

CHOC-UCI Neurodevelopmental Programs
Evaluation Report
July 2011 through June 2012

Introduction

The CHOC-UCI Neurodevelopmental Programs (NDP) 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 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.
- **CUIDAR** provides a preventive and “intervention before diagnosis” approach with 10-week COmmunity Parent Education (COPE) classes, 8-week COPEing with Toddler Behavior (CWTB) classes, and teacher training services. CUIDAR helps parents effectively manage challenging behaviors and improve family functioning, encourages healthy relationships with infants and toddlers, and helps teachers manage challenging behaviors in the classroom.
- **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 is needed, **For OC Kids Neurodevelopmental Center (NDC)** provides comprehensive evaluations, diagnosis, treatment recommendations, and management of children birth through age five who are suspected of having developmental, behavioral or learning problems, including a focus on autism and attention deficit hyperactivity disorder (ADHD). It also provides family support, education, and advocacy.

Help Me Grow, CUIDAR, EDAC, and For OC Kids Neurodevelopmental 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 the NDP is provided by the Children and Families Commission of Orange County (CFCOC), which began supporting developmental services at CHOC and UCI more than ten years ago. The NDP, as it is currently configured, was established in 2005, when

the last of the programs, Help Me Grow, was inaugurated. This evaluation report describes the accomplishments of the NDP in the 2011/12 fiscal year. Its purpose is to show how the NDP 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 GEMS, the data system of the CFCOC, or from the programs themselves. GEMS 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 Commission 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 below 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 NDP programs are shown for the past four years.

Children

Program	Number of Children Served			Number of Services to Children		
	09/10	10/11	11/12	09/10	10/11	11/12
Help Me Grow	2056	3428	4395	17,076	17,526	16,013
CUIDAR	601	564	0*	3720	4602	0*
EDAC	2218	2230	2701	9864	10,433	11,642
For OC Kids	1485	2308	1410	6041	8349	3654
TOTALS*	6360	8530	8506	36,701	40,910	31,309

* CUIDAR did not provide Social Skills classes to children in FY 2011/12

Family Members

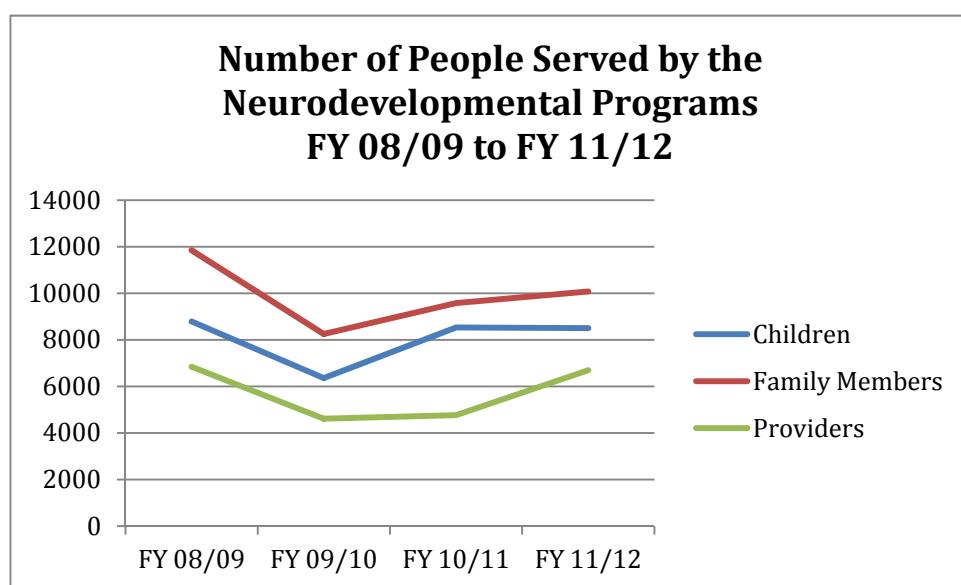
Program	Number of Family Members Served			Number of Services to Family Members		
	09/10	10/11	11/12	09/10	10/11	11/12
Help Me Grow	2056	3428	4395	17,076	17,526	16,013
CUIDAR	1200	1137	695	8021	8454	4348
EDAC	2220	2230	2701	9918	10,445	11,642
For OC Kids	2772	2784	2290	5200	6451	4285
TOTALS*	8248	9579	10,081	40,215	42,876	36,288

Service Providers

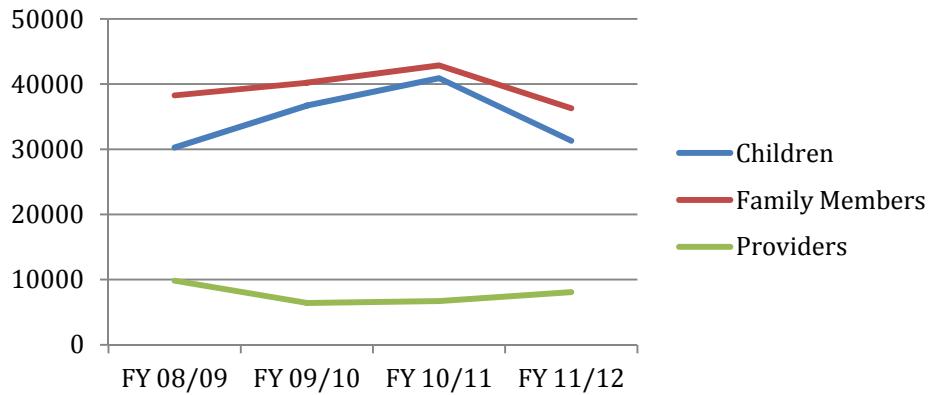
Program	Number of Providers Served			Number of Services to Providers		
	09/10	10/11	11/12	09/10	10/11	11/12
Help Me Grow	2708	3441	4592	3279	3441	4592
CUIDAR	369	385	341	1631	1701	409
EDAC	517	260	494	431	861	1819
For OC Kids	1018	679	1273	1074	694	1273
TOTALS*	4612	4765	6700	6415	6697	8093

Data Sources: Data for the first half of 09/10 come from the Commission's previous data system, OCERS.

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

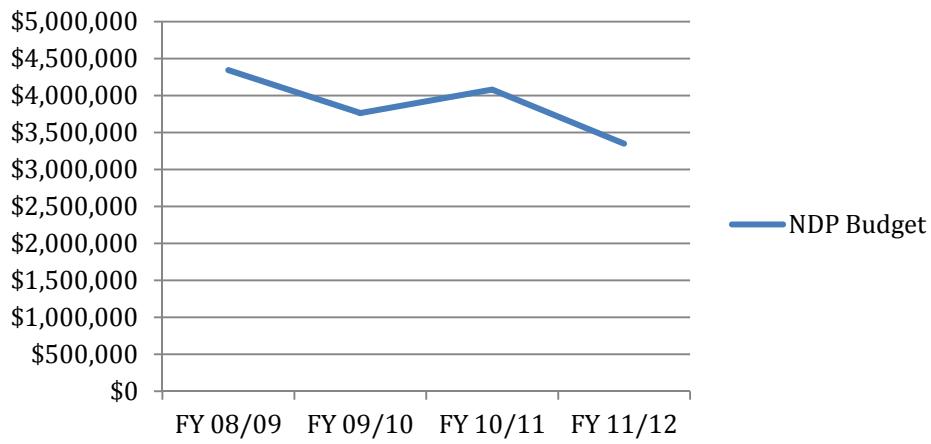


Number of Services Provided by the Neurodevelopmental Programs FY 08/09 to FY 11/12



To understand at least some of the changes in the number of people served and the number of services provided, the annual budget for all four programs combined is presented below.

