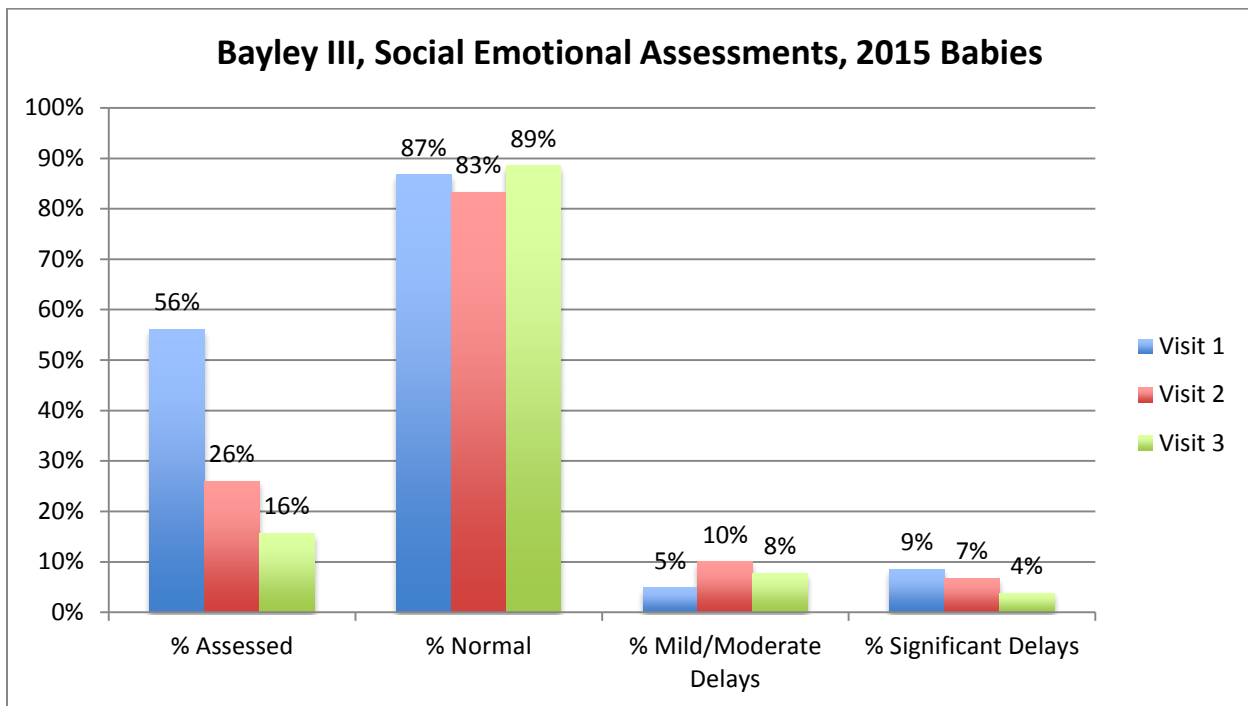


### Percent with Significant Delay on Bayley III, 2015 Babies



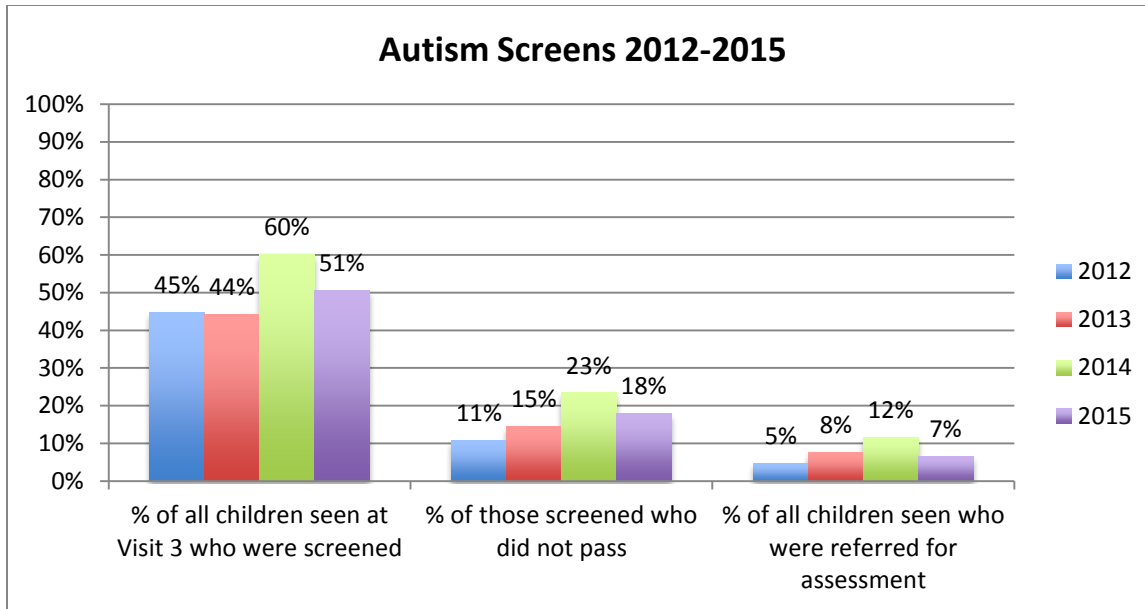


In October 2015, EDAC began administering the Social-Emotional Assessment that is part of the Bayley III, a standardized questionnaire filled out by the parents. Among the 2015 babies, 165 were assessed for social-emotional status at Visit 1 (56% of all babies seen); 60 at Visit 2; and 26 at Visit 3. The results are shown in the graph below. Among the 2014 babies, 16 were assessed for social-emotional status at Visit 3. Of these, 15 were normal and 1 had significant delays. Among the 2013 babies, 26 were assessed for social-emotional status at Visit 3. Of these, 18 were normal, 5 had mild to moderate delays, and 3 had significant delays.



EDAC uses the M-CHAT to screen for autism in toddlers between the ages of 16-30 months. Of the 166 2015 babies seen at the third visit, 84 were screened (50.6%); children with significant developmental delays were not screened because their developmental delays have already been identified and are being addressed. Of those screened, 15 (17.9%) did not pass. Eleven children were referred for further autism spectrum assessment. It is unknown how many children who were referred were screened first.

A larger percentage of children were screened in 2014 and 2015 than in 2012 and 2013 and a larger percentage of those screened did not pass. A smaller percentage of the 2015 children were referred for assessment than among the 2013 or 2014 babies.



Families whose infants or toddlers have a developmental delay or disability or an established risk condition that has a high probability of resulting in a delay may be eligible for the Regional Center’s Early Start program. The program provides early intervention and family support services for young children from birth to three years of age who meet eligibility requirements.

