DATALINK
PARTNERS

OC Children's Screening Registry

June 2023

Analysis of Registry Data
2018 through 2022

Help Me Grow
ORANGE COUNTY

Submitted to:
FIRST 5
ORANGE COUNTY

Acknowledgments

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I. OC Children’s Screening Registry Background

The OC Children’s Screening Registry (Registry) was launched in February 2018 and is an online database that allows primary health care and other community-based providers to view and enter developmental, behavioral, and adverse childhood experiences (trauma) screening data and share information on referrals and outcomes.

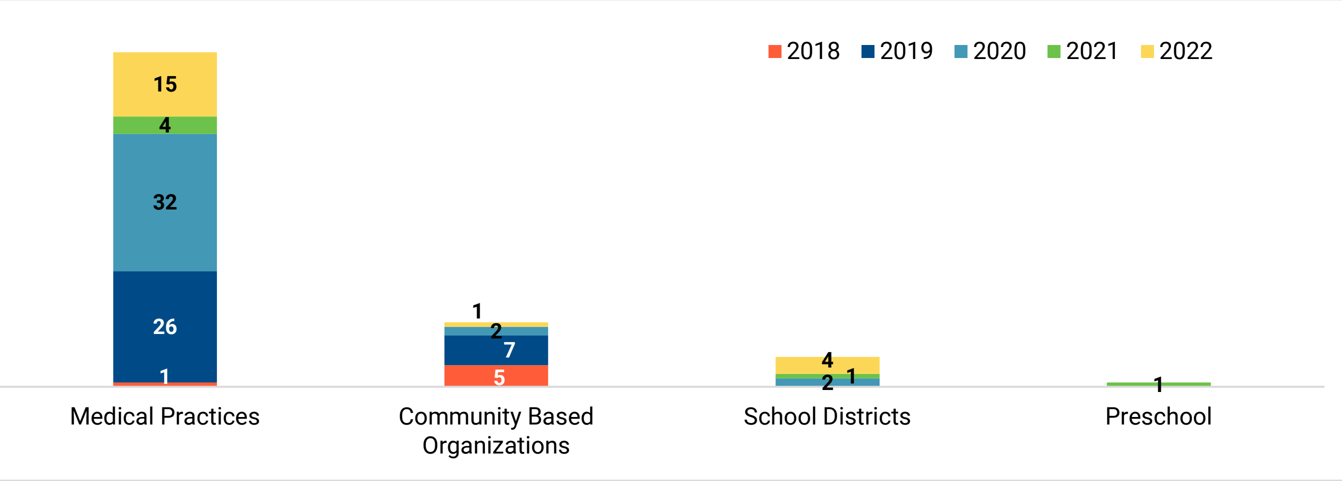
The Registry is designed to help clinical and community-based providers proactively identify children with at-risk screening results, reduce duplication of screening efforts, and assist in connecting families with appropriate resources. The Registry seeks to improve physician engagement and cross-sector collaboration, communicate screening results between organizations and health care providers, encourage providers to use evidence-based screening tools, and refer children for services when needed.

The Registry includes five screening tools:

- Ages and Stages Questionnaires-Third Edition (ASQ-3)
- ASQ: Social Emotional- Second Edition (ASQ: SE-2)
- Parents Evaluation of Developmental Status (PEDS)
- Modified Checklist for Autism in Toddler, Revised with Follow-up (M-CHAT R/F)
- Pediatric ACEs and Related Life-events Screener (PEARLS)
    - Child (0-11) Parent/Caregiver Report
    - Teen (12 and up) Parent/Caregiver Report
    - Teen (12 and up) Self Report

The Registry is administered by Help Me Grow Orange County and Children’s Health of Orange County (CHOC) and was developed with funding from the HRSA Healthy Tomorrows award. By December 2022, Registry users included: 78 medical practices, 15 community-based organizations, 7 school districts and 1 Early Childcare and Education (ECE)/preschool providers.

Figure 1: Registry users, by type and year

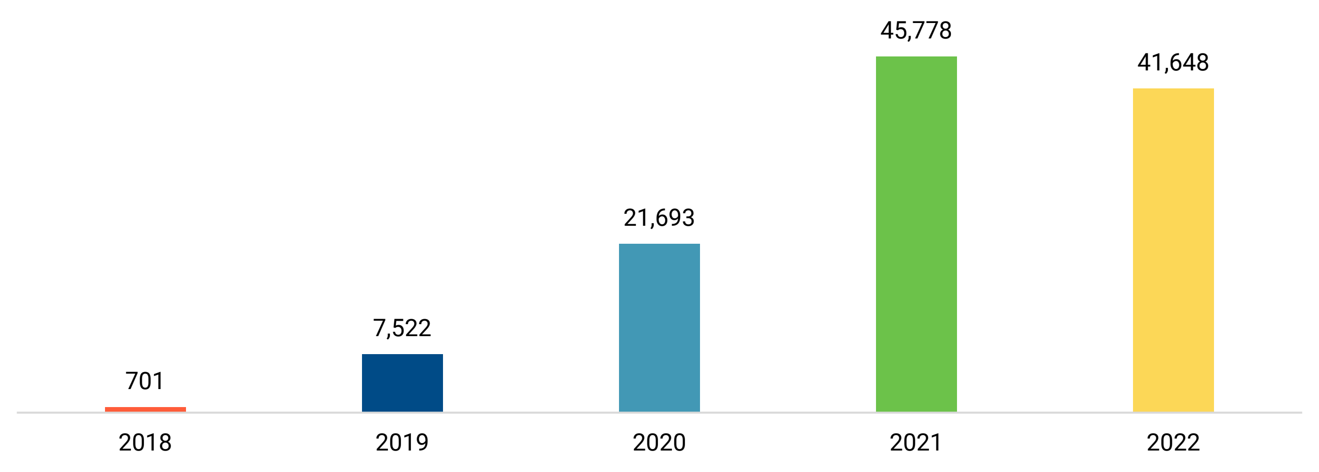


II. OC Children’s Screening Registry Data, 2018-2022

A. Total Number of Contacts in Registry

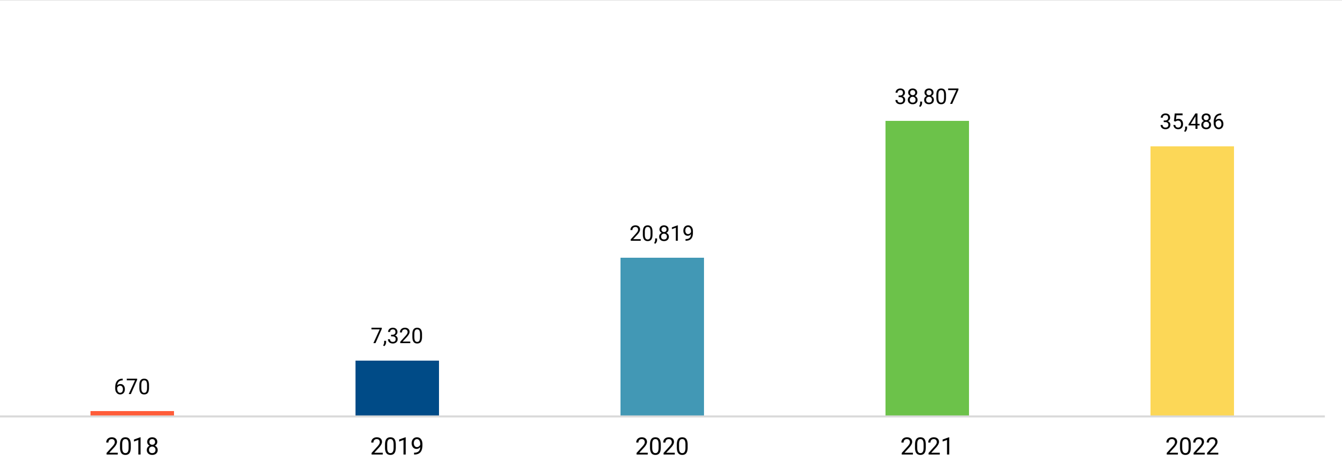
During the five-year period of 2018 to 2022, more than 117,000 children were entered into the Registry (unduplicated count within each year). Since the Registry was made available in 2018, the first year was spent gaining users.

Figure 2. Number of children entered into the Registry, by year (N=117,342)



Most of the children entered into the Registry live in Orange County (88%). The other 12% of children live outside of Orange County. The Registry holds data for children living outside of Orange County because their medical home is located in Orange County and these practices are encouraged to enter all children and screening results. The remainder of this report presents data *only on those children who live in Orange County*.

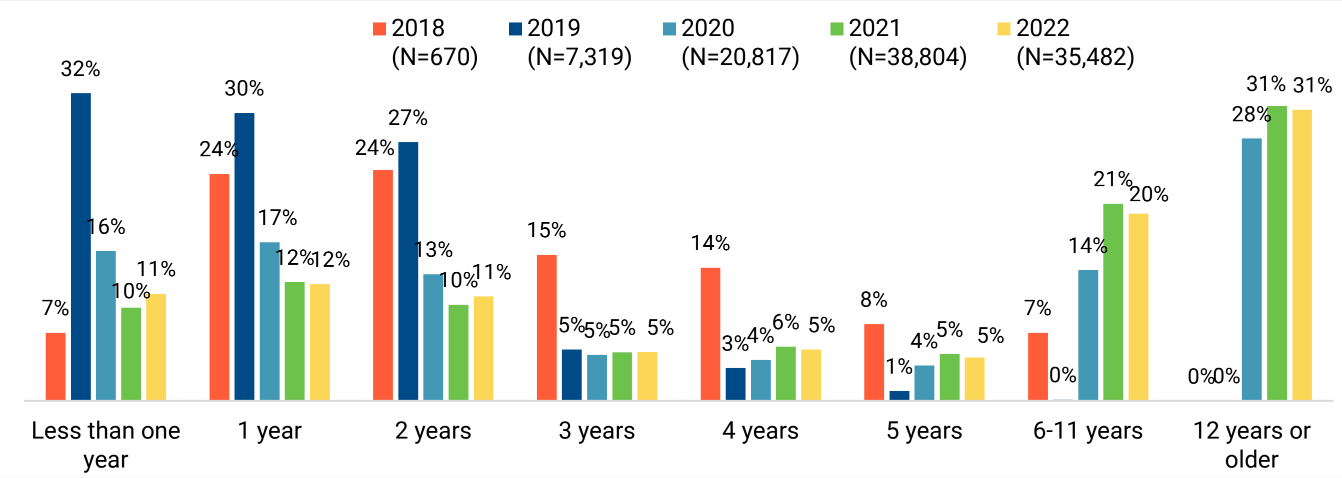
Figure 3. Number of children living in Orange County entered into Registry, by year (N=103,102)