NDP Budget FY 08/09 to FY 11/12



Progress toward milestones:

The NDP reports their progress toward specific milestones selected by the Commission based on the services each program provides. These milestones are standardized across all of the Commission'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 FY 11/12, the number of clients served during the year, and when comparable numbers are available, the number of people served during the previous year.

For all but three milestones, the programs surpassed their targets for FY 11/12. For those that fell short, it should be remembered that 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 have achieved 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.

Milestone	Description	Program	12-Month Target for 11/12	# of Clients Served in 11/12	# of Clients Served in 10/11
HC 2.1.1	Providers trained on how to screen, assess and /or identify child developmental milestones	HMG	60	125	162
HC 2.1.2	Providers educated on child development, recognizing key milestones and the importance of screening	HMG	122	142	174
		EDAC	100	452	978
		For OC Kids	150	1273	679
HC 2.2.1	Children receive developmental screening using AAP recommended tools.	HMG	50	2723	1323
		CUIDAR			351
HC 2.2.7	Children receive behavior health screening using Commission-approved tool (including but not limited to ASQ:SE)	CUIDAR	180	222	532
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-child functioning)	EDAC	1000	506*	1172*
		For OC Kids	600	335	881
HC 2.2.10	Parents receive education, resources, referrals, and support regarding their child's development	EDAC	600	1093	782
HC 4.4.1	Children receive specialty care clinic visits	For OC Kids	1600	2047**	2894**
HC 4.4.3	Parents receive specialty care	EDAC	80	1093	316

Milestone	Description	Program	12-Month Target for 11/12	# of Clients Served in 11/12	# of Clients Served in 10/11
	education, resources, referrals and support	For OC Kids	300	2000	2439
SF 2.2.4a	Parents participate in parenting education classes on healthy child development	For OC Kids	200	308	345
SF 2.2.4b	Parents participate in a parenting education class series on healthy child development	CUIDAR	520	695	1137
		EDAC			576
SF 3.1.2	Parents receive referrals to services	HMG	1800	1659	2169
SF 3.1.3	Providers receive referrals to services	HMG	350	789	521
SF 3.1.4	Parents receive follow up on referrals and services are accessed	HMG	600	754	1284
SF 4.1.1	Children receive behavioral health treatment services	CUIDAR			557
SF 4.1.3	Providers receive training on behavioral health treatment services for children 0-5	CUIDAR	120	341	300
CB 2.2.1	Developing partnerships, coordinating and collaborating with other agencies to improve services	HMG	6	6	

Source: GEMS

* 132 were foster children in 2011/12; 145 were foster children in 2010/11

** Children are counted each time they received a comprehensive assessment, so if they were assessed on three different occasions, they are counted three times.

Child Demographics

Each program collects data that describes the children and families they serve. Overall, the programs serve more boys than girls. Because of different focuses of the four programs, they serve either a subset of the 0-5 age group or all five ages. A majority of the children are Hispanic. The primary language of the families is either English or Spanish, depending on the program.

In looking at the data presented in the FY 10/11 NDP Evaluation Report, the percentages remained fairly constant from year to year with the following exceptions. For OC Kids reported serving a greater percentage of children over age 5 (31.4% in FY 10/11 compared to 44.5% in FY 11/12); a smaller percentage of their children were age 2 and under (21.4% in FY 10/11 compared to 12% in FY 11/12). Changes to the CUIDAR population (partly due to the addition of COPeing with Toddler Behavior, which previously was included in EDAC's numbers) resulted in a number of differences between FY 10/11 and FY 11/12. The program served a smaller percentage of Hispanics (71.8% in FY 10/11; 58.9% in FY 11/12) and a greater percentage of Asians (3.8% in FY 10/11; 7.1% in FY 11/12) and Whites (7.1% in FY 10/11; 18.6% in FY 11/12). This corresponds to a greater percentage of English-speaking (35% in FY 10/11; 57.7% in FY 11/12) and fewer Spanish-speaking families (65% in FY 10/11; 42.3% in FY 11/12). CUIDAR also reported serving a lower percentage of children whose mothers had not completed high school (22.1% in FY 10/11; 13% in FY 11/12) and more whose mothers had a graduate or professional degree (8.6% in FY 10/11; 20.0% in FY 11/12).

Gender	HMG	CUIDAR	EDAC	For OC Kids
Boys	62.1%	66.0%	56.0%	77.4%
Girls	37.4%	33.3%	44.0%	22.6%
Unknown	0.5%*	0.7%		
N=	1862	553	1070	1707

* Unknown because the mother is pregnant

Child's Age	HMG	CUIDAR	EDAC	For OC Kids
<1 year	8.1%	4.8%	59.0%	0.4%
1 year	16.9%	7.0%	39.5%	2.1%
2 years	20.8%	10.8%	10%	9.5%
3 years	19.9%	16.3%	<0.5%	13.5%
4 years	15.6%	32.6%		15.1%
5 years	6.3%	21.7%		15.0%
>5 years	12.4%	5.6%		44.5%
Unknown		1.2%		
N=	1862	553	1070	1707

Race/Ethnicity	HMG	CUIDAR	EDAC	For OC Kids
American Indian	0.1%	0.5%	0.1%	
Asian/Pacific Islander	10.3%	7.0%	7.8%	
Vietnamese		0.1%	0.2%	
Black	1.0%	0.5%	3.1%	
Hispanic	61.6%	58.9%	50.4%	29.2%
More than one	8.3%	10.5%	0.7%	
White	14.6%	18.6%	29.4%	
Other	1.6%	2.5%	6.3%	
Non-Hispanic				62.6%
Don't Know/ Decline to answer	2.6%	1.4%	3.0%	8.3%
N=	1862	553	1070	1707

Primary Language	HMG	CUIDAR	EDAC	For OC Kids
Arabic				0.1%
Chinese	0.1%			
English	58.2%	57.7%	49.0%	76.0%
Farsi			0.1%	
Korean	0.2%			0.2%
Spanish	40.2%	42.3%	57.6%	22.4%
Vietnamese	1.3%		0.3%	1.1%
Sign Language				0.1%
Other	0.1%		3.0%	0.1%
Unknown				0.1%
N=	1862	695	1070	1707

Household Income	CUIDAR*
Less than \$29,000	53.2%
\$29,001-\$49,000	16.2%
\$49,001-\$71,000	6.2%
\$71,000-\$106,000	8.4%
\$106,000 or more	16.1%
N=	337

*216 Decline to Answer, Do Not Know and Missing responses are not included in the calculations of percents.