The next table shows the percent of children who were receiving Early Start services at each visit, along with the percent referred to Early Start at the visit, and the percent determined to be ineligible. A greater percentage of the 2015 babies were already receiving Early Start services at Visits 1 and 2 than the groups from 2012, 2013, and 2014. By Visit 3, the percent receiving Early Start was about the same for all three years. The percent deemed ineligible was quite low at all visits in all years.

Regional Center Early Start Services	2012	2013	2014	2015
VISIT 1 Receiving Early Start services	29.0%	31.4%	39.7%	45.2%
VISIT 2	35.4%	39.5%	46.1%	50.2%
VISIT 3	42.4%	41.9%	39.8%	39.2%
VISIT 1 Referred to Early Start services	18.7%	21.6%	28.2%	23.1%
VISIT 2	23.4%	24.9%	22.2%	20.8%
VISIT 3	24.8%	21.5%	30.5%	14.5%
VISIT 1 Determined ineligible for Early Start	2.8%	1.6%	3.8%	0.3%
VISIT 2	0.6%	1.2%	0.6%	0.0%
VISIT 3	0.8%	1.2%	0.8%	1.2%
VISIT 1 Total number of children seen	214	315	209	294
VISIT 2	158	253	167	231
VISIT 3	125	172	128	166

## The Center for Autism & Neurodevelopmental Disorders

Since 2015/16, twice a year, The Center has been asking parents who brought their child for a follow-up visit or ongoing therapy/treatment to complete a survey while they were in the waiting room. Parents who were visiting The Center for the first time are not asked to fill out the survey. Respondents are not required to answer every question, so the number of respondents (N) varies for each question.

In 2017/18, 134 parents completed the questionnaire; 54 parents completed the survey in 2016/17; 98 parents completed it in 2015/16.

### *Respondent Characteristics*

The first four tables show characteristics of the families who completed the surveys each year. They show that there are some substantial differences in the families that should be considered when interpreting year-to-year differences in the responses to other questions about The Center. For example, respondents in 2016/17 and 2017/18 were newer to The Center than respondents in 2015/16. Fewer respondents in 2017/18 had been going to The Center for more than 5 years. For the first time, in 2017/18, 10% of the surveys were completed by parents whose child was under age 3. In 2015/16 and 2016/17, most of the children about whom the parents were responding were age 6 or older (81% in 2015/16 and 87% in 2016/17). In 2017/18, only 57% were about children age 6 or older.

<b>How long have you been bringing your child to The Center?</b>			
	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>
Less than 1 year	6.5%	18.9%	17.5%
1 year	12.0%	5.7%	6.1%
2 years	18.5%	9.4%	18.4%
3 years	17.4%	13.2%	14.9%
4 years	14.1%	11.3%	15.8%
5 years	5.4%	1.9%	11.4%
More than 5 years	26.1%	39.6%	15.8%
N=	92	53	114

<b>How old is the child you bring to The Center?</b>			
<b>Child's Age</b>	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>
Less than 1 year	0.0%	0.0%	2.7%
1 year	0.0%	0.0%	4.4%
2 years	0.0%	0.0%	2.7%
3 years	5.5%	1.9%	6.2%
4 years	3.3%	3.8%	12.4%
5 years	9.9%	7.5%	15.0%
6-10 years	49.5%	49.1%	24.8%
11-15 years	26.4%	26.4%	21.2%
Age 16 or older	5.5%	11.3%	10.6%
N=	91	53	113

Parents who completed the survey in 2017/18 tended to have less experience with services available at The Center, with a few exceptions. More said they or their child had attended autism education series, received one-to-one support from a social worker, and received occupational therapy. Fewer indicated they had received a medical assessment, follow-up medical management, speech and language services, or ABA/Behavioral Therapy.

<b>Which of the following services have you or your child received from The Center</b>			
	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>
Medical assessment	81.9%	77.6%	64.2%
Follow-up medical management	69.9%	73.5%	55.2%
Attended autism education series	27.7%	30.6%	35.8%
Attended IEP training or Families and Schools Together (FAST) workshops	24.1%	28.6%	23.9%
One-to-one support from a social worker	19.3%	12.2%	23.9%
Speech and language services	21.7%	32.7%	18.7%
Counseling	9.6%	16.3%	18.7%
Participated in a parent support group	16.9%	18.4%	18.7%
ABA/Behavioral Therapy	27.7%	22.4%	16.4%
Wellness programs, such as Pacific Symphony events or arts and crafts	13.3%	14.3%	16.4%
Parent classes, such as Potty Training or Managing Tantrums	7.2%	14.3%	16.4%
Occupational therapy	7.2%	8.2%	14.2%
Other*	13.3%	14.3%	6.7%
N=	83	49	134

\*In 2015/16, other included 6 responses of Social Skills; 2 for Referrals; 1 each for Meds, Friday Club and Art therapy, and Neuro follow-up

In 2016/17, other included 2 for Social Skills; 2 for puberty class; and 1 each for "parent training," "It Takes Two to Talk" and "classes offered."

In 2017/18, other included 3 for Social Skills and 1 for Lego therapy; 5 people did not indicate what the other service was.

Having a diagnosis that is believed to be correct is an important step toward successful treatment and therapy. Unlike the two previous years, when about 80% of parents said their child had received a diagnosis from The Center, in 2017/18, only 43% said their child had received a diagnosis. More than one quarter of respondents said their child already had a diagnosis before they came to The Center and 29% said they had not received a diagnosis from The Center.

2015/16	2016/17	2017/18	Statement
75.5%	83.0%	43.1%	Yes, my child received a diagnosis from The Center
19.4%	11.3%	27.7%	My child already had a diagnosis before we came to The Center
5.1%	5.7%	29.2%	No, my child did not receive a diagnosis from The Center
N=98	N=53	N=130	
2015/16	2016/17		Diagnosis
60.4%	70.8%	56.4%	Autism only
15.4%	12.5%	11.7%	Autism and ADHD
14.3%	6.3%	21.3%	ADHD only
1.1%	6.3%	2.1%	Autism and another diagnosis
2.2%	4.2%	1.1%	ADHD and another diagnosis
6.6%	0.0%	3.2%	Autism, ADHD, and another diagnosis
0.0%	0.0%	4.3%	Another diagnosis (NOT Autism or ADHD)
N=91	N=48	N=94	

In 2015/16, the “other” diagnoses included oppositional defiance disorder, obsessive-compulsive disorder, anxiety, Fragile X, Fetal Alcohol Syndrome, Tourette’s syndrome, and sensory processing disorders.

