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Telephone-Based Developmental Screening and Care Coordination Through 2-1-1: A Randomized Trial

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abstract

BACKGROUND AND OBJECTIVES: Despite professional guidelines to conduct universal early childhood developmental screening, primary care providers often struggle with early identification of developmental delays, referrals to interventions, and connecting families to services. In this study, we tested the efficacy of telephone-based developmental screening and care coordination through 2-1-1 Los Angeles County, which is part of a national network of call centers, compared with usual care alone.

METHODS: Children ages 12 to 42 months old who receive well-child care at a community health center serving predominantly Hispanic families were recruited and randomly assigned to intervention and control groups. Families in the intervention group were connected with 2-1-1, in which a trained care coordinator conducted developmental screening over the phone using the Parental Evaluation of Development Status Online system and made referrals to intervention services on the basis of developmental risk. The 2-1-1 care coordinator then followed-up with families to assist with connections to evaluations and services. After 6 months, primary outcomes included the following: (1) percentage of children referred for developmental evaluation and intervention services and (2) percentage of children actually receiving services.

RESULTS: One hundred and fifty-two children were randomly assigned to intervention ($n = 77$) and control ($n = 75$) groups. On the basis of intention-to-treat analyses, significantly more children assigned to the intervention group were referred (32% vs 9%; $P = .001$) and were receiving services (16% vs 1%; $P = .002$) within 6 months compared with children assigned to usual care alone.

CONCLUSIONS: Telephone-based developmental screening and care coordination through 2-1-1 appears to be an effective approach for increasing the numbers of young children referred to, and receiving, intervention services for developmental delays.



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Dr Nelson conceived the study concept and design, supervised implementation of the intervention, data collection, and analysis, and wrote the manuscript; Ms Thompson supervised implementation of the intervention, data collection, and analysis and revised the manuscript draft; Ms Herrera and Ms Aceves designed and implemented the intervention, collected data, participated in data analysis and interpretation, and revised the manuscript draft; Mr Biely conducted data analyses (Continued)

WHAT'S KNOWN ON THIS SUBJECT: Despite guidelines recommending universal early childhood developmental screening, previous studies have revealed multiple barriers to screening, referrals, follow-up, and care coordination in primary care.

WHAT THIS STUDY ADDS: In this study, we tested the efficacy of telephone-based developmental screening and care coordination among children ages 12 to 42 months through 2-1-1 Los Angeles County and showed significant improvements over usual care in screening rates, referrals, and enrollment in intervention services.

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Developmental delays, if not identified early and treated appropriately, pose serious long-term risks to health and productivity. The American Academy of Pediatrics recommends developmental surveillance at all well-child visits during the first 5 years; universal developmental screening by using a structured, validated tool at the 9-, 18-, and 24- to 30-month visits; and specific screening for autism spectrum disorder at the 18- and 24- to 30-month visits.^{1,2} These recommendations rely on evidence that using structured tools leads to better early detection of developmental and behavioral problems³ and that early interventions (EIs) can improve outcomes.⁴⁻⁷ Despite these recommendations, national estimates that are based on parent report suggest that less than half of children <5 years of age receive developmental screening in primary care.^{8,9} Barriers include lack of time, lack of familiarity with tools, and challenges in connecting families with evaluations and services.¹⁰ Quality improvement efforts show that screening rates can be improved,^{3,11} but these and other studies demonstrate additional barriers to referral, follow-up, and connection of children to services when concerns are detected.^{11,12}

2-1-1 is a national telephone access number to state and county call centers that connect individuals and families to local health and human services.¹³ In 2009, 2-1-1 Los Angeles County (211LA) developed an innovative model for telephone-based early childhood developmental screening and care coordination to detect and address early childhood developmental and behavioral concerns among families who called 2-1-1 for assistance with basic needs, such as food, housing, employment, and child care. Under this program, the 2-1-1 information and referral specialist answering the phone

offered screening to families with children ages 0 to 5 years and transferred willing families to a specialized care coordinator. The care coordinator then conducted the screening by phone using the Parental Evaluation of Developmental Status (PEDS) Online system, which includes the PEDS, the PEDS: Developmental Milestones, and the Modified Checklist for Autism in Toddlers, Revised (MCHAT-R).¹⁴⁻¹⁶ The care coordinator entered parent responses into PEDS Online and, using automated risk assessments and shared decision-making with parents, connected families to EI for children ages 0 to 3 years or to Early Childhood Special Education (ECSE) for children ages 3 to 5 years with suspected developmental delays or disabilities as well as behavioral health services, social-support services, and early care and education (ECE), such as child care or preschool (including Head Start). Care coordinators subsequently followed-up with families and service agencies to support connections, address barriers, and track outcomes of referrals until they confirmed all recommended connections or until families declined additional follow-up. Initial results of this program have been described elsewhere.¹⁷