Health Insurance Status	HMG	EDAC	For OC Kids
Caloptima (Medi-Cal assigned)	52.8%		51.1%
California Children's Services		62.0%*	0.1%
Healthy Families	8.7%		1.6%
Healthy Kids	0.2%		
Medi-Cal (Direct - unassigned)	3.3%	1.4%**	2.1%
None/Self-Pay	2.9%		0.5%
Private Insurance-HMO	15.2%	14.0%	13.6%
Private Insurance – POS	1.0%	6.0%	1.0%
Private Insurance-PPO	14.4%	15.0%	29.9%
TOTAL Private Insurance	30.6%	35%	44.5%
Tri-Care (Military Insurance)	0.3%		
Other	1.4%	4.1%	
Missing			
N=	1874	~ 700***	1707

* MediCal is secondary insurer

** Includes all MediCal direct and CalOptima

*** EDAC data is only on those patients qualified for service through CCS; the percents add up to more than 100 because some children have more than one insurer.

Mother's Education	CUIDAR	EDAC
Did not complete High School	13.0%	18.5%
High School Diploma or GED	20.5%	37.0%
Some college or vocational school	25.4%	21.0%
Associate Degree		
Bachelors Degree	21.2%	14.8%
Graduate or Professional Degree	20.0%	8.6%
Missing/Other	*	**
N=	507	~ 700

* 46 Decline to Answer or Missing responses were not included in the calculation of percents

** EDAC data is only on those patients qualified for service through CCS. The percents were adjusted to exclude 19% who did not provide information about the mother's education.

Why Families Seek NDP Services

The reasons families seek services from the NDP varies 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, which are shown in the data below.

Help Me Grow – Families contact HMG for a variety of reasons; the most common are shown in the table below:

Percent of All Concerns*			Reason for Call
11/12	10/11	09/10	
20.4	19.4	17.5	Communication
14.8	16.1	16.2	Behavioral
13.9	11.4	5.7	General Development
8.8	7.0	9.6	Parental Support
5.8	4.5	**	Developmental concerns
5.0	5.9	2.7	Hearing
4.7	6.1	9.6	Childcare
4.6	4.4	4.8	Diagnosis
3.5	3.6	0.4	Family Issues
3.4	2.4	2.8	Mental Health
2.8	1.9	4.3	Education
2.6	3.3	3.2	Basic Need
1.7	3.9	10.8	Social/Emotional
1.7	2.7	3.2	Health/Medical
1.5	2.0	2.0	Health Insurance
***	***	2.4	Motor (Gross and Fine)
1.3	1.6	***	Gross Motor
1.3	0.9	1.0	Adaptive
0.6	0.7	***	Fine Motor
0.5	0.6	0.2	General Information
0.2	0.2	0.3	Cognitive (Learning)
0.1	0.1	0.2	Vision
0.0	0.2	0.4	Living Condition
0.7	1.1	2.6	Other
2420	3267	2894	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 by HMG.

** New category added in 10/11

*** Motor skills were broken out by Fine and Gross starting in 2010/11; comparisons with previous years are not advisable.

CUIDAR – 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. In FY 2011/12, CUIDAR also took over the COPEing with Toddler Behavior classes for parents of high-risk infants and toddlers who wish to learn more about encouraging and nurturing a healthy and positive relationship with their infant/toddler, including infant bonding and attachment, as well as development.

EDAC – Infants referred to EDAC had the following developmental concerns and diagnoses:

Percent	Developmental Concern	Percent	Diagnosis
50.0	Movement Control	51.0	Preterm
38.0	Postural Alignment	22.0	Infant of Substance Abusing Mother
18.0	Oral Motor Feeding	8.5	Neurologic Condition
14.5	Low Tone	6.3	Major Surgical
10.0	Sensory Processing	4.5	Respiratory Condition
9.8	High Tone		
7.0	Hearing		
5.6	Visual		

By the first visit in the EDAC, 50% have significant gross motor delays and 26% have fine motor delays. Of those seen for a third visit, 40% present with language delays. In the 18-24-month-old toddlers, nutrition concerns are diminishing for underweight babies, but there is an increase in those who are overweight.

For OC Kids

For OC Kids 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 For OC Kids 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.) For OC Kids also sees children with possible delays or who are at-risk for delays, such as infants of substance abusing mothers, children in foster care or being adopted.

Outcome Measures

Each program collects outcome measures to demonstrate that their program is meeting the needs of the community and the clients they serve. Outcome measures often demonstrate a short or intermediate-term effect of the program because the long-term effects are difficult to measure and may not be as attributable to the program as shorter-term effects are.

Help Me Grow

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 have contacted Help Me Grow seeking referrals because they have concerns about a child's development. The table below shows the cities that make up the greatest number of contacts to HMG (the top eleven cities) and compares the percent of HMG contacts to the percent of all Orange County births represented by each of those cities. In FY 11/12, these eleven cities accounted for 83% of HMG's clients and 70% of all Orange County births.

Where HMG's Clients Live

City	Percent of HMG clients by city		Percent of Orange County births by city
	2011/12	2010/11	
Santa Ana	28.6	27.6	16.8
Anaheim	17.8	14.3	14.6
Garden Grove	5.6	4.8	6.1
Huntington Beach	5.2	5.0	4.9
Irvine	4.7	4.8	5.9
Costa Mesa	4.7	3.5	4.0
Orange	3.9	3.9	4.8
Fullerton	3.7	3.9	4.2
Westminster	3.4	2.6	2.8
Tustin	3.0	3.9	3.2
Buena Park	2.8	2.6	2.6
Cumulative percent	83.4	76.9	69.9
N=	1777	2432	40,431

Birth data is for 2009 as reported in the 17th Annual Report on the Conditions of Children in Orange County.

How callers heard about HMG

The next table shows how callers learned about HMG in FY 11/12 and FY 10/11. In both years, more callers heard about HMG through their health care provider than any other source (29.4% in FY 11/12). The second most common way for callers to have learned about HMG is through a community agency or program, such as For OC Kids, WIC, MOMS, or the Social Services Agency (collectively, 19.9%). Developmental screening programs (through Early Head Start, Pretend City and others) referred 14.9% of the callers. Just over

6% of the callers learned about HMG after calling 2-1-1 Orange County and either listening to the automated answering machine or talking to a 2-1-1 Resource Specialist. A growing percentage of the callers are repeat callers (5.6%). The Regional Center of Orange County was the source for 3.0% of the calls, and public school districts for 4.5%. Other ways callers learned about HMG included their childcare provider (4.4%), a friend (3.5%), a family member (1.0%), a library (0.8%), via a HMG presentation or website (2.4%), or through a resource fair, newspaper or online media (1.7%).

Source	Percent of Callers by Source	
	FY 11/12	FY 10/11
Health Care Provider	29.4	31.5
Community Agency	19.9	21.5
Developmental Screening Program	14.9	11.9
2-1-1 Orange County	6.4	10.5
Previous Caller	5.6	2.7
Public School	4.5	3.4
Childcare Provider	4.4	3.4
Friend	3.5	4.0
Regional Center of Orange County	3.0	4.0
HMG Presentation or Website	2.4	2.8
Resource Fair, Newspaper, Online Media	1.7	0.6
Hospital	1.2	0.9
Family Member	1.0	0.8
Library	0.8	1.1
Private School	0.3	0.6
Other	1.0	0.3
N=	1862	2430

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 (each accounting for at least 1% of referrals) made by HMG are shown in the next table. Services with the least referrals (less than 1.0% of all referrals in FY 11/12 and FY 10/11) included legal assistance, psychiatry, psycho-educational testing, feeding, and physical therapy. Only 0.5% of referrals were for services out of Orange County.