In 2016/17, the “other” diagnoses were Asperger’s, anxiety, mixed expressive receptive language disorder, social pragmatic disorder, fetal alcohol syndrome, cerebral dysfunction, and learning disorder.

In 2017/18, the “other” diagnoses were described as fetal alcohol syndrome, intellectual disability, developmental delay, oppositional defiant disorder, and dyspraxia syndrome.

### *Parent Perspectives on The Center’s Services*

Most parents said they were very confident that the diagnosis their child received from The Center was correct, although the percentage that was very confident dropped from over 90% in 2015/16 and 2016/17 to 74% in 2017/18. In all years, very few parents said they had no confidence in the diagnosis. Very few parents had sought a second opinion and most of those who did said the second opinion was exactly or mostly the same as the diagnosis they received from The Center. Only in 2017/18 did one parent say the diagnosis was completely different.

<b>Level of confidence with the diagnosis they received from The Center</b>	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>
Very confident	90.7%	95.6%	74.4%
Somewhat confident	7.0%	4.4%	23.3%
Not confident	2.3%	0.0%	2.3%
N=	86	45	86
<b>Sought a second opinion after receiving a diagnosis from The Center</b>			
Yes	11.2%	13.0%	7.7%
N=	89	46	91
<b>Compared to the diagnosis from The Center, the second opinion was:</b>			
Exactly the same	60.0%	100.0%	28.6%
Mostly the same	40.0%	0.0%	57.1%
Completely different	0.0%	0.0%	14.3%
N=	10	6	7

Parents were asked which of 7 therapies or treatments were recommended for their child, whether the child received the therapy or treatment, and whether they had encountered any problems obtaining the therapy or treatment, regardless of whether the child received it.

In all three years, ABA/Behavioral Therapy was the most common therapy recommended, although a lower percentage of parents reported that it was recommended in 2017/18, which is consistent with the reduced experience these respondents had with The Center. Although over two-thirds of parents for whom ABA was recommended had received it, they indicated it was one of the more challenging therapies to obtain, citing the cost, long wait lists, and inconvenience of when or where it was offered. Very few parents said they did not think it would be helpful to their child.

Speech therapy was the second most-recommended therapy, and while parents had more success in obtaining it for their child, they also had challenges with the cost/insurance coverage and wait lists. In 2017/18, parents also noted that speech and language services were inconvenient to obtain.

Counseling and individual counseling were recommended least often and were the least likely to be obtained, with cost/insurance coverage presenting the greatest problem in all three years, along with the inconvenience of when and where services were offered in 2017/18. These were also the therapies that parents were most likely to think would NOT be helpful. In between, parents were especially challenged by long wait lists for occupational therapy, insurance/cost issues for social skills groups, and inconvenient access to occupational therapy, social skills groups, and parent training (2017 respondents only).

Although not recommended as often, parents had great success in receiving parent training and rarely cited problems with cost, wait lists, or convenience. Very few parents thought parent training would NOT be helpful.

Therapy/ Treatment	Recommended			Received (if recommended)		
	15/16	16/17	17/18	15/16	16/17	17/18
ABA / Behavioral Therapy	82.7%	82.7%	59.7%	67.9%	67.4%	68.8%
Speech Therapy	72.4%	80.8%	51.5%	83.6%	83.3%	81.2%
Occupational Therapy	61.2%	57.7%	41.8%	75.0%	60.0%	71.4%
Parent Training	54.1%	51.9%	38.8%	79.2%	70.4%	82.7%
Social Skills Group	60.2%	71.2%	31.3%	69.5%	64.9%	66.7%
Counseling	37.8%	36.5%	20.1%	71.8%	57.9%	51.9%
Individual counseling (to address anxiety, depression, etc.)	30.6%	38.5%	18.7%	67.7%	55.0%	56.0%
	N=98	N=52	N=134	*	*	*

\* The percent who received the therapy/treatment is calculated based on the number of parents who said the therapy/treatment was recommended, so it varies by therapy/treatment.

	Too expensive/ not covered by insurance			Long wait list			Inconvenient, due to hours offered, language, location, or no childcare			We didn't think it would be helpful		
	15/16	16/17	17/18	15/16	16/17	17/18	15/16	16/17	17/18	15/16	16/17	17/18
ABA / Behavioral Therapy	17.3%	14.0%	28.8%	12.3%	16.3%	15.0%	12.3%	14.0%	12.5%	2.5%	0.0%	1.3%
Speech Therapy	2.7%	11.9%	13.0%	4.1%	16.7%	11.6%	4.1%	4.8%	15.9%	0.0%	0.0%	1.4%
Occupational Therapy	6.7%	6.7%	12.5%	10.0%	20.0%	8.9%	6.7%	10.0%	19.6%	3.3%	3.3%	1.8%
Parent Training	1.9%	3.7%	3.8%	0.0%	0.0%	3.8%	1.9%	11.1%	5.8%	7.5%	3.7%	1.9%
Social Skills Group	11.9%	18.9%	28.6%	8.5%	8.1%	9.5%	8.5%	13.5%	16.7%	5.1%	2.7%	4.8%
Counseling	12.8%	21.1%	22.2%	5.1%	10.5%	14.8%	0.0%	10.5%	22.2%	7.7%	5.3%	7.4%
Individual counseling (to address anxiety, depression, etc.)	15.5%	25.0%	32.0%	3.1%	10.0%	8.0%	0.0%	5.0%	24.0%	9.4%	5.0%	8.0%
Percents were calculated using the number for whom the therapy/treatment was recommended as the denominator. In 2015/16, the N varied from 81-32; in 2016/17, the N varied from 43-19; in 2017/18, the N varied from 80-25												



In 2017, 16 parents wrote comments about their experiences obtaining the recommended therapies/treatments for their child.

- 5 talked about scheduling challenges, especially with finding late afternoon or after-school appointments
- 4 mentioned issues with cost, specifically mentioning social skills groups and counseling
- 3 commented on challenges related to insurance – for example, one said their insurance would only pay for one provider at a time, so they had to move to a single provider for both ABA and social skills; another said they didn't get an appropriate explanation of need sent to their insurer and had to wait over a year to get another speech therapist.
- 3 offered compliments to The Center and its staff for their help in obtaining services for their child
- 2 commented on long wait lists
- 2 wrote about challenges finding services that are compatible with the level at which their child functions
- 1 parent expressed interest in getting a second opinion, and 1 commented on how long it took to get ABA started

Four quotes provide an indication of the experiences the parents had with obtaining services for their child.