B. Children’s demographics

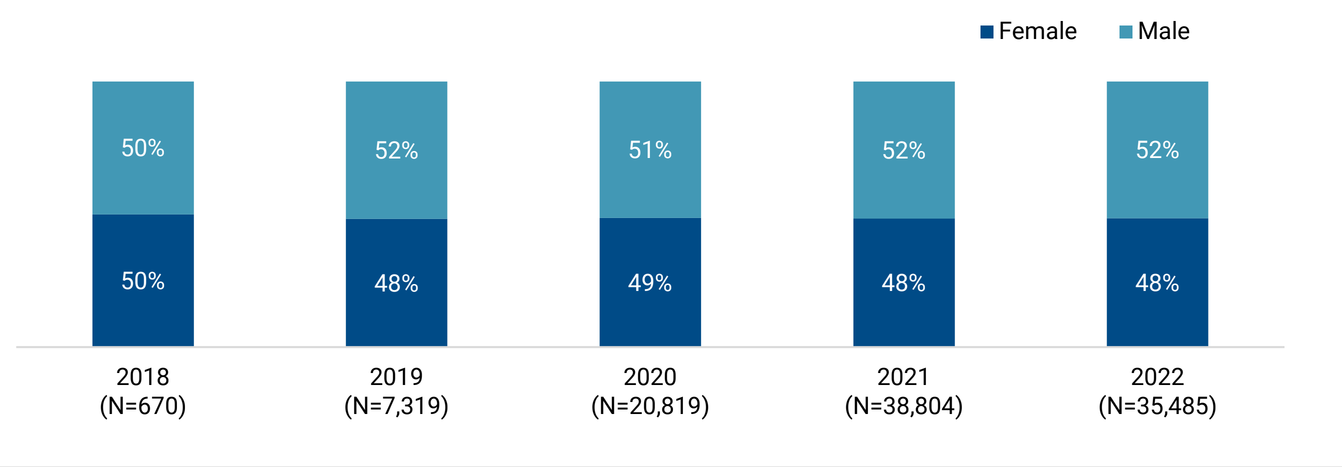
The age ranges of children entered into the Registry has fluctuated. In 2019, a vast majority of children entered into the Registry were ages 2 or younger (90%). By 2020, a plurality of children entered in the Registry were ages 12 and older. This is likely due to the expansion of the Registry to include the three variations of the PEARLS tool in January 2020. Also by 2020, a majority of the screenings were for PEARLS, whether for ages 0-11 or 12-19.

Figure 4: Distribution of children entered into the Registry, by age (N=103,092)



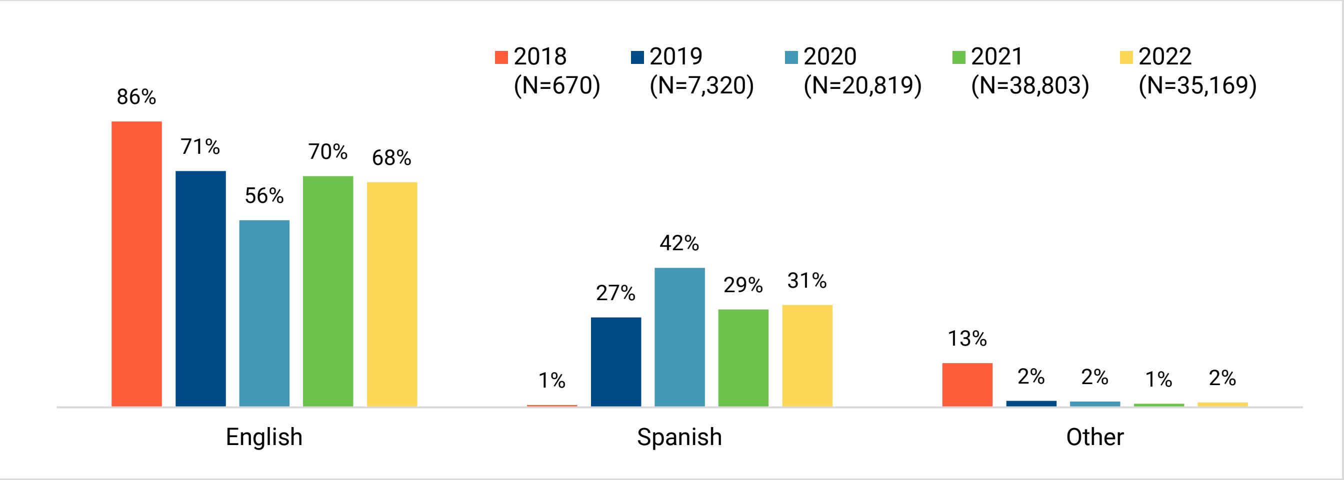
The proportion of males and females entered into the Registry remained relatively consistent between 2018 and 2022. Overall, more males than females have had their screening entered into the Registry (52% and 48%, respectively, in 2022).

Figure 5: Distribution of children entered into the Registry, by gender (N=103,097)



English is the language most spoken by children whose information has been entered into the Registry. In 2020, there was a higher proportion of Spanish speakers entered into the Registry than other years.

Figure 6: Distribution of children entered into the Registry, by primary language (N=102,781)



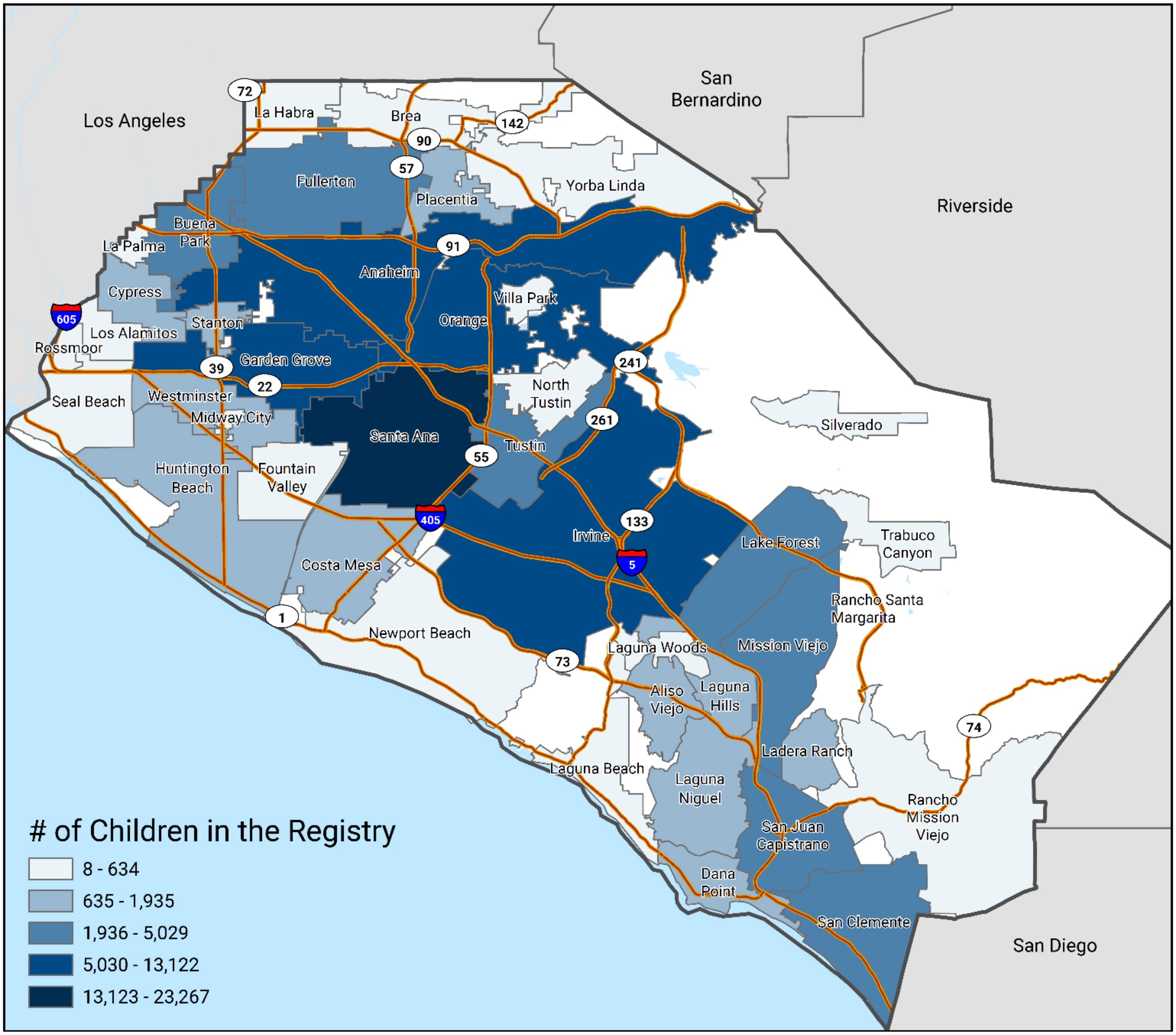
Children who live in Santa Ana account for more than one in five children entered in the Registry. Thirteen percent of children live in Anaheim; 7% each live in Irvine and Orange.

Figure 7: Distribution of children entered into the Registry, by top 10 cities (N=103,102)

	2018		2019		2020		2021		2022		TOTAL	
	#	%	#	%	#	%	#	%	#	%	#	%
Santa Ana	120	18%	1,546	21%	5,494	26%	8,356	22%	7,871	22%	23,387	23%
Anaheim	64	10%	826	11%	2,935	14%	4,585	12%	4,776	13%	13,186	13%
Orange	15	2%	332	5%	1,197	6%	2,737	7%	2,735	8%	7,016	7%
Irvine	86	13%	668	9%	803	4%	2,925	8%	2,449	7%	6,931	7%
Garden Grove	50	7%	365	5%	1,461	7%	2,208	6%	2,220	6%	6,304	6%
Tustin	28	4%	275	4%	856	4%	2,027	5%	1,871	5%	5,057	5%
San Clemente	11	2%	352	5%	835	4%	1,711	4%	1,409	4%	4,318	4%
Fullerton	13	2%	169	2%	826	4%	1,271	3%	944	3%	3,223	3%
Lake Forest	14	2%	253	3%	423	2%	1,018	3%	1,161	3%	2,869	3%
Everywhere else in OC	269	40%	2,534	35%	5,989	29%	11,969	31%	10,050	28%	30,811	30%

The map below presents the distribution in Orange County of where the children live who have been entered into the Registry.