Percent of all Referrals		Type of Referral
2011/12	2010/11	
14.9	16.8	Parenting/Education
11.5	12.9	Communication/Speech & Language
8.3	5.2	Educational/Enrichment

Percent of all Referrals		Type of Referral
2011/12	2010/11	
6.2	6.8	Developmental Screening
6.0	4.0	Mental Health/Counseling
5.3	6.6	Childcare
4.7	4.6	Parent/Child Participation
4.6	4.0	Recreation/Sports/After School/Camps
4.5	4.1	Regional Center of Orange County
4.0	4.6	Behavioral Services
3.9	3.5	School District
3.8	4.0	Health/Neurodevelopmental Subspecialists
3.3	3.8	Family Support
2.4	2.3	Basic Needs
1.9	3.2	Health/Primary Care
1.8	1.5	Early Literacy
1.7	0.2	Allied Health Professionals
1.3	0.9	Advocacy
1.2	2.4	Access to Health Insurance
1.2	1.8	Social Skills
1.0	1.4	Occupational Therapy
0.7	1.0	Health/Medical Specialists
7091	9360	Total Number of Referrals for the Year

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 in FY 11/12 and FY 10/11, followed by the number and percent of those who were reached when the follow-up attempts were made.

	2011/12	2010/11
Total number of callers who agreed to a follow-up call	1315	1930
Total number of callers who were reached on a follow-up call and received care coordination	928	1422
Percent of callers who agreed to a follow-up call who were actually reached	71%	74%

Each caller may receive multiple referrals, so HMG tracks the status of each referral. The next table shows the number of referrals about which HMG was able to determine the status when they made the follow-up call for both FY 11/12 and FY 10/11. It then shows the status of the referrals. In 2011/12, HMG reported an improvement in the rate at which children were connected to the referrals provided by HMG and a decrease in the rate of referrals for which the children were not connected. The rate of pending referrals, meaning they had a scheduled appointment at the time of follow-up, was about the same.

There are a number of reasons children are not connected to a referral, including lack of follow through by the parent, the program was full, the parent decided against it, there were transportation issues, the service overlapped with another referral, etc.

	2011/12	2010/11
Number of referrals about which HMG was able to learn whether the child was connected to the service	1776	2721
Number of referrals for which a child was connected to service	881	1156
Percent of referrals for which a child was connected to service	49.6%	42.5%
Number of referrals for which a connection was pending*	209	304
Percent of referrals for which a connection was pending*	11.8%	11.2%
Number of referrals for which the child was not connected to service	639	1220
Percent of referrals for which the child was not connected to service	36.0%	44.8%
Number of referrals for which the status was unknown	47	41
Percent of referrals for which the status was unknown	2.6%	1.5%

* Pending means they had a scheduled appointment at the time of follow-up, but had not yet received the service

In 2011/12, Help Me Grow prepared a report describing the Connection Cafés that it has offered for five years and presenting the results of participant feedback forms. Key findings are presented below, and the full report can be found on the HMG website at:

<http://www.helpmegrowoc.org/facts.html>.

Connection Cafés were introduced by HMG in FY 2007/08 as a way to develop consistent networking events among agencies that provide developmental and behavioral services to children and families in Orange County. Each Café includes an update on services from Help Me Grow, a “Family Showcase,” a networking activity, and a featured guest speaker in a Café-like setting. Agencies have an opportunity to share information about their programs and services as well as verify the accuracy of their program’s information in the resource inventory used by Help Me Grow and 2-1-1 Orange County.

Over the five-year period from July 2007 through June 2012, there were 29 Connection Cafés with an average attendance of 55 service providers representing an average of 32 organizations per Connection Café. About 280 different organizations have participated over five years. Attendance ranged from a low of 30 to a high of 99 participants. Forty-two percent of respondents indicated they were attending their first Connection Café, meaning over half (58%) had found the events worthwhile and returned for additional Cafés.

Participants rated the value of the Connection Cafés, the networking activities, and the featured presentations highly – between 4 and 5 on a 5-point scale, where 5 was the highest rating that could be given and 1 was the lowest rating. The rating of how useful the Connection Cafés are was lowest in the first year of the program (4.38) and highest in the fifth year (4.62).

Average Rating	Topic	Number of Cafés
4.56	The Connection Café was useful	27
4.48	The networking activity was valuable	17
4.48	The information presented by the guest speaker was useful	8
4.42	A lot was learned from the information presented by the guest speaker	8
4.41	Respondents are likely to follow-up with someone they met at the Connection Café	8

CUIDAR

Outreach Efforts

In 2011/12, CUIDAR eliminated the social skills classes for children and started charging a \$20 fee for the classes. Because of the impact of these changes on enrollment, CUIDAR undertook greater outreach efforts to increase awareness of CUIDAR and its value in the community and to serve as many families in Orange County as possible. The outreach efforts included more face-to-face contact with families at workshops, presentations, resource fairs, and schools events. In addition, CUIDAR attended workshops and made presentations throughout the professional community to emphasize that CUIDAR is still 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 FY 2011/12, the number of events attended, the number of attendees for each type, and the number of hours spent attending the outreach events.

Outreach Type	Example of Type of Event	# of Events	# of Attendees	# of Hours
Community Collaboration / Consultation	Buena Clinton Coalition mtg. with community reps	15	971	37
Medical Health Professional Collaboration / Consultation	AAP Conference	7	170	15
Community Event	Children and Youth Summit	10	1312	42
Promotion of Project	SCAN monthly meeting, health fairs	11	888	49
Scientific/Media Presentation	Zero to Three Conference in Washington, DC	1	198	3
Training/Education Seminar	Connection Cafés, parent training	8	313	17
Workshop	Conf. for Foster Adaptive Kinship parent workshops	2	111	3
TOTALS		24	3,963	166

Serving low-performing school districts

One goal of the CUIDAR program is to serve families who live in school districts with low Academic Performance Index (API) scores. In FY 2011/12, 34 out of 42 (81.0%) COPE groups were in school districts with low API scores. This is a slightly higher percent than reported in 2010/11, when 35 out of 46 (76.1%) COPE groups were in school districts with low API scores.

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.

The **Parenting Strategies Assessment (PSA)** allows parents to rate the frequency and utility of suggested parenting strategies at the first and last COPE session. From FY 2005/06 to FY 2010/11, parents rated the ease and frequency with which they were able to apply the strategies discussed in the COPE classes. Over this period of time, comparisons of pre and post questionnaires consistently showed significant increases in the use of positive strategies and a decrease in the use of physical punishment after participation in the COPE classes.