- It is difficult to get appointments after school but the front office staff is very accommodating.
- There are numerous speech therapists available but not many at the 'expert level' for pragmatics/social skills for high functioning autism. Same problem finding a 'good' child counselor with experience with autism. But then the expert we did find was way too expensive. We also found that talking about bringing attention to negative aspects of my son's life actually worsened his thoughts/emotions.
- It is a very confusing process and a long one as I'm still waiting on ABA speech approval from insurance
- The Center was extremely helpful and proactive with getting referrals, authorizations, and approvals. I'm super grateful.

Parents were asked to react to a set of 7 statements about the care and services they received at The Center and whether they had seen improvement since coming to The Center. Their reaction was recorded using a 6-point scale from strongly disagree to strongly agree. The results are presented by grouping responses of strongly and moderately agree, then the middle ratings – slightly agree or slightly disagree – and finally strongly or moderately disagree. The rating average is also provided, which is another way to see the strength of the parent response. Rating averages can range from 1 to 6, with 1 meaning every parent strongly

disagreed and 6 meaning every parent strongly agreed. Rating averages above 3.5 indicate that, on average, parents agreed with the statement at some level.

In all three years, a number of respondents STRONGLY DISAGREED with all the statements, but then, in other responses, including written comments, indicated a high level of satisfaction with the services they received from The Center. Because of the design of the survey form, it is possible that parents quickly selected the left-most column, thinking it was STRONGLY AGREE, without noticing the headings across the top of the page that defined each column in the table. In these cases, the responses were removed from the analysis for this set of statements. In total, 18 responses were deleted from the 2015/16 responses, 4 were deleted from the 2016/17, responses and 5 from the 2017/18 responses. The survey form will be changed to make the response scale clearer.

The table below shows the responses for the most recent year, 2017/18. The second table below shows the percentages of parents that strongly or moderately agreed and the average rating for each statement for all three years.

<b>2017/18</b>				
<b>Statement</b>	<b>Strongly or Moderately Agree</b>	<b>Slightly Disagree or Slightly Agree</b>	<b>Strongly or Moderately Disagree</b>	<b>Average Rating</b>
I am satisfied with the care we received from The Center	87.4%	9.0%	3.6%	5.35
The services we received from The Center met my expectations	88.7%	7.5%	3.8%	5.33
The Center is family-oriented	87.2%	7.3%	5.5%	5.32
The Center has contributed to the changes I see in my child	80.9%	13.6%	5.5%	5.13
My child's condition has improved since we've been coming to The Center	79.1%	14.5%	6.4%	5.07
The diagnosis we received from The Center helped my child obtain services from the school district and/or Regional Center	68.5%	22.8%	8.7%	4.85
The diagnosis we received from The Center led to changes in the services my child receives from the school district and/or Regional Center	70.9%	19.8%	9.3%	4.80
For all calculations, NA responses were removed. The number of responses per statement ranged from 86 to 111, with the last two statements in the table having the highest number of NA responses.				

Statement	Strongly or Moderately Agree			Average Rating		
	2015/16	2016/17	2017/18	2015/16	2016/17	2017/18
I am satisfied with the care we received from The Center	92.5%	93.8%	87.4%	5.55	5.63	5.35
The services we received from The Center met my expectations	82.5%	91.5%	88.7%	5.35	5.60	5.33
The Center is family-oriented	88.9%	93.9%	87.2%	5.48	5.76	5.32
The Center has contributed to the changes I see in my child	80.8%	79.5%	80.9%	5.21	5.27	5.13
My child's condition has improved since we've been coming to The Center	81.8%	76.7%	79.1%	5.17	5.14	5.07
The diagnosis we received from The Center helped my child obtain services from the school district and/or Regional Center	69.6%	69.4%	68.5%	4.70	4.94	4.85
The diagnosis we received from The Center led to changes in the services my child receives from the school district and/or Regional Center	59.0%	51.7%	70.9%	4.36	4.17	4.80
N=	61-81	29-49	86-111	61-81	29-49	86-111

In all three years, parents showed a high level of satisfaction with the care they received from The Center. The level of agreement that their child's condition has improved and The Center has contributed to those changes also was quite high. There was less agreement that The Center has helped their child obtain or modify services from the school district or Regional Center.

In order to continue improving their services, in 2016/17, The Center made a significant effort to better understand their wait list by piloting an in-person triage system and overhauling their overall process for tracking and managing interest calls and intake information. This helped them better address the needs of families seeking assistance by offering a new non-billable service with the help of two full-time intake coordinators. In 2017/18, The Center expanded their team of intake coordinators to four and continued to improve their triage and tracking system to prioritize services to young children.

In 2017/18, there was a 19-percentage point increase in the respondents who said the diagnosis from The Center led to changes in the services their child receives from the School district and/or Regional Center. This may be thanks to new grant funding The Center received from the California Department of Developmental Services to screen families and assist them with information about accessing the services provided at the Regional Center. In addition,

more of The Center’s providers are comfortable assisting families through the school system, including the Families and Schools Together (FAST) program, and the Center’s ABA providers and psychologists are assisting families with school issues more frequently.

A series of three questions asked parents to rate their perspective on 11 items of knowledge, attitude and action they may have or take about their child’s condition. The first question asks them to indicate how they currently feel about each item. The items are presented in the same order in all the tables that follow, from highest current knowledge or ability and most positive attitude to the lowest. In addition, an average score for each item was developed, with 1 representing the most negative or lowest response and 4 representing the most positive or best response. The highest average score possible is 4.

<b>How do you rate yourself today on each of the following items?</b>	<b>Very Poor/ Neg</b>	<b>Poor/ Neg</b>	<b>Good/ Pos</b>	<b>Very Good/ Pos</b>
	<b>2017/18</b>			
Knowledge of your child’s condition	0.9%	4.3%	62.4%	32.5%
Acceptance of your child’s condition	1.7%	5.1%	59.0%	34.2%
Knowledge of how to work with your child	0.9%	6.8%	62.4%	29.9%
Knowledge of how to locate and obtain services for your child	2.6%	6.1%	62.6%	28.7%
Attitude about your child’s condition	0.0%	9.4%	65.0%	25.6%
Sense of empowerment to help your child	1.7%	8.5%	56.4%	33.3%
Willingness to take your child to stores/ restaurants	0.0%	10.3%	58.1%	31.6%
Effectiveness in obtaining services for your child	1.7%	9.4%	62.4%	26.5%
Feelings of hope for your child’s future	1.7%	9.5%	58.6%	30.2%
Effectiveness in working with your child	0.0%	11.4%	63.2%	25.4%
Ability to control your child’s behaviors	0.9%	13.7%	58.1%	27.4%
N=	114-117			

In 2017/18, over 85% of parents said they felt positive or very positive about all 11 items, similar to the two previous years. Parents felt the most positive (the most VERY positives) about their acceptance of their child’s condition, their sense of empowerment to help their child, and their knowledge of their child’s condition. They were least likely to say they felt VERY positive about their effectiveness in working with their child, their attitude about their child’s condition, and their effectiveness in obtaining services for their child. More parents said they felt poor or

negative about their ability to control their child’s behavior, their effectiveness in working with their child, and their willingness to take their child to stores or restaurants.