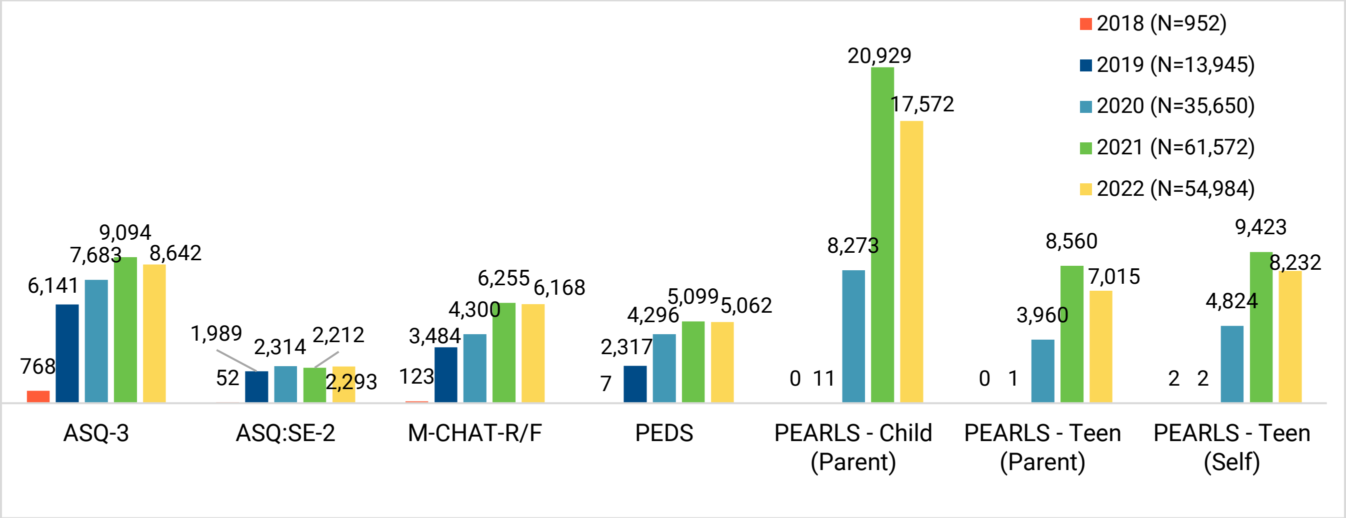
Figure 8: Distribution of children entered into the Registry, by city



C. Entries by Screening Tool and Year

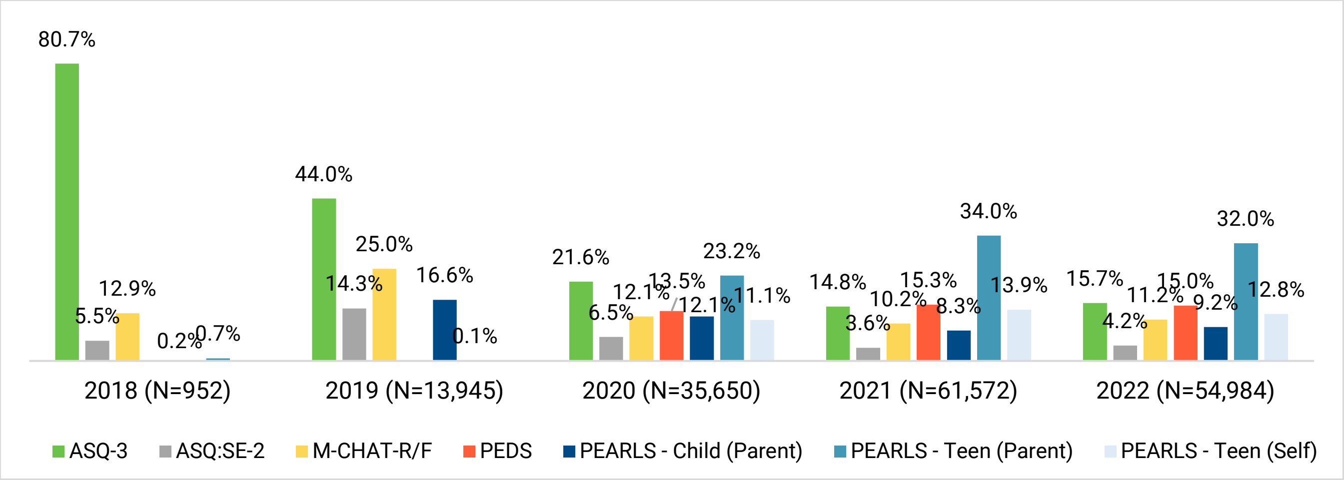
Over the course of five years, each tool had an increase in the number of entries per year, except for 2022 when the was a slight decline. In 2018 and 2019, there were no or few PEARLS screenings entered into the Registry. By 2021, most screenings entered in the Registry were PEARLS.

Figure 9: Number of screenings, by tool (N=167,103)



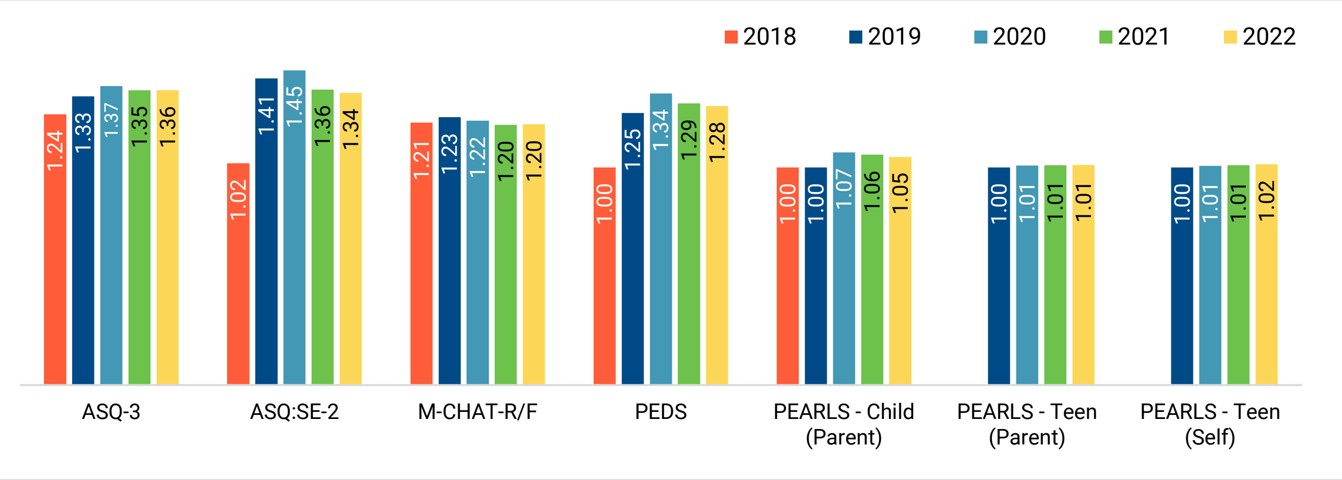
There are differences in the screening tools used within each year, partially due to the PEARLS tool not being added until 2020. In 2019, a plurality (44%) of screenings entered into the Registry were the ASQ-3, whereas there were almost no PEARLS screenings, regardless of version, aside from those added retroactively. On the other hand, in 2022, almost one-third (32%) of the tools entered into the Registry were for PEARLS Teen (Parent Report) and only 16% of screenings were for the ASQ-3. Additionally, the PEARLS tool is recommended to be completed once a year, while the other tools are recommended at closer intervals, 9, 18, and 24 or 36 months such as the ASQ-3 and PEDS.

Figure 10: Distribution of Screenings (Percentage within Year), (N=167,103)



The average number of screenings per child per year had a range of 1.2 to 1.45. The exception is the PEARLS tools, which averaged just one screening per child per year. PEARLS guidelines indicate one screening per child per year, so it appears providers are screening according to best practice.

Figure 11: Average number of screenings per child, by tool (N=103,102)