The **SWAN Rating Scale (SWAN)** is a parent report form used to measure changes in child behavior upon completion of the COPE program. Between FY 2005/06 and 2010/11, the SWAN Rating Scale was collected at sessions 1 and 10. Over this period of time, the results of the SWAN consistently showed significant reductions (i.e., improvements) in both the inattentive and hyperactivity domains.

Because the outcomes of the PSA and SWAN were so reliably demonstrated over time, the Commission approved a waiver from collecting these data in FY 2011/12.

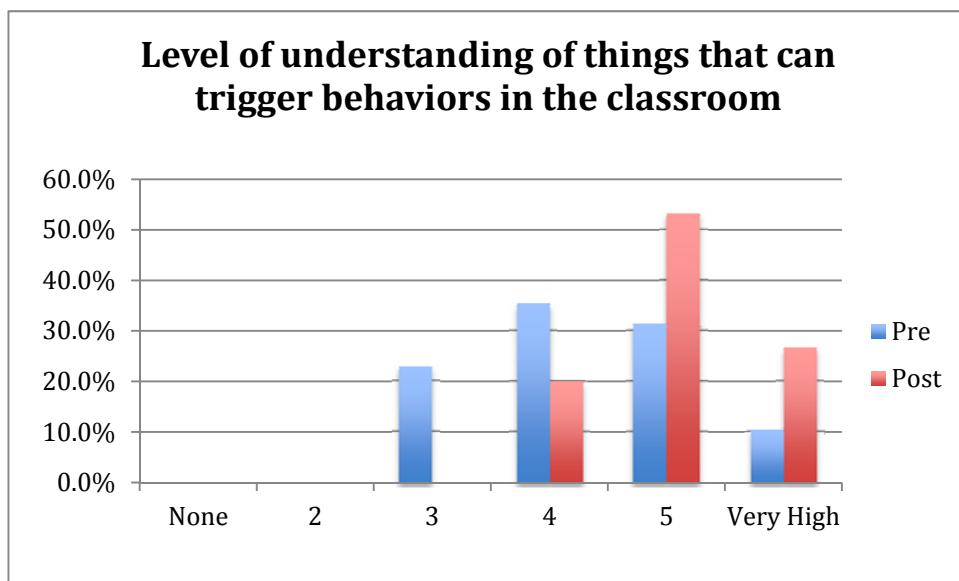
Parents felt strongly that CUIDAR was beneficial to them in a number of ways. Rating a series of statements on a six-point scale, with 1 being strongly disagree and 6 being strongly agree, each of the five statements scored a mean of 5.2 or better in 2011/12. The ratings were similar to those reported in FY 2010/11.

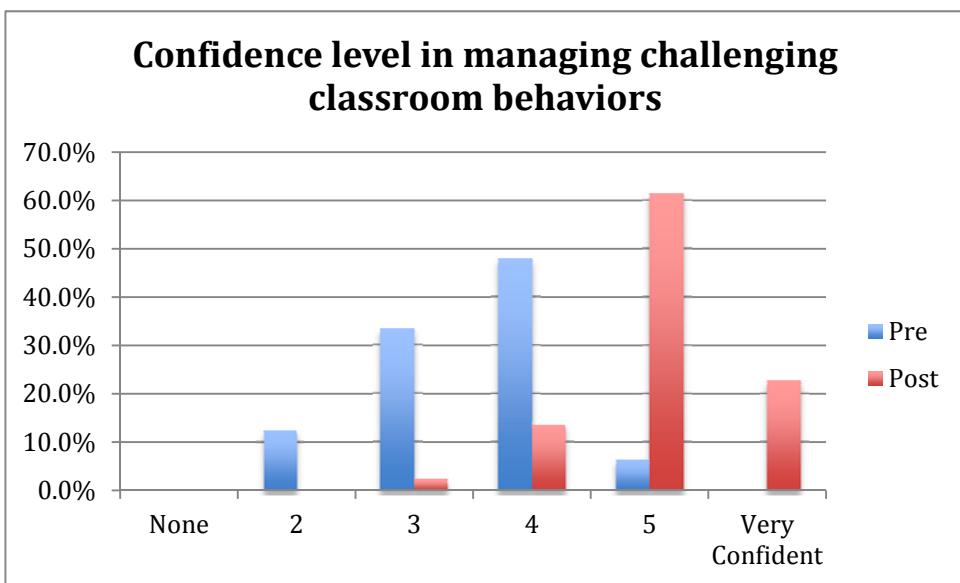
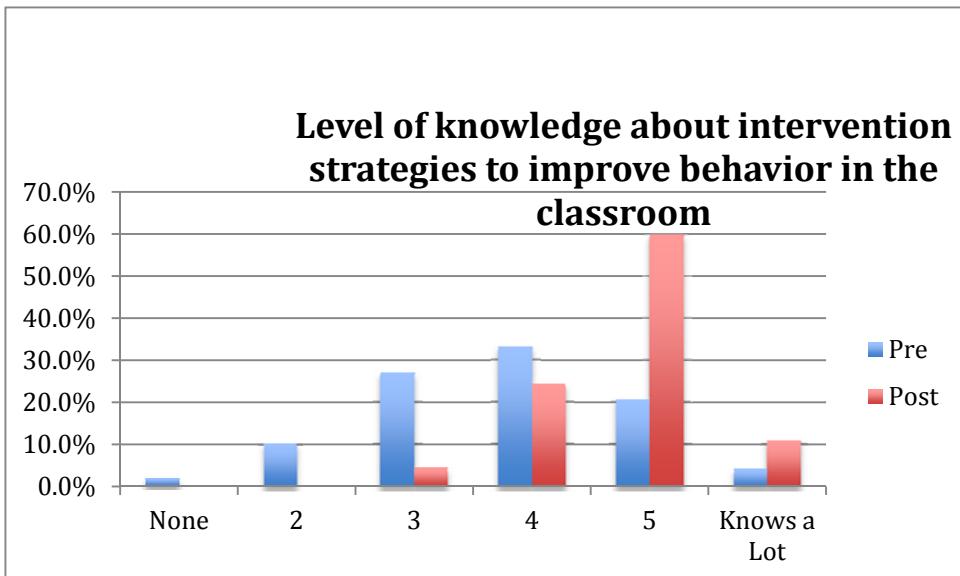
Statement	Mean Rating (highest rating possible is 6)	
	2011/12	2010/11
I have been able to apply many of the parenting strategies.	5.5	5.7
I feel more confident in my parenting skills.	5.3	5.5
I have noticed improvements in my child's behavior.	5.2	5.5
I feel that the relationship with my child has improved.	5.3	5.5
I feel that I am a better parent as a result of this course.	5.4	5.5
N=	273	598-603

Teachers are better able to manage challenging behaviors

CUIDAR provides **education to teachers** to help them better understand and identify triggers that may lead to problem behaviors in the classroom. Proactive behavior management strategies are taught as a tool for maintaining a calm and productive learning environment in the classroom. Using a survey administered before and after the training, teachers indicated they had gained an understanding of the sources that may trigger behaviors and felt better prepared and more confident in their ability to address the behavior in the classroom.