Parents in 2017/18, for the most part, rated their feelings about each item lower than in previous years. They were close to the previous years’ average scores on only two items – effectiveness in obtaining services for their child and ability to control their child’s behaviors.

How do you rate yourself today on each of the following items?	Average Score			% Very Good/Positive and Good/Positive		
	15/16	16/17	17/18	15/16	16/17	17/18
Knowledge of your child’s condition	3.63	3.58	3.26	99.0%	96.2%	94.9%
Acceptance of your child’s condition	3.53	3.58	3.26	96.9%	100.0%	93.2%
Knowledge of how to work with your child	3.36	3.46	3.21	94.8%	98.1%	92.3%
Knowledge of how to locate and obtain services for your child	3.19	3.25	3.17	89.6%	88.5%	91.3%
Attitude about your child’s condition	3.57	3.44	3.16	95.8%	94.2%	90.6%
Sense of empowerment to help your child	3.43	3.42	3.21	94.7%	94.2%	89.7%
Willingness to take your child to stores/ restaurants	3.46	3.53	3.21	90.6%	90.2%	89.7%
Effectiveness in obtaining services for your child	3.18	3.08	3.14	86.6%	82.4%	88.9%
Feelings of hope for your child’s future	3.49	3.31	3.17	97.9%	86.5%	88.8%
Effectiveness in working with your child	3.26	3.23	3.14	92.9%	92.3%	88.6%
Ability to control your child’s behaviors	3.12	3.13	3.12	88.3%	86.5%	85.5%
N=	94-98	51-52	114-117	94-98	51-52	114-117

The next question asked how the parents had changed on these items since coming to The Center. In 2017/18, between 80 and 91 percent said they had become a little or a lot better, with most saying they had become a little better. More parents said they had become a lot better about their acceptance of their child’s condition, their knowledge of how to locate services for their child, and their sense of empowerment to help their child. Seven to sixteen percent said they had stayed the same. Only one to three percent said things had gotten work, with most of those indicating a decline in their attitude about their child’s condition and their willingness to take their child to stores or restaurants.

<b>How have you changed on each of these items since your child started coming to The Center?</b>	<b>Become worse</b>	<b>Stayed the same</b>	<b>Become a little better</b>	<b>Become a lot better</b>
	<b>2017/18</b>			
Knowledge of your child's condition	1.7%	7.0%	59.1%	32.2%
Acceptance of your child's condition	0.9%	12.2%	45.2%	41.7%
Knowledge of how to work with your child	0.9%	7.8%	57.4%	33.9%
Knowledge of how to locate and obtain services for your child	1.7%	9.6%	47.8%	40.9%
Attitude about your child's condition	2.6%	9.6%	50.0%	37.7%
Sense of empowerment to help your child	1.7%	8.7%	49.6%	40.0%
Willingness to take your child to stores/ restaurants	2.6%	16.5%	49.6%	31.3%
Effectiveness in obtaining services for your child	1.7%	13.0%	53.0%	32.2%
Feelings of hope for your child's future	1.7%	9.6%	53.9%	34.8%
Effectiveness in working with your child	0.9%	10.4%	50.4%	38.3%
Ability to control your child's behaviors	0.9%	10.4%	51.3%	37.4%
N=	114-115			

Parents who completed the survey in 2017/18 tended to be less likely to say they had become a lot better, therefore the average scores for many of the items are lower in 2017/18 than previous years.

How have you changed on each of these items since your child started coming to The Center?	Average Score			% who said they became a little or a lot better		
	15/16	16/17	17/18	15/16	16/17	17/18
Knowledge of your child's condition	3.55	3.46	3.22	89.7%	88.5%	91.3%
Acceptance of your child's condition	3.48	3.27	3.28	85.6%	80.4%	87.0%
Knowledge of how to work with your child	3.44	3.44	3.24	89.7%	86.5%	91.3%
Knowledge of how to locate and obtain services for your child	3.34	3.18	3.28	84.2%	76.5%	88.7%
Attitude about your child's condition	3.47	3.40	3.23	84.5%	84.6%	87.7%
Sense of empowerment to help your child	3.44	3.43	3.28	87.5%	82.4%	89.6%
Willingness to take your child to stores/ restaurants	3.34	3.22	3.10	80.4%	72.0%	80.9%
Effectiveness in obtaining services for your child	3.24	3.22	3.16	80.9%	80.4%	85.2%
Feelings of hope for your child's future	3.52	3.27	3.22	86.6%	82.4%	88.7%
Effectiveness in working with your child	3.43	3.33	3.26	88.5%	80.8%	88.7%
Ability to control your child's behaviors	3.32	3.21	3.25	83.5%	76.9%	88.7%
N=	94-97	50-52	114-115	94-97	50-52	114-115

The third question asked to what extent they attributed the change they have seen to The Center. In 2017/18, over 80% of parents gave The Center moderate to full credit for the change in their knowledge, attitude, or ability to take action on all 11 items. In 2016/17, over 80% of parents gave The Center moderate or full credit on 5 items; in 2015/16, over 80% gave moderate or full credit on 8 items.

In 2017/18, more parents gave moderate or full credit to The Center for changes in their knowledge and acceptance of their child’s condition than they did for other items. Although the numbers are small, more parents did NOT credit The Center for changes in their willingness to take their child to stores or restaurants, their effectiveness in obtaining services for their child, their knowledge of how to locate and obtain services for their child, or their knowledge of how to work with their child.