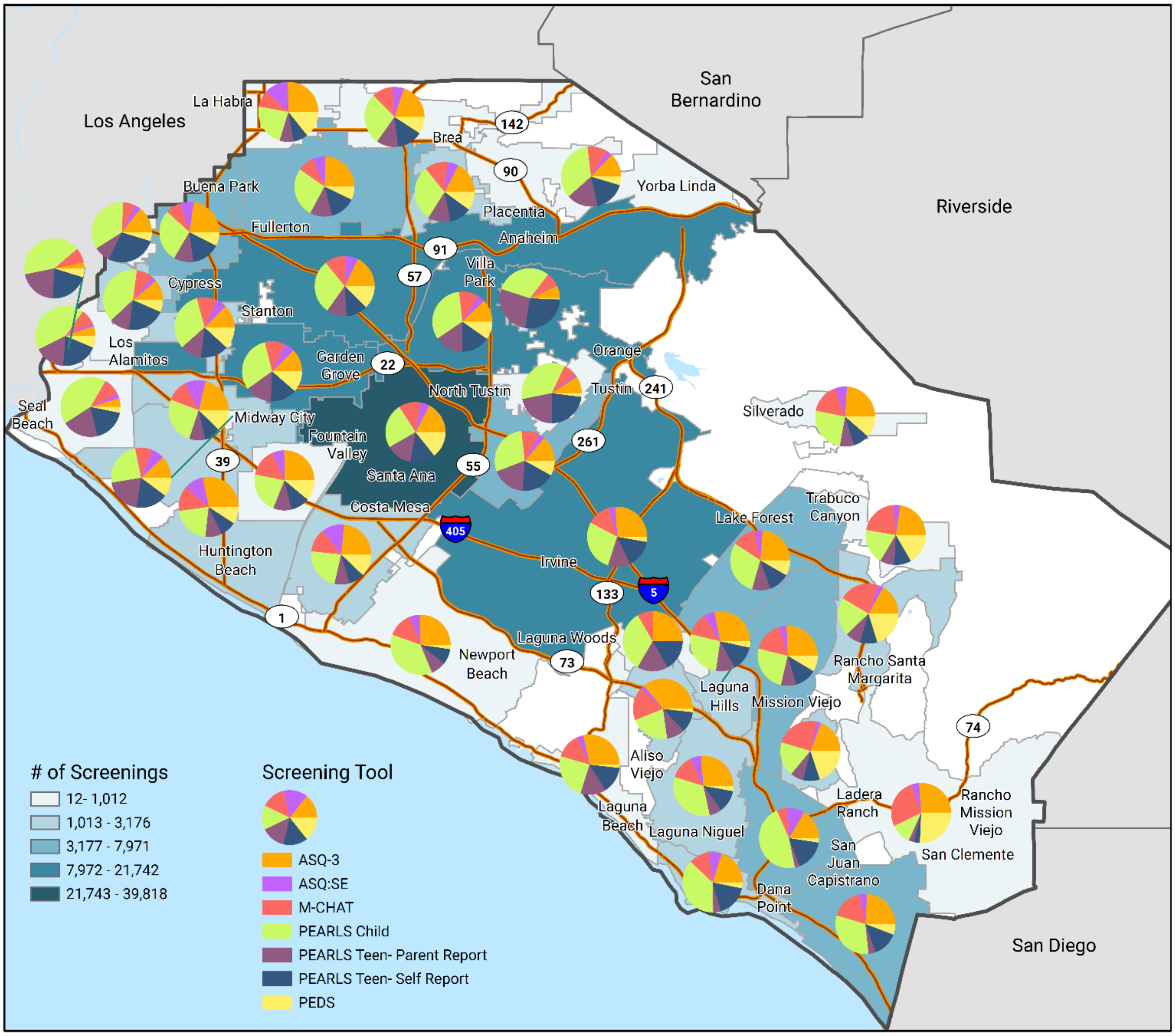


Similar to Figures 7 and 8, for where the children entered into the Registry live, most screenings entered into the Registry are for children living in Santa Ana.

Figure 12: Distribution of number of screenings in Registry, by tool and top 10 cities, 2018-2022

	ASQ-3	ASQ:SE-2	M-CHAT-R/F	PEDS	PEARLS – Child (Parent)	PEARLS – Teen (Parent)	PEARLS – Teen (Self)	Total
Santa Ana	7,044	1,969	4,759	5,670	9,659	5,557	5,355	40,013
Anaheim	3,925	1,436	2,531	2,685	6,350	2,354	2,540	21,821
Orange	1,382	412	1,209	1,081	3,658	1,730	1,715	11,187
Irvine	2,785	377	1,332	292	2,891	1,242	1,580	10,499
Garden Grove	1,331	575	1,163	1,179	3,208	1,497	1,472	10,425
Tustin	1,118	259	792	643	2,316	1,430	1,449	8,007
San Clemente	1,564	269	1,107	375	2,015	250	878	6,458
Fullerton	1,354	375	497	391	1,475	659	754	5,505
Lake Forest	1,091	189	576	375	1,347	446	506	4,530
Buena Park	959	301	351	314	1,194	442	647	4,208
Everywhere else in OC	9,775	2,698	6,013	3,771	12,679	3,929	5,585	44,450

Figure 13: Number of screenings entered into the Registry, by tool and city (N= 167,103)



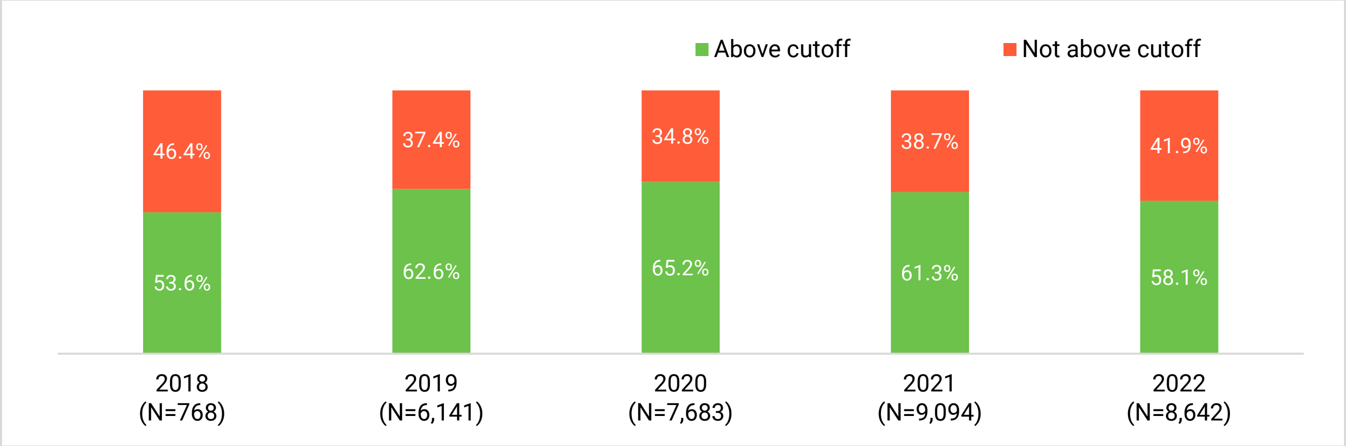
D. Results by Screening Tool

Ages & Stages Questionnaires, Third Edition (ASQ-3)

The ASQ-3 is a developmental screening tool for children between the ages of one through 66 months. The ASQ-3 is comprised of five domains: communication, gross motor, fine motor, problem solving, and personal-social. When scoring, children who are above the cutoff are considered on track developmentally, whereas children below cutoff would need consideration for further assessment and/or evaluation. Children who score in the monitoring zone should be provided follow-up activities, re-screened within 2 months and/or given referrals as appropriate.

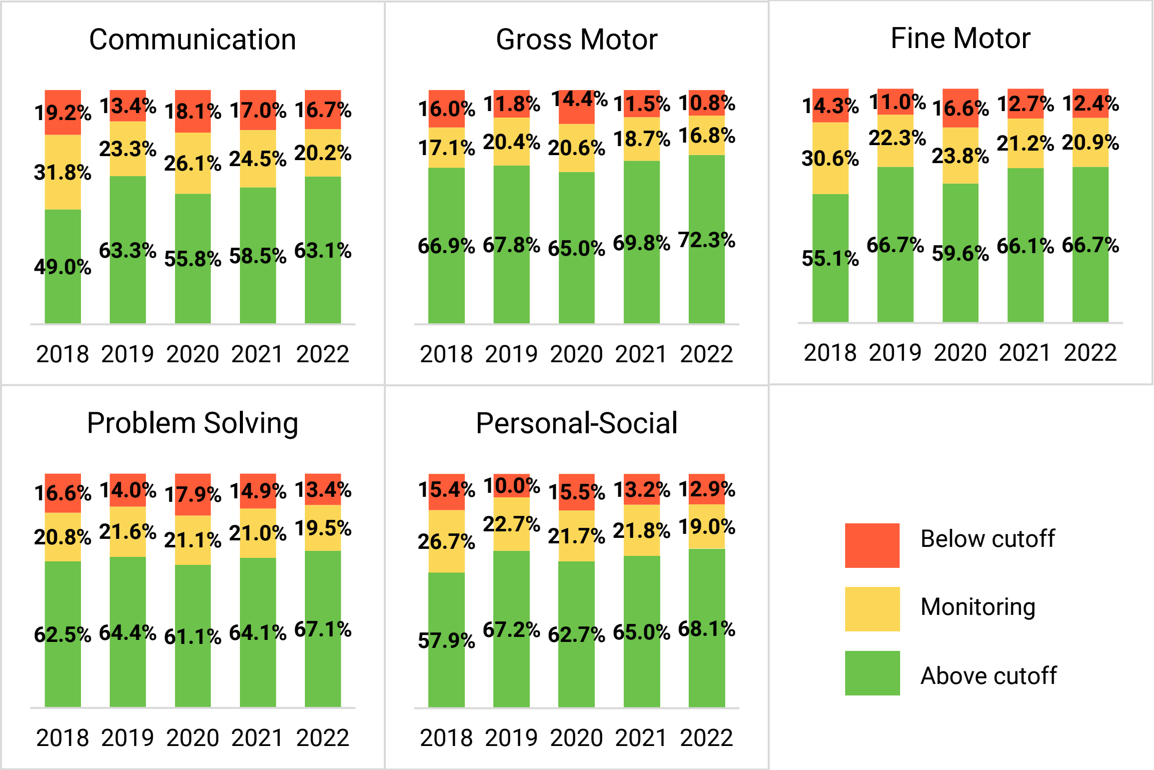
Overall, around 60% of the ASQ-3 screenings resulted in a score that was above the cut-off in all domains. Note that 2018 is an outlier as the Registry was emerging as a countywide database, and the initial agency entering the screenings was primarily entering children whose scores were below the cutoff.

Figure 14: Distribution of ASQ-3 results, by overall score (N=32,328)



For children who are not above the cutoff, the Registry collects information about their scores on each of the five domains. In 2022, of the subset of children who were not above the cutoff (meaning that they scored below the cutoff or monitoring in at least one domain) the percentage of children ranged from a low of 10.8% in Gross Motor to a high of 16.7% in Communication. Note that charts in Figure 15 below include just those children who have at least one area that was below the cutoff (i.e., a child may be above the cutoff in all areas except for one, in which case they are included in charts below).