In the graphs below, the results of questionnaires administered before and after the teacher trainings are presented. The teachers were asked to use a 6-point scale to rate how well they understood the potential sources or causes that trigger behaviors in the classroom. Before the training, most of the teachers (58% at levels 3 and 4)) rated their understanding in the mid-range of the scale (blue bars in Figure 1). After the training, over 80% of the teachers indicated they had a high to very high understanding of what could trigger problem behaviors in the classroom (red bars). A similar improvement in knowledge and confidence was found, with over 70% indicating a high level of knowledge of intervention strategies following training. Over 80% indicated a high level of confidence in managing challenging classroom behaviors following the training, an increase from 6% before the training.





EDAC

Referrals provided

EDAC tracks data on the services for which children are referred. Data on whether families are able to obtain these services was not analyzed for this report.

Service	Referred for
Physical Therapy	41%
Occupational Therapy	15%
Feeding Therapy	13%
Infant Development	8%
Speech and Language	2%

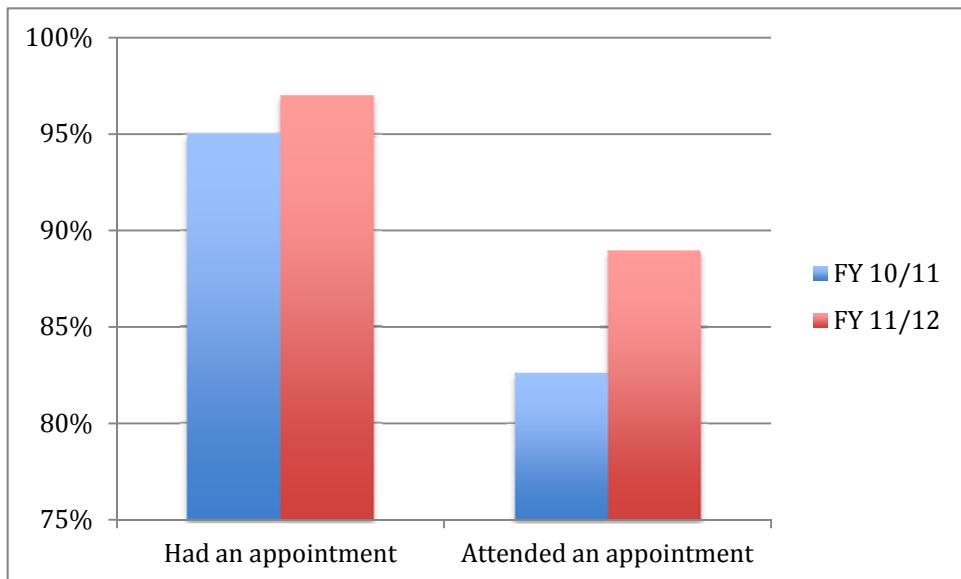
MCHATs (Modified Checklist for Autism in Toddlers) are performed on all patients between 16-30 months adjusted. As recorded in the California Children's Services – High Risk Infant Follow-up (CCS HRIF) database, 27% failed this screening and 23% were referred for autism evaluation and additional resources. Four percent were not referred due to existing diagnosis or significant developmental and sensory impairment.

Care Coordinators improve appointment attendance rates

In an effort to improve the rates at which CCS patients attend appointments, HRIF coordinators began running reports from the CCS-HRIF database to see whether patients had made recommended appointments. If no appointment was found in the database, the Coordinator called the family and CCS to assess the situation and help the family schedule the appointments.

At the beginning of FY 10/11, the High Risk Infant Follow-up program began tracking CCS-eligible patients to learn whether they had made appointments and had attended their appointments. Nationwide estimates are that HRIF patients attend only 70% of their appointments. In 2010/11, 95% of eligible patients had appointments, and 82.6% of patients had attended an appointment. Those numbers improved in FY 2011/12 to 97% with appointments and 89% having attended an appointment (see the figure below).

The Number of CCS-Eligible Patients who had an Appointment and Attended an Appointment in FY 2010/11 and FY 2011/12.



Patient satisfaction

Patient satisfaction data is available through the Press Ganey system. All EDAC clients receive surveys. The mean for the EDAC program in parent satisfaction was 88% for FY 2011/12. This is similar to the 92% rating in a six-month period of FY 2010/11.

Additional parent support services, including a Spanish support group (starting in February) have been added to the services provided by EDAC. In collaboration with the Neurology Clinic at CHOC, educational materials and peer support systems are being developed.

For OC Kids -

In FY 2010/11, For OC Kids developed three parent surveys based on input from staff about what outcomes they thought would tell the story of For OC Kids and show that it makes a difference for children and families. The three surveys were administered in both FY 2010 and FY 2011/12. Each survey is described below with the results from both years. The surveys were given to parents who were returning to For OC Kids for at least a second visit. The sample sizes are small in both years, in part because the surveys were being pilot tested to see if any changes would be necessary before expanded implementation. In FY 2012/13, efforts will be made to collect 100 responses on each survey.

Parent Survey 1 asked about parents' confidence with the diagnosis they received from For OC Kids, whether they had sought a second opinion and the results of that. It also asked whether their child was able to obtain the services recommended by For OC Kids, and if not, why not.

FY 11/12	FY 10/11	Parent Survey One
81%	86%	Parents were very confident that their child had received a correct diagnosis from For OC Kids
4	6	Number of parents who had sought a second opinion
3	4	Number of parents who said the second opinion was completely or mostly the same as the diagnosis they received from For OC Kids
83%	87%	Parents said their child had received all or most of the therapies or treatments recommended by For OC Kids
Number of respondents who claimed the following reasons to explain why their child did not receive a recommended therapy or treatment:		
8	5	Insurance did not cover the cost
3	2	I didn't think the therapy would be helpful
2	5	The service was not available at convenient hours
2	3	There was a long wait list
2	2	It was too expensive
2	2	I didn't think the therapy was necessary
2	1	There was no provider close to us
1	1	The therapy was not available in our language
0	1	I didn't know who to call for an appointment
0	1	I didn't know how to access the therapy
0	1	I could not get childcare for my other children
0	1	I did not have transportation to the provider
7	4	We had no problems obtaining therapies
N=38*	N=47*	

* Missing or not applicable responses were not included when calculating percentages

Other explanations provided in written comments about difficulty in obtaining services included challenges with Regional Center and school approval and payment for services.

Parent Survey 2 is a series of Likert-style questions that asks parents whether they agree or disagree with a series of statements about the care they received from For OC Kids.

% Who Agree or Strongly Agree		Statement - Parent Survey Two
FY 2011/12	FY 2010/11	
87%	82%	The diagnosis we received from For OC Kids helped my child obtain services from the school district and/or Regional Center*
80%	74%	The diagnosis we received from For OC Kids led to changes in the services my child receives from the school district and/or Regional Center*
84%	78%	My child's condition has improved since we've been coming to For OC Kids
86%	73%	For OC Kids has contributed to the changes I see in my child
95%	81%	The services we received from For OC Kids have been effective
95%	82%	The services we received from For OC Kids met my expectations
95%	82%	The services we received from For OC Kids were what I needed
98%	89%	A team approach is important for serving families like mine
89%	72%	For OC Kids uses a team approach to care for children and families
98%	87%	A family-oriented approach is valuable for families like mine
97%	82%	For OC Kids is family-oriented
91%	91%	I am satisfied with the care we received at For OC Kids
N=57	N=58	

* the percentages are calculated based on the number of respondents who disagreed or agreed, and excludes those for whom the question did not apply.