<b>To what extent have the doctors, nurses, therapists, and services received at The Center contributed to the change you have had on each of these items?</b>	<b>Not at all</b>	<b>A little bit</b>	<b>A moderate amount</b>	<b>All or nearly all</b>
	<b>2017/18</b>			
Knowledge of your child’s condition	1.8%	9.6%	64.9%	23.7%
Acceptance of your child’s condition	2.7%	8.8%	61.9%	26.5%
Knowledge of how to work with your child	3.5%	15.0%	57.5%	23.9%
Knowledge of how to locate and obtain services for your child	3.6%	12.7%	57.3%	26.4%
Attitude about your child’s condition	0.9%	13.2%	66.7%	19.3%
Sense of empowerment to help your child	1.8%	13.5%	58.6%	26.1%
Willingness to take your child to stores/ restaurants	4.4%	13.3%	55.8%	26.5%
Effectiveness in obtaining services for your child	3.6%	11.6%	59.8%	25.0%
Feelings of hope for your child’s future	2.6%	11.4%	56.1%	29.8%
Effectiveness in working with your child	2.7%	12.4%	62.8%	22.1%
Ability to control your child’s behaviors	2.6%	10.5%	62.3%	24.6%
N=	110-114			

Parents in 2017/18 were more likely to say The Center had contributed a moderate amount to changes they had seen. In previous years, parents were more likely to credit The Center for all or nearly all of the change they had seen. Therefore, while the combined percentages of those who said moderate or all/nearly all are similar across all three years for most items, the average scores for 2017/18 are lower for most items. The one exception to this is willingness to take their child to stores or restaurants – parents in 2017/18 were much more likely to give The Center credit for progress in this area than in previous years.



To what extent have the doctors, nurses, therapists, and services received at The Center contributed to the change you have had on each of these items?	Average Score			% who said a moderate amount or all or nearly all		
	15/16	16/17	17/18	15/16	16/17	17/18
Knowledge of your child's condition	3.44	3.33	3.11	91.5%	86.3%	88.6%
Acceptance of your child's condition	3.26	3.14	3.12	83.0%	78.0%	88.5%
Knowledge of how to work with your child	3.29	3.16	3.02	84.0%	84.3%	81.4%
Knowledge of how to locate and obtain services for your child	3.15	3.02	3.06	76.3%	75.5%	83.6%
Attitude about your child's condition	3.36	3.33	3.04	90.4%	86.3%	86.0%
Sense of empowerment to help your child	3.32	3.16	3.09	87.8%	80.0%	84.7%
Willingness to take your child to stores/ restaurants	2.90	2.76	3.04	67.7%	63.3%	82.3%
Effectiveness in obtaining services for your child	3.13	2.96	3.06	78.7%	70.0%	84.8%
Feelings of hope for your child's future	3.30	3.24	3.13	86.2%	82.0%	86.0%
Effectiveness in working with your child	3.29	3.10	3.04	85.1%	74.5%	85.0%
Ability to control your child's behaviors	3.16	2.98	3.09	80.6%	70.0%	86.8%
N=	90-94	49-51	110-114	90-94	49-51	110-114

When asked for any comments they wanted to share about how The Center has helped them and their child, 14 parents wrote statements about the services they have received and 6 commented that the survey is too long. Of the 14 who wrote comments, 12 praised The Center for their help, with comments like, "The Center has helped our family tremendously. By providing us a diagnosis and parent training and initial therapies, our world has changed for the positive... Having such a great team of experts is hugely comforting." One wrote, "better service hours." Another expressed concerns with how quickly the provider had made a diagnosis, without taking enough time to get to know the child. This parent also said the social skills group was not helping, there was too much homework, and they did not receive sufficient feedback on how best to help their child. Additional samples of the positive comments are provided in the next section of this report.

## Success Stories and Parent Appreciation

Sometimes, the best way to communicate what a program does is to share the stories of individual children and families who have received the services of that program. Below are stories of a few of the children and families who have been helped by Early Developmental Services and testimonials from parents. The complexity of the families and the services they need comes through in a way that the data cannot fully show.

*All names are fictitious.*

### Help Me Grow

#### *Robert*

Robert was referred into the HMG screening program by the Social Services' First Response Team at 16 months of age. On the Ages and Stages Questionnaire (ASQ), Robert scored at risk in communication, fine motor and problem solving. His mother, Annie, was very concerned with his communication, behaviors and social skills. At the time of the screening, Robert could say dad, daddy, drink and this, but he was not pointing or understanding simple commands. Annie stated that he was very aggressive and would hit, bite, and pull hair. She also noted that his eye contact was sporadic. Robert would engage socially a little bit, but then would get over excited and just throw things. Annie said she talked with the pediatrician who was concerned about possible autism and referred Annie to HMG for resources.

Annie told the pediatrician that she had just completed a developmental screening through HMG. After going over the results with Annie, HMG explained that the next step would be a developmental evaluation and described the different ways she could access one. Annie agreed for HMG to send a direct referral to the Regional Center of Orange County (RCOC) for Robert. HMG also referred Annie back to the pediatrician for a referral to a pediatric neurologist to assess for autism. At follow up, Annie reported the RCOC evaluation found him eligible for speech therapy and physical therapy. Annie said they were starting services next week. Annie also stated that both the pediatrician and the RCOC therapist had recommended that Robert be assessed by a pediatric neurologist. Mom was thankful for all the help connecting her to services.

#### *Jane*

A teacher sent a referral to HMG due to a child's poor attendance and to help the family with transportation. When the HMG Care Coordinator met with the mother, Jane, to discuss the attendance issue, Jane reported she was recently fired from her job and requested help with counseling because she was feeling depressed and was having difficulty getting through the day. Jane recently found out she was pregnant with her second child. The pregnancy was unplanned and she was feeling extremely worried that she wouldn't be able to manage two children and complete courses to get her high school diploma by May 2014. Jane described

having no emotional support from her aunt, with whom she lived, and minimal emotional support from her biological parents. Jane also indicated that she had attempted suicide when she was 15 years old, was hospitalized, and received treatment during that time.

The Care Coordinator discussed several options for counseling and provided her with three referrals for crisis counseling and long-term counseling services. The first option was for a direct referral to the Early Head Start (EHS) Mental Health Consultant due to Jane's past history of suicidal ideation and lack of family support. Jane gave consent for the direct referral. The second option was to contact Kaiser Behavioral Health Services to get referred to long-term counseling or therapy. The third option was to contact the Santa Ana College Continuing Education Department for Personal Counseling.

The Care Coordinator prepared a Family Partnership Agreement with Jane to meet with the EHS Mental Health Consultant for short-term counseling and to follow up with long term therapy via Kaiser Health Insurance to address her depression. The Care Coordinator suggested Jane enroll in the MOMS Orange County home visitation program due to the pregnancy, but she declined because she was receiving prenatal care through Kaiser.

The Care Coordinator received a follow-up contact from the EHS Mental Health Consultant indicating receipt of the direct referral and that a meeting was scheduled to meet with Jane. On a follow-up contact, Jane reported she had met with the EHS Mental Health Consultant regularly and completed the sessions. On a later follow-up contact with Jane, she reported she had an appointment to meet with a psychiatrist through Kaiser Behavioral Health for long-term therapy. Jane also reported her child's father was supportive and drove her daughter to the Early Head Start program daily. He also drove Jane to her therapy sessions and prenatal appointments at Kaiser. Mother was very grateful for the help she received from Help Me Grow.