Figure 15: Distribution of ASQ-3 results, by component (N=12,690)

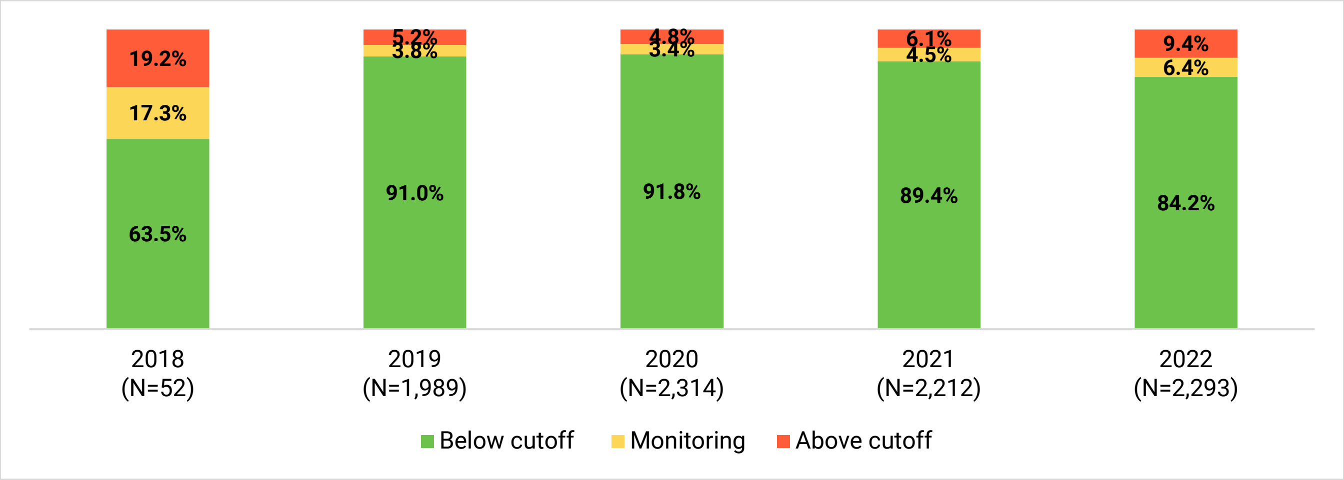


Ages & Stages Questionnaires: Social-Emotional-2 (ASQ:SE-2)

The ASQ:SE-2 is a parent-completed tool focused solely on social-emotional development in young children ages one through 71 months. Unlike the ASQ-3, children who are below the cutoff on the ASQ:SE-2 are **on track developmentally** whereas children above the cutoff need consideration for further assessment and/or evaluation. Children who score in the monitoring zone should be provided follow-up activities, re-screened and/or given referrals as appropriate.

Over the past four years, there has been a slight increase in the percentage of children who are above the cutoff and in need of further assessment. Similar to the ASQ-3, 2018 is an outlier as the Registry was in its nascent stage, and the main agency conducting the screenings was primarily entering children whose scores were above the cutoff.

Figure 16: Distribution of ASQ:SE-2 results, by overall score (N=8,860)

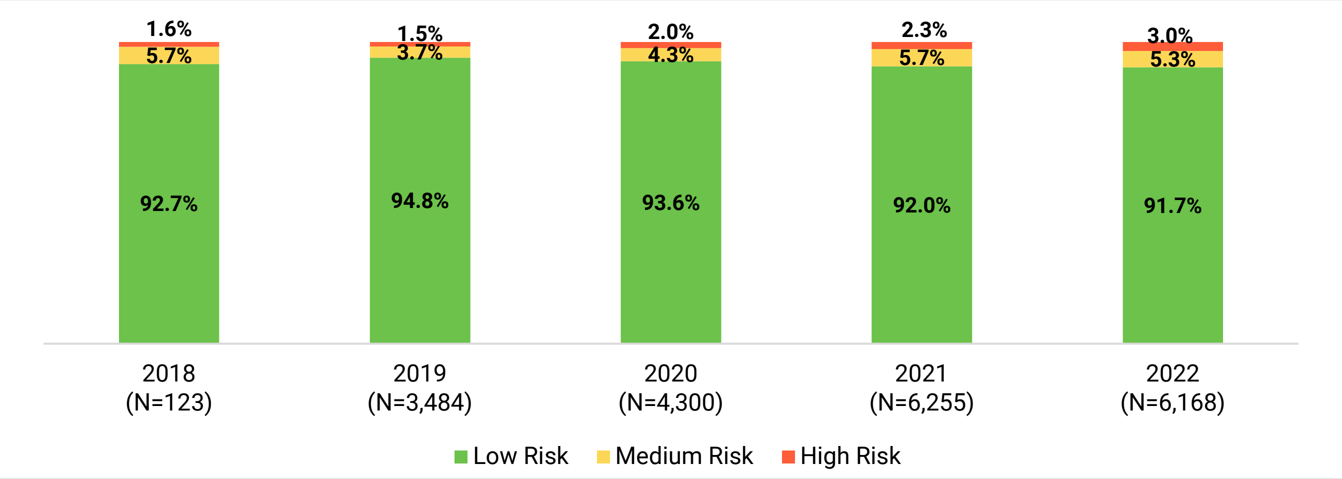


Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT R/F)

The M-CHAT-R/F is a two-stage parent-report screening tool to assess risk for autism spectrum disorder (ASD) for children ages 16 through 30 months of age. The recommended intervals for M-CHAT-R/F screening are at 18 and 24 months of age. Children are scored from 0-20. A score of 0-2 indicates a low risk, with no follow-up needed. A score of 3-7 indicates medium risk with a recommended follow-up administered with parents to get additional information about at-risk responses. After the follow-up is administered, the child will measure either low or high risk. A score of 8-20 is high risk, no follow up interview is needed, and it is recommended the child be considered for referral to early intervention and further diagnostic evaluation.

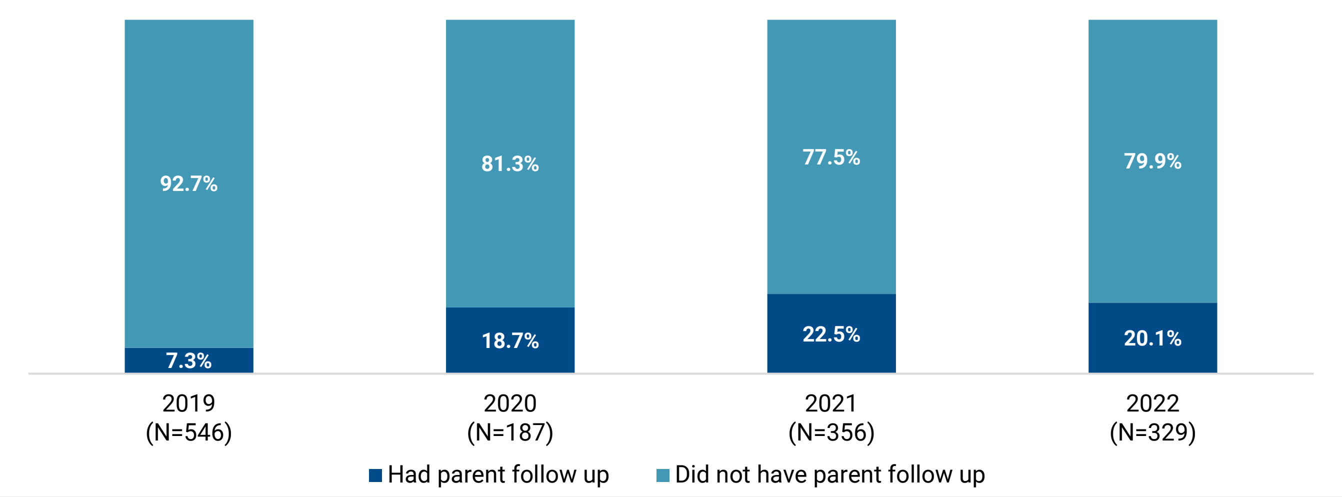
More than 90% of children scored low risk on the initial M-CHAT R/F screening.

Figure 17 Distribution of M-CHAT-R/F results, by overall score (N=20,330)



Of those children who had M-CHAT R/F scores in the medium risk range (score of 3-7), a vast majority did not receive a follow up interview. While the percentage of children with the M-CHAT R/F follow up is increasing, it is still a small proportion of children who receive a follow up. It is an M-CHAT R/F best practice to have a follow up when a child scores in the medium risk zone, indicating that this is an area that could be improved by those conducting the screening.

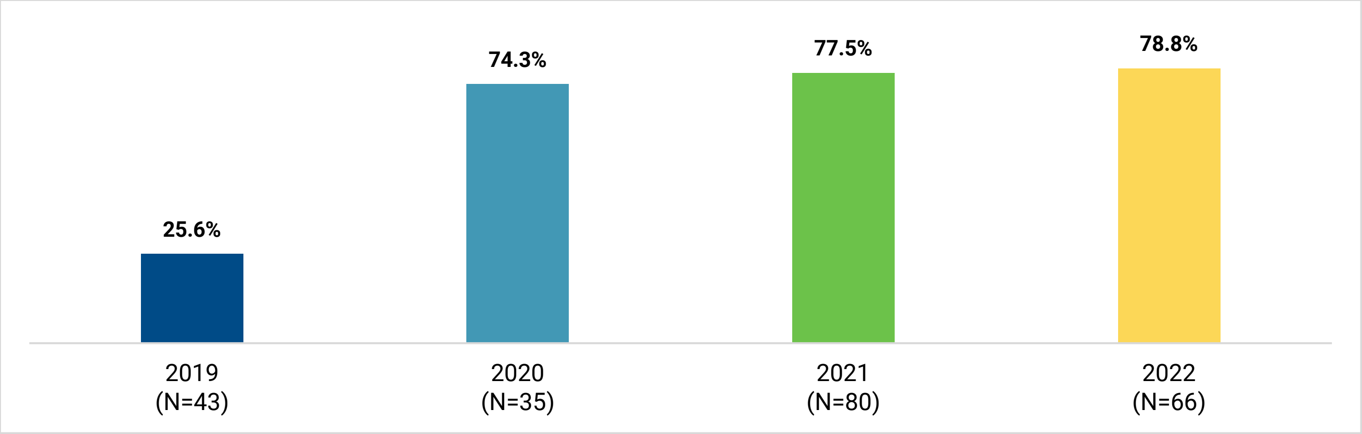
Figure 18: Distribution of M-CHAT R/F screens with parent follow up (for those with medium risk scores) (N=1,418)



Note: 2018 data not included as there were fewer than 10 records.

For the M-CHAT R/F follow up interview, a score of 0 - 1 indicates low risk and no further action is required unless surveillance indicates risk for ASD. A score of 2 or more indicates high risk and action is required, with recommendations that the child be referred for further evaluation and possible eligibility for early intervention. Of the children who had a parent follow-up interview, more than three-quarters scored in the range that would necessitate a referral for further assessment.

Figure 19: Proportion of M-CHAT R/F screens that need further action with a follow-up score of 2+ (N=224)



Note: 2018 data not included as there were fewer than 10 records.