Parent Survey 3 is another series of Likert-style questions that asks parents to think about how things were when they first came to For OC Kids and how things are now. Parents respond to a series of statements and indicate their level of knowledge or ability before and now. On the rating scale, 1 = very low/poor, 3 = average, and 5 = very high/good. The average rating was calculated for each item.

The Table below presents the average ratings for how parents felt at the time they took the survey (after more than one visit to For OC Kids) and the change in average rating from how they felt before going to For OC Kids. Although not presented in the table, the average ratings before their first visit ranged from a low of 2.0 (Ability to control child's behavior) to a high of 3.3 (Feelings of hope for child's future) in FY 2011/12. The same two items were the lowest and highest rated items in FY 2010/11.

In both years, the average improvement was 1.5 points from before to now. The areas with the greatest improvement varied between the two years. In FY 2010/11 the biggest improvements were seen in knowledge of the child's condition, knowledge of how to advocate for services for the child, and acceptance of the child's condition (each with a 1.7 point improvement). In FY 2011/12, the greatest improvements came in the areas of knowledge of how to work with the child, knowledge of how to locate services, and knowledge of how to advocate for services (each with a 1.8 point improvement). In FY 2010/11, the area with the least improvement was knowledge of community services for the child (improved by 0.6 point). In FY 2011/12, the least improvement was seen in the knowledge about the child's condition, acceptance of the child's condition, and willingness to take the child to restaurants (all up by 1.1 points).

Parent Survey Three	Average Rating Now	Average Rating Now	Change in rating	Change in rating
How would you rate your:	2011/12	2010/11	2011/12	2010/11
Knowledge about your child's condition	3.5	4.5	+1.1	+1.7
Attitude about your child's condition	4.1	4.3	+1.4	+1.4
Knowledge of how to work with your child	4.2	3.9	+1.8	+1.3
Effectiveness in working with your child	3.8	4.2	+1.2	+1.6
Ability to control your child's behavior	3.6	3.9	+1.5	+1.5
Sense of empowerment to help your child	4.0	4.3	+1.6	+1.5
Knowledge of how to locate services for your child	4.1	4.1	+1.8	+1.6
Knowledge of how to obtain services for your child	3.8	4.0	+1.6	+1.6
Knowledge of how to advocate for services for your child	4.0	4.1	+1.8	+1.7
Effectiveness in advocating for services	3.8	4.0	+1.5	+1.5
Acceptance of your child's condition	4.4	4.5	+1.1	+1.7
Knowledge of community services for your child	3.7	2.9	+1.6	+0.6
Willingness to take your child to restaurants	4.1	4.2	+1.1	+1.2
Feelings of hope for your child's future	4.5	4.5	+1.2	+1.5
	N ranges from 31-33		N ranges from 38-41	

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 the Neurodevelopmental Programs 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

1. HMG, in partnership with the Orange County United Way, offers developmental and behavioral screening for siblings of children on the Autism Spectrum. A recent success story involves a family of four who enrolled in our screening program through For OC Kids. The concerned parents, Mark and Marie, have two children; a 12-month-old son, Adam, and a 3-year-old diagnosed with autism. They were worried about Adam's development and wanted to monitor it a bit more closely. After enrolling in the screening program, Mark and Marie filled out the 12-month Ages and Stages Questionnaire (ASQ) and ASQ: Social-Emotional for Adam. He scored below the cutoff in communication and fine motor and in the monitoring zone in all other developmental domains on the ASQ. After reviewing these results with Marie and listening to her concerns, a direct referral was made to the Regional Center of Orange County (RCOC). At follow-up, Marie reported that Adam was evaluated and found eligible for Early Start services and was receiving individual infant applied behavioral analysis (ABA) in their home. Mark and Marie were extremely pleased that Adam's delays were identified early through the Help Me Grow- OC screening program as well as with the support they received in connecting to the RCOC services.
2. Morrie is currently participating in Early Head Start and receiving home visits. He is also a client of Regional Center and receiving services. At the last Individualized Family Service Plan (IFSP) meeting, the service coordinator suggested that his mother, April, look into parenting classes. April has voiced concern because she feels Morrie does not listen to her. April recently gave birth and is overwhelmed by both children. After a discussion with April, she was referred to Children's Bureau and at follow up was found to have begun services there.
3. Yolanda requested a resource to help her wean her 2-year-old child from breastfeeding. The HMG Care Coordinator provided Yolanda with the number for the La Leche League help line. At follow up, Yolanda shared that La Leche was very helpful in providing her tips, guidance and support. She applied the techniques and has been very happy with the results.
4. Areli was in the process of separating from her husband and needed guidance on what steps to take to ensure she had basic need resources to help care for her child. The HMG Care Coordinator referred Areli to the Orange County Social Services Agency for food

stamps and child support. Areli applied and is now receiving these subsidies. She also was referred to Helping Other Prepare for Eternity (HOPE) for basic need resources (food, diapers, and toiletries) and was connected to this agency. Areli requested rental assistance and was referred to the Illumination Foundation for help. At time of follow-up, Areli shared that she is on the waitlist for the rental assistance.

CUIDAR

Parents who participated in the COPE program provided testimonials about how the program has benefited them.

COPE:

"Very helpful - should be mandatory for all parents!"

"Very helpful program! I've been recommending it to other people who may benefit."

"I probably could have stopped coming after the 3rd or 4th week and have been helped. Having stuck it out for the entire session & now feel I have the tools to face any possible future challenges."

CWTB:

"I took your class about 3 years ago when my daughter was 2. She is now 5 and our family has grown with 9 month old twins...thanks for all your great tips, we practice them to this date."

"We feel very fortunate to have found CWTB. Among the numerous, great tips and ideas we learned, the 3 parental types profoundly affected my understanding of how to be a good parent. Your class has changed our lives. We will remain forever grateful"

Teacher Training:

"I'm glad I came to both sessions, I have gained understanding in how to manage behaviors in both professional and personal level. Thanks!!!"

"Thank you so much for an awesome presentation I have come away with information that I can apply to my professional environment as well as my personal."

EDAC

1. Yesenia had concerns about the feeding intake and slow growth of her daughter, Angel. She consulted with her pediatrician a few times. Every time, the pediatrician informed her that Angel was just small and will catch up, and that there was nothing to worry about. After hearing of the great reputation of the fragile feeder program at EDAC, she self-referred Angel for an evaluation. The EDAC financial coordinator/case management assistant explained the referral process and made the appointment as soon as she received the call from Yesenia. The case was discussed with the RN High Risk Infant Follow-UP (HRIF) Coordinator.