### *Eduardo*

Eduardo contacted HMG requesting help finding a job. He had gone to a temp agency and the Santa Ana Work Center, but hadn't found permanent full-time employment. His certificate as a food handler was going to expire in 2015. When asked why he had worked at several jobs for short periods of time, he replied that he was diagnosed with epilepsy in 2009 at the age of 19 and when he had seizures on the job, employers usually terminated him on the spot.

The Care Coordinator asked Eduardo if he had registered with the California Department of Rehabilitation, which can provide help with employment and other services for adults with a medical diagnosis and disability. However, he did not know anything about the agency and was not registered with any type of program. The Care Coordinator asked Eduardo to obtain his medical records to show proof of the diagnosis. Then the Care Coordinator called the CA Department of Rehabilitation and, along with Eduardo, spoke to the intake counselor about his situation before scheduling an orientation meeting. The Care Coordinator also referred Eduardo to the Epilepsy Support Network Foundation and Goodwill Industries.

Eduardo resides with his girlfriend, with whom he has twins (a boy and girl). Both children are enrolled in the Early Head Start Preschool. The Care Coordinator discussed safety concerns with Eduardo because of the potential danger of him having a seizure when walking the children to school. The parents decided the grandmother would bring the twins to preschool.

At a follow-up meeting, Eduardo reported he is now registered with the CA Department of Rehabilitation, has met with his counselor, and submitted his medical records. The counselor was helping him get 2 suits for job interviews and a monthly bus pass registered as a disabled person. Eduardo will receive a placard for his girlfriend's car because she drives him to medical appointments, and a disability dog to alert him of impending seizures. He will be assigned a new primary care physician and a new neurologist. Eduardo completed the SSI application and Goodwill Industries let him know they would contact him when a job becomes available; he will have to wear a safety helmet on the job. The Care Coordinator also encouraged Eduardo to contact the Epilepsy Support Network so he and his family could learn what to do in an emergency.

The family was grateful to Help Me Grow for connecting Eduardo to a counselor who coordinated continued services for him.

### **Child Behavior Pathways**

#### **Thank you notes from parents to COPE Facilitators and/or Social Skills Providers**

Thank you for all the hard work and patience with the little ones, especially ours – we were able to maintain our focus because we were confident our son was in good hands. Over the past nine weeks, we have seen a tremendous shift in his ability to cope with strong emotions. Thank you for making learning fun and relatable; each of you has made a lasting impact on our child.  
With Gratitude,  
The XXXXs

We are eternally grateful for your positive support, resources and spirit of hope during our 9-week course. Our son has truly blossomed over these last 2 months and we owe it to you. We are all so much happier as a family; especially watching him build his independence and just be a happy child.

Thank you,  
XXXX and XXXX

Thank you so much for the time and effort you clearly put into facilitating and teaching, you do a wonderful job leading a diverse group through productive discussion and your knowledge and insight have been really helpful. We got so much valuable information from this class.

Kind Regards,  
XXXX and XXXX

## Quotes from evaluation forms

Follow the program and you will see changes. Stay consistent and it will change your parenthood.

Thanks for the follow-up! (My child) has been asking to go to your class all week. Looking forward to class tonight =)

Thank you so much Nicole! I learned that I can reinforce good behavior in a gentle way that really is powerful than being loud or mean. I can solve things with love and build a bigger bond.

So helpful! It got our family on the same page and helped create a peaceful home.

It helped me understand better parenting and discipline skills - now I need to work hard to implement what I learned. Great instructor.

## EDAC – Early Developmental Assessment Center

### *Marti*

Little Marti was born at 35 weeks gestation surrounded by at least a dozen providers to assure a safe delivery. Marti was diagnosed prenatally with a very small jaw, absent tongue, fused vocal cords and micro jaw and trachea. The delivery team (OB GYN, Neonatologist, ENT and anesthesiologist) at UCI performed an EXIT procedure (Marti's head and neck was exposed from the uterus and a tube directly into his trachea was inserted) to safely deliver Marti and provide him with an airway since he could not breathe on his own with his severe anomalies. He also required a tube directly into his stomach for nutrition. His NICU stay was complicated, however he was a fighter and he went home with his parents.

His airway was via trach and he had a G-tube for his nutrition and multiple specialty appointments, one being EDAC (High Risk Infant f/u) at 6 months adjusted age. When we saw Marti at 6 months of age his development was age appropriate, however he was showing early signs of frustration due to his inability to communicate (he still had a trach). He was social and understood everything asked of him. We recommended a developmental program with a sign language emphasis. Marti could hear, but could not express himself. The mother exhausted her resources to get her and Marti sign language training. The case manager for EDAC dialoged with the Regional Center and the school district describing how Marti was a unique case. The mother needed sign language training in addition to Marti. Marti's mother also had difficulties coordinating all his specialists.

The EDAC coordinator referred her to Marti's insurance's care coordination department so the mother would have one person at the insurance company to help with authorizations and care

coordination. When Marti came in for his 3<sup>rd</sup> EDAC visit, mom was pleased to inform the team that Marti was receiving speech therapy / sign language training and also was in a group program with other children learning sign language. Marti was connected to all specialists and he continues to thrive. Overall his development is on track even though he still has the trach and G-tube. Marti's mother thanked the EDAC team for their diligence with connecting Marti to his medical and developmental therapy teams.

### *Jacob*

The CHOC EDAC High Risk Infant Follow-Up (HRIF) coordinator received a phone call from Portland, Oregon. A developmental pediatrician there had followed a post-NICU baby, Jacob, who met medical eligibility criteria equivalent to California's HRIF service and was making a referral because the family was about to relocate to Orange County. The pediatrician was concerned that the child could be lost in the system because the parents had no knowledge of how to apply for Medi-Cal and how to navigate through multiple specialty services that the patient required. He had felt that CHOC EDAC HRIF program would be the best place for care coordination and case management service for this fragile and vulnerable child.

A few weeks later, Jacob's mother called and stated that she had obtained Medi-Cal for Jacob but the family was near Miller Children's Hospital, therefore, she'd like to follow-up there with all specialty providers. The coordinator provided information and a contact person at Stramski Children's Developmental Center, Miller Children's Hospital, and guided Jacob's mother on how to get established with a pediatrician first. Also, the HRIF program information and service was explained to her.

Two weeks later, she called back and reported that there were issues with Medi-Cal and she couldn't find a pediatrician for Jacob through Medi-Cal. He was being assigned to CalOptima and she would have to search for several new providers for Jacob again. She was on the verge of tears and expressed anxiety and helplessness. The coordinator listened carefully, provided support and empathy, and guided her step-by-step on how to find a pediatrician who would be the medical home for Jacob. In addition, the coordinator provided education regarding the specialty referral process, outlining each service that Jacob needed. Mother expressed huge relief and gratitude that someone was there to listen and help her through tough times.