Parents' Evaluation of Developmental Status (PEDS)

The PEDS assesses parents' concerns about children, ages 0 through 8 years, for cognition, receptive and expressive language, fine motor, gross motor, self-help skills, early academic skills, behavior and social-emotional. The PEDS scoring algorithm includes 5 potential paths:

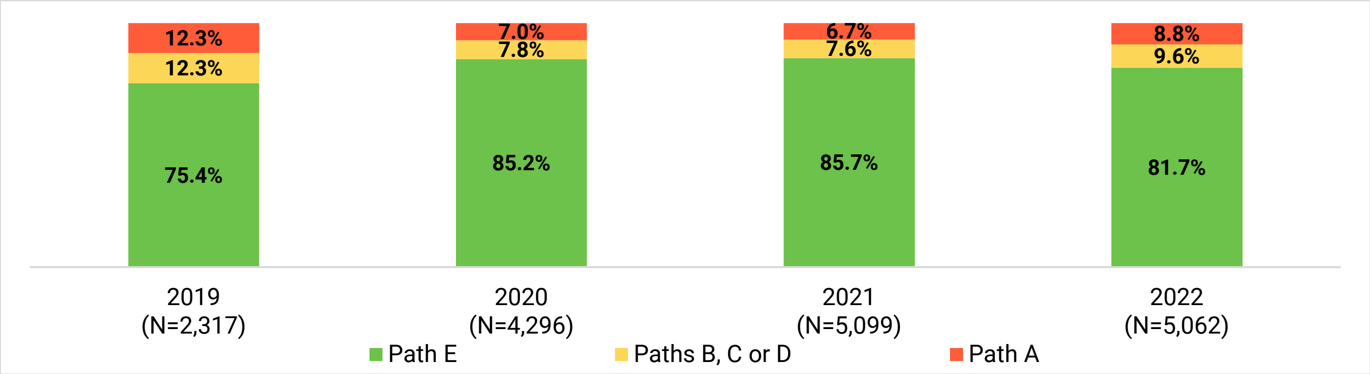
Path A (2 or more concerns): High Risk. Referral for diagnostic evaluation

Path B, C or D: Borderline scores; conduct second stage screen:
<u>Path B</u>: Moderate Risk. PEDS: DM or ASQ-3
<u>Path C</u>: Low Risk. Under 4 years old: developmental surveillance and screen at recommended intervals. Over 4 years old: ASQ:SE-2 or Mental Health screen
<u>Path D</u>: Unable to score. A hands-on screening such as an ASQ-3 is suggested, or caregiver should seek a professional to conduct an in-person screening.

Path E: Low Risk (continue developmental surveillance screen at recommended intervals)

Over the course of four years, the number of children scoring in Path E was increasing each year, except 2022 when there was a slight decline and fewer children scoring low risk.

Figure 20: Distribution of PEDS results, by path (N=16,774)



Note: 2018 data not included as there were fewer than 10 records.

Pediatric ACEs and Related Life Events Screener (PEARLS)

The PEARLS tool was designed to identify exposure to childhood adversity and events that may increase a child's risk for toxic stress and negative health outcomes. There are three versions of PEARLS:

- PEARLS-Child (0-11 years) Parent/Caregiver Report
- PEARLS-Teen (12 years and up) Parent/Caregiver Report
- PEARLS-Teen (12 years and up) Self Report

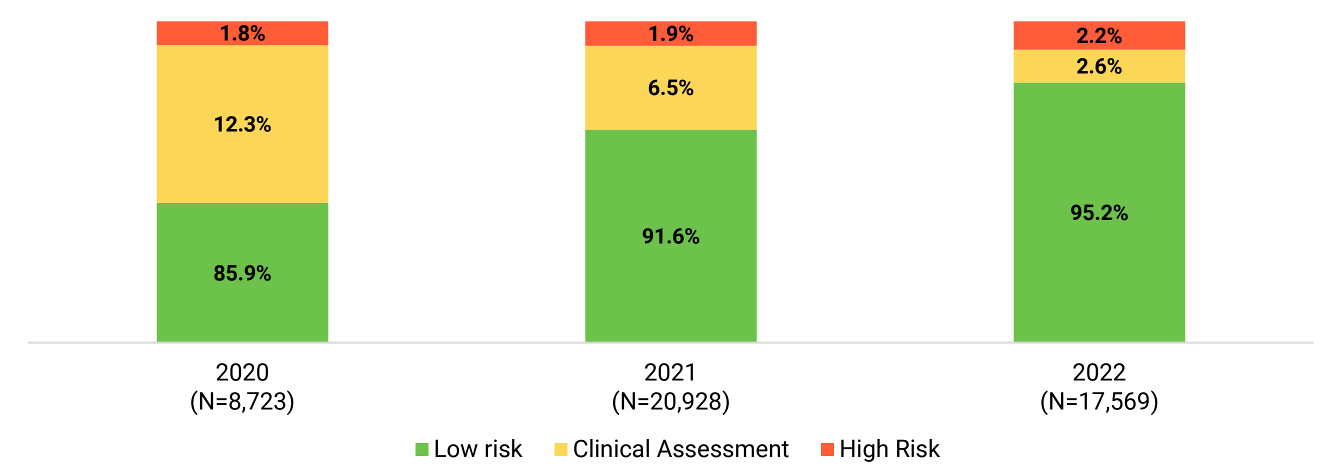
If the PEARLS score is 0, the child is at low risk. If the PEARLS score is 1-3 without ACE-Associated Health Conditions, the child is at intermediate risk. If the PEARLS score is between 1 and 3, a clinical assessment is recommended to determine if the patient has at least one ACE-associated condition. If the PEARLS score is 4 or higher, the child is at high risk.

Note that it is possible for a child to have both a Teen (Parent/Caregiver) and a Teen (Self) PEARLS tool completed in the same visit, whereby there would be two PEARLS tools completed for one teen.

PEARLS-Child (Parent/Caregiver Report)

In 2022, a vast majority (95%) of children with PEARLS (Parent) screenings were at low risk, while only 2% were high risk. Note that in 2018 and 2019, there were very few, if any, PEARLS screenings, and thus data are not reported.

Figure 21: Distribution of PEARLS-Child results, by Risk (N=46,770)



Of those children who were in the clinical assessment range (scored 1-3 on the PEARLS-Child/Parent/Caregiver report tool), about one-fifth of them received a clinical assessment, per the guidelines.

Figure 22: Distribution of Clinical Assessments with PEARLS-Child (for those scoring 1-3) (N=2,837)

	2020		2021		2022	
	#	%	#	%	#	%
Had clinical assessment	204	20.1%	291	21.3%	329	72.8%
Did not have clinical assessment	813	79.9%	1,077	78.7%	123	27.2%
Total	1,017	100%	1,368	100%	452	100%

Of those children with a clinical assessment, between 1% and 2% were then found to have high risk.

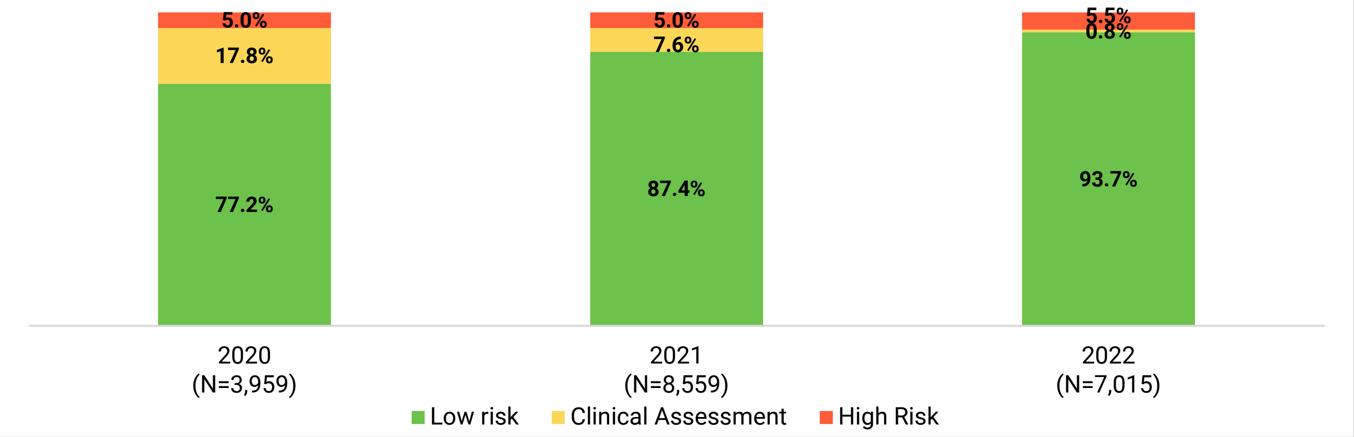
Figure 23: Distribution of Clinical Assessments with PEARLS-Child with risk (N=824)

	2020		2021		2022	
	#	%	#	%	#	%
Intermediate risk	203	99.5%	286	98.3%	307	93.3%
High risk	1	0.5%	5	1.7%	22	6.7%
Total	204	100%	291	100%	329	100%

PEARLS-Teen (Parent/Caregiver Report)

Since the introduction of the PEARLS tool in 2020, there has been an increase in the percentage of entries with low-risk results. In 2022, almost 95% of teens with PEARLS screenings reported by their parents/caregivers were at low risk, 1% indicated a clinical assessment was needed, and 6% indicated high risk.

Figure 24: Distribution of PEARLS-Teen (Parent/Caregiver) results, by Risk (N=19,533)



Of those teens who were in the clinical assessment range (scored 1-3 on the PEARLS-Teen parent report tool), about one-tenth of them received a clinical assessment documented in the Registry, per the guidelines.

Figure 25: Distribution of Clinical Assessments with PEARLS-Teen (Parents) (for those scoring 1-3) (N=1,407)

	2020		2021		2022	
	#	%	#	%	#	%
Had clinical assessment	61	8.7%	78	12.0%	46	83.6%
Did not have clinical assessment	643	91.3%	570	88.0%	9	16.4%
Total	704	100%	648	100%	55	100%

Of those teens with a clinical assessment following the completion of the PEARLS- Teen Parent Caregiver tool, none indicated a high risk in 2021 or 2022.