At the first visit in the clinic, Angel showed failure to thrive state, suboptimal oral intake, suboptimal weight gain and growth, difficulties with oral motor/feeding skills and motor issues. The RN HRIF coordinator, dietitian, Speech/Language Pathologist and physical therapist worked closely with the parents and developed a plan of care. Angel had a total of 3 fragile feeder visits; at each visit, she demonstrated significant improvement in feeding skills, weight gain and motor development. Extremely satisfied with the outcome of Angel's development and education from the EDAC team, the parents decided to move forward with feeding therapy sessions at CHOC Rehabilitation Services. They said, "We are so thankful to the EDAC team, and will never go to another hospital for our children's care."

Due to possible motor developmental delay, Angel's parents decided to have a developmental assessment and follow-up care in EDAC. Angel has now had 2 EDAC visits, has completed physical therapy treatment, and is currently receiving feeding therapy at Rehabilitation Services. She is showing marked improvement in feeding abilities/skills and appropriate growth.

2. EDAC HRIF coordinators have identified several infants who were eligible for services and who may have been lost to follow up without the involvement of EDAC. One of these infants was Jessie, a girl who was born at a CCS-approved NICU in the community. The HRIF coordinator made contact with the mother, Sara, who expressed interest in the program and stated she was not aware of the authorization. The coordinator provided education about the program and obtained additional information from Sara regarding Jessie's neonatal course. She then collaborated with the High Risk Infant coordinator at the birth hospital to obtain the discharge summary and ensure continuity of care.

During the initial phone contact with Sara, she expressed concern that Jessie had not yet had outpatient follow-up with the ophthalmologist due to insurance authorization issues. Because preterm and high-risk infants are at risk for ophthalmologic disorders, diagnostic ophthalmology codes are included in the authorization for high risk infant services. This was explained to Sara and the HRIF coordinator coordinated follow-up with a pediatric ophthalmologist so that Jessie could receive the necessary follow-up care. Sara expressed gratitude that Jessie's care was being coordinated. Assessment at the initial EDAC appointment revealed that Sara was able to successfully make a follow-

up appointment with ophthalmology and that Jessie had been examined prior to her first developmental evaluation.

3. Another example involved Miguel, who had a complex cardiac history starting from his birth in Kern County. In addition to his complex cardiac history and complex neonatal course, Miguel had a complicated social history, necessitating placement in foster care. He was placed in foster care in Los Angeles County and the Kern County CCS issued an authorization to CHOC Children's HRIF. During the process of appointment reconciliation, the EDAC HRIF coordinator identified the infant as being at high risk of not attending the recommended appointment. She phoned the foster parent, who was unaware of the authorization. The coordinator provided education about the purpose of the appointment and the caregiver was enthusiastic about attending an appointment in EDAC. The appointment was attended and Miguel was found to have severe delays. He was referred to appropriate community services and recommendations for therapy were made. His next appointment is pending.

For OC Kids

1. Mark and Brad are brothers who were both diagnosed with autism and global developmental delays. The brothers were first seen at For OC Kids when Mark was 3 years old and Brad was 4 years old. The brothers were originally diagnosed and treated in Riverside County and then moved to Orange County where they established care at For OC Kids.

We will first present Marks story. Mark's parents requested an urgent appointment because they had just moved to Orange County and had run out of Mark's medications. Additionally, they could not control his aggressive behavior and hyperactivity. Because of the move, they had not yet been approved for services through the Regional Center (RCOC). The parents were desperate for help. The provider determined there should be an adjustment in Mark medication, the adjustment was made and the family was told to return in a month. At the next visit his behavior was worse and the parents still did not have approval for Applied Behavioral Analysis (ABA) services; in addition, the patient had excessive weight gain. The provider then decided to change the medication completely. For OC Kids worked at securing at-home ABA for Mark. At the next appointment, Mark was calmer and was actually able to watch TV for a while and his weight dropped slightly. Additionally, the provider worked with educating the parents regarding setting limits and not reinforcing negative behavior. Mark is now 8 years old. Although there are still challenges, he has improved immensely. He is better focused and he pays more attention in trying to learn.

Mark's brother Brad was first seen at For OC Kids when he was 5 years old. Brad had a history of head banging, sleep problems and speech and language delays. Upon initial evaluation the provider felt Brad was over-medicated and decided to taper down his medication. At the next visit, his behavior was much better at school and he was making

excellent progress; his teacher stated “He demonstrates very good social skills at school and he is a pleasure to have in class.” His mother felt the medication change “woke up” Brad and she was relieved his behavior issue at school had improved. However, he continued to have aggressive behavior towards his mother. The provider worked with and supported the mother to learn how to work with her child to improve his behavior. Brad is now 9 and he is better focused, learning multiplication tables, and plays soccer with his school friends. He also is less aggressive with his mother and his sleeping habits have improved. Mark and Brad’s parents are so thankful for their provider and the services provided to them by For OC Kids.

2. Tim was diagnosed with autism and global developmental delay when he was 3 years old and was seen at For OC Kids at age 5. The family had just moved to Orange County from Nebraska and they were awaiting benefits from the Regional Center.

Tim’s mother is a monolingual Vietnamese speaker. She has four children, two with autism, and her husband lives and works in Bakersfield most of the time. Essentially, Tim’s mother is a single parent. At the first visit, the mother was crying and felt her children’s autism was her fault. Also, she felt imprisoned in her home because she could not control her children’s behavior and would never leave the house. The provider and social work counseled the mother and expressed to her that it was not her fault, and we would do everything we can to help her and her family. She was given information to attend our SEEPAC class, which was offered in Vietnamese. At the end of the initial visit, the mother felt relieved and Tim would be seen again in two months.

Tim’s ABA was approved and the mother was attending SEEPAC class. Both were improving. However, Tim was having behavior issues in school and the teacher was concerned regarding his inattention and hyperactivity. The provider adjusted his medication and counseled the mother on how to administer a reward system for Tim. With the help of the ABA provider and For OC Kids the mother excelled in learning how to work with her children with autism; and her morale improved greatly. Tim is now 9 years old, his hyperactivity has improved, he has no problems at school, and his sleep has improved. At the last visit Tim’s mother shared that she took all four of her children on a vacation (which they had never done before) to Las Vegas and the Grand Canyon. The provider expressed how proud she was of the mother’s achievements with her kids.

3. Ray was first seen at For OC Kids when he was 4 years old. He is diagnosed with Autism, ADHD, disruptive behavior disorder, hearing loss, and visual acuity deficit. At the age of 6 he was placed in foster care and currently has a very caring foster parent. He had extreme behavior concerns for both violence and inappropriateness. He was doing well academically at school, but his behavior was “out of control.” At his first appointment, after he was placed in foster care, his ADHD medication was adjusted, he was referred to counseling and the foster mother was counseled on how to work with and care for Ray. Ray had his ups and downs, however, his foster mother was consistent and stable with him. He continued to be treated at For OC Kids and both he and his foster mother were provided with positive reinforcement of Ray’s

improvements. Ray is now 8 years old and is doing great at school and has demonstrated an improved ability to self regulate even when he is sad or disappointed. Ray was recognized as Student of the Month and the criteria was "personal responsibility and exemplary behavior." According to his foster mom, he was beaming with joy. We will continue to work with Ray and address challenges as they arise. As long as we all work together, he will continue to succeed. In a letter his foster mother sent to the provider she said, "It certainly takes a Village" and we are glad to be a part of Ray's village.