The coordinator referred Jacob to the Regional Center of Orange County (RCOC) for the Early Start program and mother was to follow through with the eligibility process. A month later, Jacob's medical home pediatrician called the EDAC HRIF coordinator and thanked her for supporting Jacob's mother and directing the care necessary for Jacob. Further discussion took place for all referrals that Jacob would need and it was determined that CHOC specialty providers would be the best choice for Jacob. Since then, Jacob was seen in CHOC Pulmonary clinic for ongoing management of chronic lung disease, Cardiology for congenital cardiac issues, Ophthalmology for management of retinopathy of prematurity (ROP), RSV Prevention clinic for Synagis during the RSV season, and Rehabilitation Services for physical therapy.

The pediatrician and the EDAC HRIF coordinator concurred that Jacob should be followed in EDAC sooner than the projected 2<sup>nd</sup> HRIF visit time (he had the initial developmental visit at 4 months adjusted age in Portland, Oregon) for neurodevelopmental assessment in order to determine further needs. Mother called back to report that every encounter with all specialty providers, therapy center and RCOC was wonderful and she was looking forward to seeing the team at EDAC HRIF. We'll serve him and his family in March 2017. We are looking forward to meeting Jacob and his family as well.

### *Ryan*

Ryan was born extremely premature with extremely low birth weight. His NICU course was complex and he had multiple surgeries due to hydrocephaly from intracranial hemorrhage and G-tube placement. He developed seizures and was placed on anti-seizure medications. He had multiple specialty follow-ups after NICU discharge. His parents were young, had to finish high school, and started working.

Ryan's maternal grandmother became his primary caregiver, because his parents had to work long hours. She made diligent efforts to follow-up with multiple specialty providers but his condition required 2-3 week follow-ups with several specialty providers and she couldn't keep up with all appointments. Also, he was hospitalized numerous times or seen in the emergency department (ED) due to VP shunt revision, seizures, Broviac central line-related issues and infections.

Ryan's fragile medical condition delayed outpatient follow-ups further. His grandmother couldn't get him established with a medical home pediatrician even though there was one assigned by Medi-Cal. He received all of his immunizations either in the ED or specialty providers' offices and missed several EDAC HRIF appointments. EDAC HRIF coordinators and financial coordinators made tireless efforts to connect with Ryan's mother and grandmother and have him seen in EDAC for HRIF services.

Ryan was seen in EDAC for the first time at 17 months of adjusted age (20 months chronological/ calendar age). His development was severely delayed and his neurological exam was abnormal. CCS Medical Therapy Program (MTP) was providing therapy services but due to his multiple hospitalizations and ailments, he couldn't attend therapy sessions and couldn't follow through with the Regional Center of Orange County (RCOC) services.

The EDAC HRIF coordinator and social worker spoke to his mother and grandmother and provided education on every single service that Ryan would need including specialty providers that he had missed and therapy services. We explored resources for family support, because the grandmother was overwhelmed with his medical and therapy needs. The coordinator contacted his pediatrician, RCOC liaison for visual therapy service, CCS MTP for ongoing therapy services, CalOptima for case management service, specialty providers for setting up appointments/referrals and connected the family with the Orange County Care Coordination Collaborative for Kids (OC C3 for Kids) PHN. The PHN referred him directly to OC Public Health

Nursing (he had originally been a client but the family initially declined the PHN service) and the OC PHN guided and helped the family tremendously.

A team of care coordinators was established beyond one hospital and clinic. The RCOC case coordinator, CCS MTP, OC C3 PHN, OC PHN and the EDAC HRIF coordinator communicated, corroborated and collaborated for Ryan and family. Now he attends CCS MTP therapy sessions and Blind Children's Learning Center/RCOC regularly and he follows specialty providers as outlined. CCS has authorized a specially-fitted infant chair and he's well established with a diaper service. He'll be followed by audiology and ophthalmology in the near future. The team of community partners will continue its care coordination for Ryan and family.

### **The Center for Autism & Neurodevelopmental Disorders**

#### *Praise from the parent survey*

"I feel they have the knowledge to work with my son. I'm really happy with the Center what specialties on 'Autism Developmental Disorders'. We feel hope!!! Thank you all!"

"Great staff and doctors, the girls at the front desk are super welcoming and nice to my kids."

"The center continues to be the cornerstone in our lives when it comes to Autism, SPD and mixed expressive and language disorder. Every month I watch my sons grow and have the support from other services from the center to see how these goals in therapy can be supported in other environments. The entire staff is loving, encouraging and supportive; whom I have come to consider like family."

"Diagnosis to in house services. It is nice having a team for my child from ABA to IEP help, and a medical team."

"The most important thing is feeling safe and understood. I get that from my providers at the center."

#### *Ricardo*

When Ricardo was only 16 months old, his parents noticed that he wasn't pointing, making good eye contact, and wouldn't even attempt to make animal noises during playful moments. With an older daughter, her parents knew what milestones to expect in a baby, and they just weren't seeing them.

Their pediatrician referred the family to The Center for Autism & Neurodevelopmental Disorders. There, the doctor interviewed the parents, and observed Ricardo as he interacted with toys. At the end of the evaluation, he was diagnosed with an autism spectrum disorder. Initially, Ricardo was not able to communicate verbally. This was particularly tough for the



parents because without knowing how to communicate with their son, mom reported that it was extremely frustrating for everyone in her family. He would go into a toy store and not even understand that he was surrounded by fun things to play with. In the beginning, Ricardo would only pull toys back and forth. He didn't play with others, including his sister, and nothing really held his interest.

Through the services offered at The Center, Ricardo began behavioral therapy and speech therapy. A few months later, the parents were delighted that things started to change. Ricardo started to communicate! And through the ABA therapy provided by The Center, mom reports that the 'change in him is unbelievable'.

That's not to say that Ricardo's progress has been simple. But as mom says "all the help he has gotten at The Center has been so right for him, so perfect, that I found myself no longer going to bed at night with 100 thoughts and worries in my head. I know he is getting the right treatment. I know we are getting the right advice. As a parent of any young child we never really rest, but at least I could sleep. Today, we sit down together as a family and play board games. He and his sister can sit and play, and when they fight it is no different than any other pair of siblings who fight. They argue, they work it out and they keep playing. Even more incredible to me is that thanks to the work by the dedicated team at The Center, Ricardo has just been mainstreamed into a regular kindergarten. We could not have gotten here without The Center."