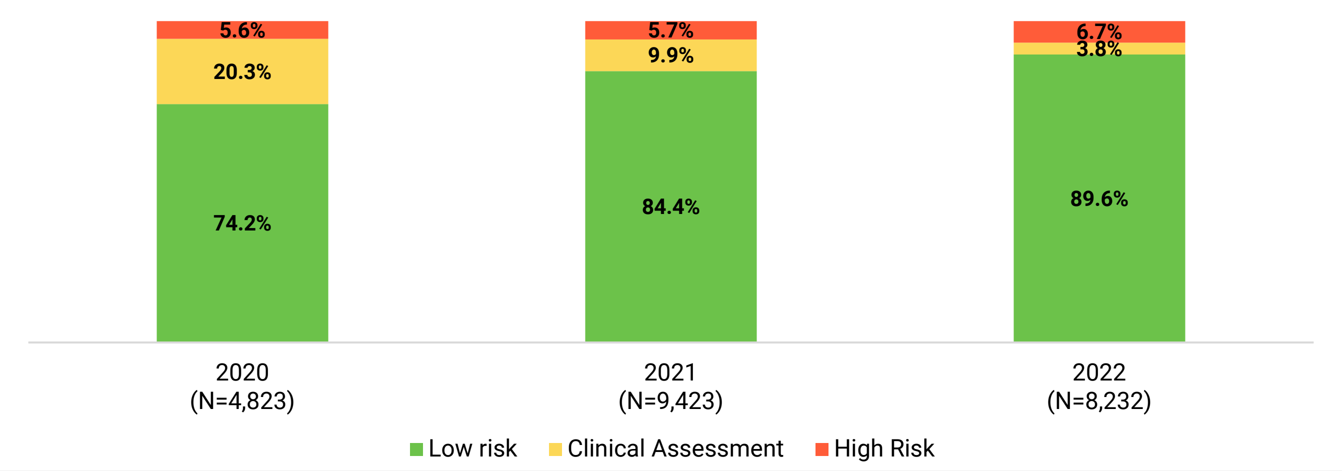
Figure 26: Distribution of Clinical Assessments with PEARLS-Teen (Parents) with risk (N=185)

	2020		2021		2022	
	#	%	#	%	#	%
Intermediate risk	56	91.8%	78	100.0%	46	100.0%
High risk	5	8.2%	0	0.0%	0	0.0%
Total	61	100%	78	100%	46	100%

PEARLS-Teen (Self Report)

In 2022, 10% of teens with PEARLS screenings that were self-reported indicated a clinical assessment was needed, and 7% indicated high risk. When self-reporting, there is a higher proportion of teens in clinical assessment and high risk, than when parents complete the tool (see Figure 24 above).

Figure 27: Distribution of PEARLS-Teen (Self) results, by risk (N=22,478)



Of those teens who were in the clinical assessment range (scored 1-3 on the PEARLS-Teen self-report tool), in 2022, almost 90% of them received a clinical assessment, per the guidelines.

Figure 28: Distribution of Clinical Assessments with PEARLS-Teen (Self) (for those scoring 1-3) (N=2,216)

	2020		2021		2022	
	#	%	#	%	#	%
Had clinical assessment	185	18.9%	245	26.4%	270	87.1%
Did not have clinical assessment	792	81.1%	684	73.6%	40	12.9%
Total	977	100%	929	100%	310	100%

Of those teens with a clinical assessment that was a self-report, 4% indicated a high risk in 2022.

Figure 29: Distribution of Clinical Assessments with PEARLS-Teen (Self) with risk (N=700)

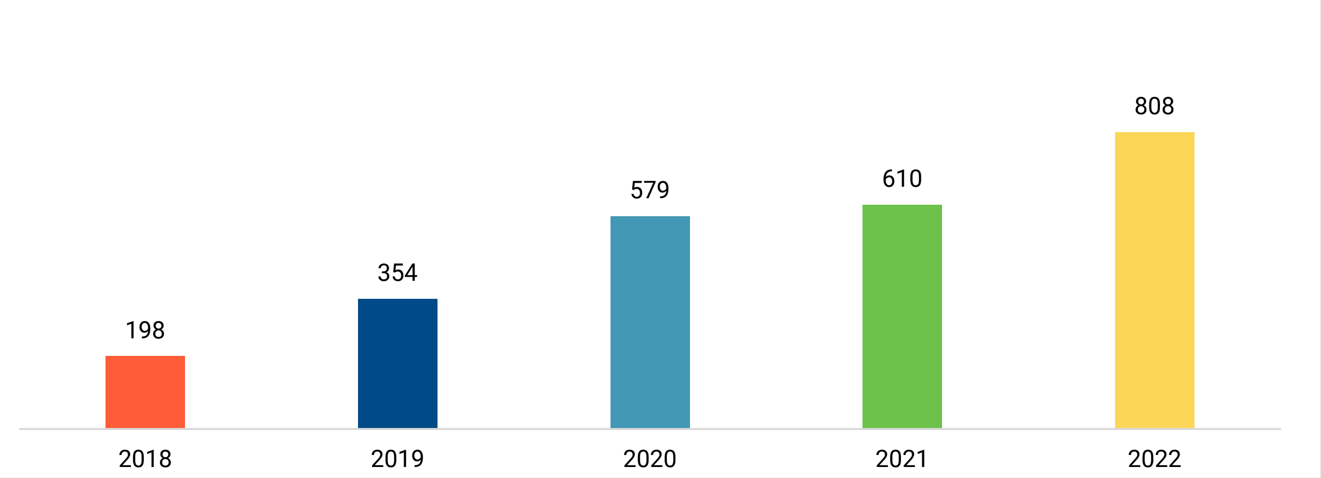
	2020		2021		2022	
	#	%	#	%	#	%
Intermediate risk	174	94.1%	241	98.4%	258	95.6%
High risk	11	5.9%	4	1.6%	12	4.4%
Total	185	100%	245	100%	270	100%

E. Referrals Provided and Connection

Direct referrals can be made through the Registry to Help Me Grow, Orange County. This automated referral is accepted into the Help Me Grow System for Tracking Access to Referrals (STAR). Families are contacted directly via phone or email to discuss their child's needs, based on the available screening results. Help Me Grow's care coordination encompasses a myriad of developmental promotion, resources, referrals and follow up care coordination to ensure a closed loop referral. These efforts are documented for each record and informs the Registry of the referrals provided to the family and their outcomes, allowing for the referring party to see this information.

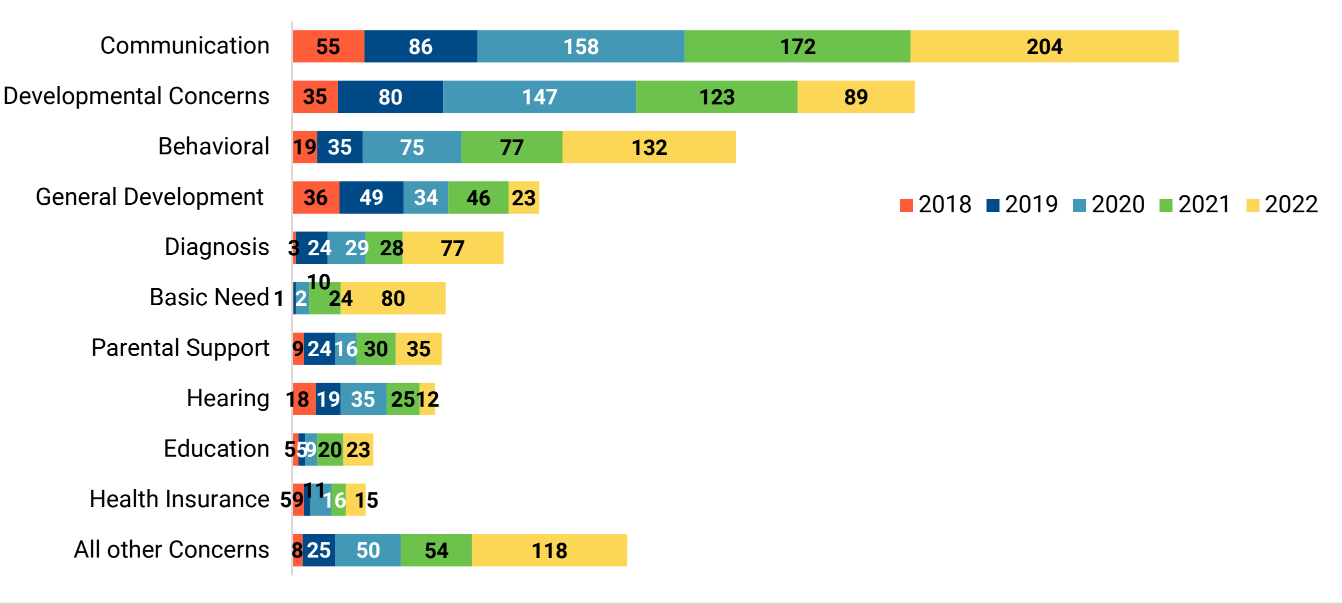
The following Figures 30 – 34 are based on referrals provided **by** Help Me Grow. Between 2018 and 2022, there were 2,549 referrals provided. The number of referrals provided to the families has been growing each year.

Figure 30: Number of Referrals Provided, by Help Me Grow by Year (N=2,549)



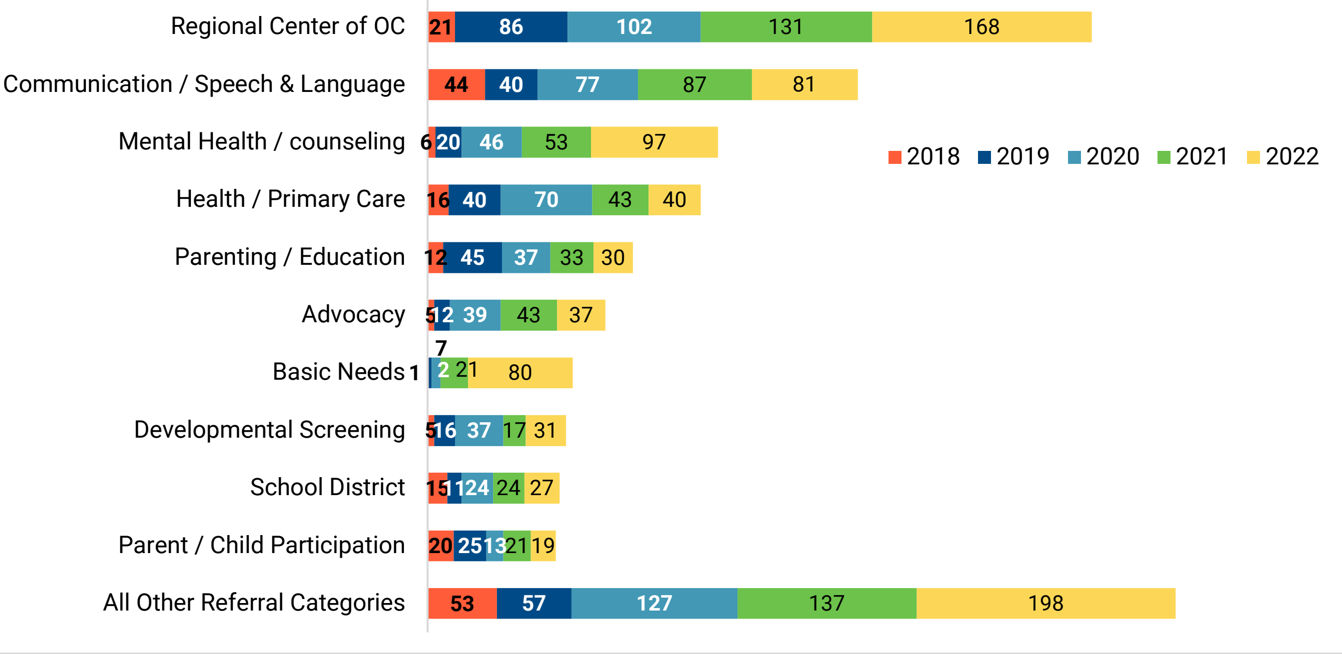
Help Me Grow discusses the goals parents have for their children and when appropriate identifies any concerns or questions they may have regarding their child's healthy development. Communication, developmental concerns, and behavior are consistently noted as the area of need for referral to services.

Figure 31: Type of Concern, by Year (N=2,549)



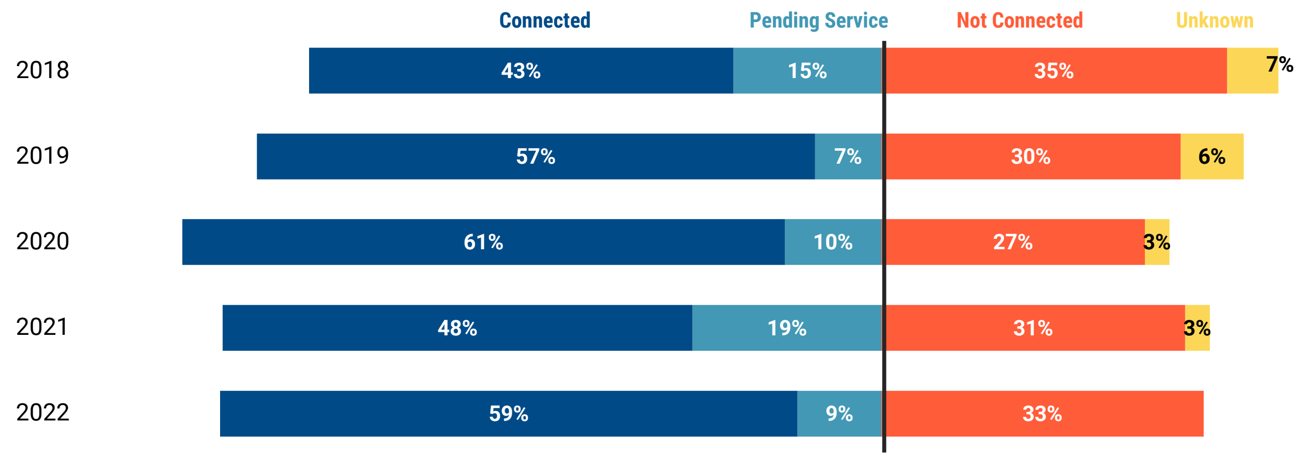
A plurality of referrals was provided to the Regional Center of Orange County, followed by referrals for communication / speech and language.

Figure 32: Category of Referral, by Year (N=2,549)



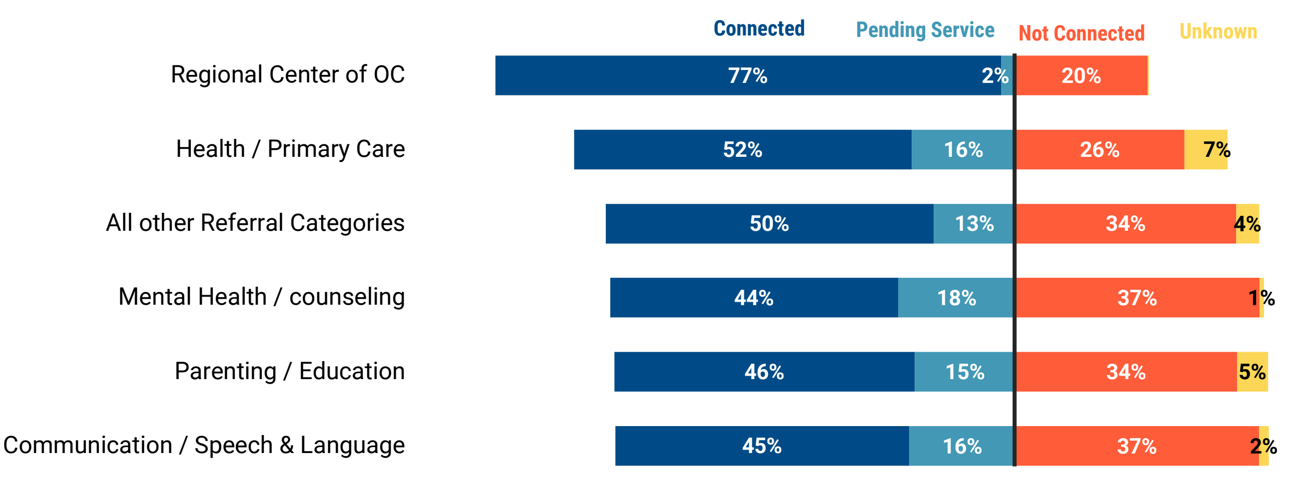
Of the 2,549 referrals provided between 2018 and 2022, outcome data was available for 1,930 referrals. The year 2020 has had the highest rate of referrals that were connected or pending services (71%), meaning the child was receiving or about to receive services. In 2022, two-thirds of referrals were connected or pending services.

Figure 33: Referral Outcome found by Help Me Grow by Year (N=1,930)



More than three-quarters of children referred to the Regional Center of Orange County were connected or pending eligibility. Children who were referred for communication / speech & language challenges had the lowest rate of connected or pending services.

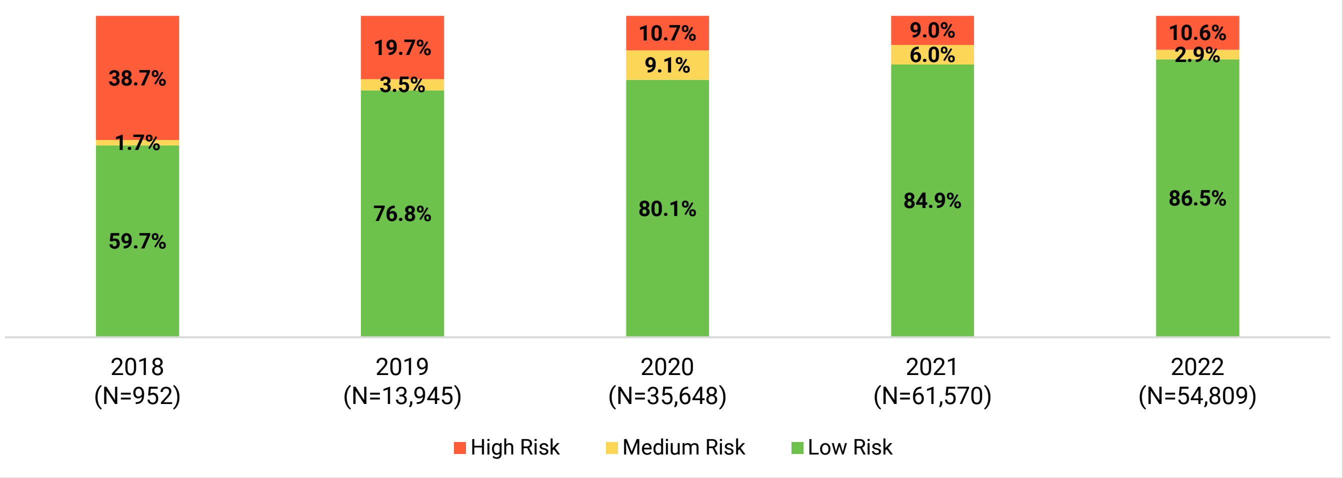
Figure 34: Referral Outcomes by Referral Category, 2018-2022 (N=1,930)



III. Summary & Conclusions

For calendar years 2018 through 2022, more than 117,000 children had more than 167,000 screenings entered into the OC Children's Screening Registry. Figure 35 below presents the standardized results across all the screening tools. There is a general trend of fewer kids with screenings in the medium or high-risk categories.

Figure 35: Overall risk by screening tool, 2018-2022 (N=166,924)



Note: there were 172 screens in 2022 that had an “unknown” result, hence the N for Figure 35 is smaller than the number of screenings entered in the Registry.

A. Future Opportunities

Recommendations for future opportunities to expand and enhance the Registry’s impact in Orange County include:

- Consider inclusion of additional tools related to early childhood, such as the Survey of Well-being of Young Children (SWYC).
- Finalize Registry use by Orange County Head Start, Inc. which can add approximately 3,000 screenings per year.
- Continue to expand Registry use by health care providers and encourage use of the Registry during chart preparation for well child visits to identity children who are lacking recommended screenings and to decrease duplication if screening already completed.
- Increase the number of school districts with signed agreements for use of the Registry with the goal of having all school districts with early childhood programs contributing screening results to the Registry.
- Conduct additional research with the more than 100,000 children’s records entered in the Registry. Consider analyzing the deidentified data to learn more about trauma screening results (PEARLS tools) and how it compares to a child’s development measured by the developmental screening results.