Our purpose for this study was to test the efficacy of the 211LA model of telephone-based developmental screening and care coordination, in partnership with a local community health center, by using a randomized controlled trial (RCT). Our goal was not to replace primary care-based developmental services but to supplement existing care and compare this enhanced model to usual care. To our knowledge, this is the first RCT used to test telephone-based developmental screening and care coordination through a 2-1-1 call center. Because 2-1-1 call centers operate across the United States and cover >90% of the population,¹⁸ this model has potential for rapid

replication and dissemination, leveraging existing infrastructure. In addition, some 2-1-1 call centers collaborate with platforms, such as Help Me Grow, that help local communities support developmental promotion, early detection of concerns, referrals, and linkages to services.^{19,20} Rigorously examining the effectiveness of 211LA's telephone-based screening and care coordination model would inform efforts to improve early childhood systems of care.

METHODS

This study was approved by the University of California, Los Angeles Institutional Review Board and registered at clinicaltrials.gov.

The Sample

Clínica Monseñor Oscar A. Romero (CMOAR) is a federally qualified health center with 2 clinic sites in mainly Hispanic and underserved neighborhoods of Los Angeles. Pediatric primary care is provided by pediatricians, family physicians, and supervised physician assistants. Potential participants were recruited from June 2015 to January 2016 by the study's research associate (RA) in clinic waiting rooms, by clinic staff when patients checked in for visits, and through phone calls by clinic staff to patients in the appropriate age range. We included patients between ages 12 and 42 months at baseline if they received primary care at CMOAR, were not currently receiving intervention services for a developmental delay or disability, and spoke primarily Spanish or English.

Randomization and Control Conditions

The recruitment sample and randomized assignments are described in Fig 1. After informed consent, each family was randomly assigned to the intervention or control group by using a random

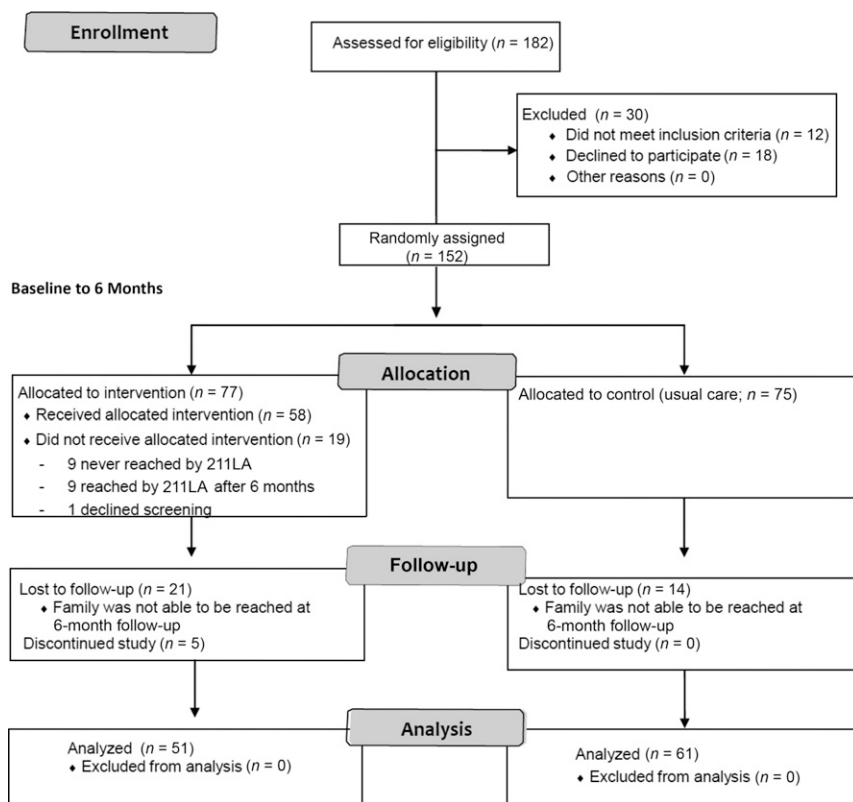


FIGURE 1

Consolidated Standards of Reporting Trials diagram. The figure shows the number of potential participants approached for enrollment, actually enrolled, randomly assigned, and followed and the number of potential participants whose data were analyzed in this RCT, according to Consolidated Standards of Reporting Trials guidelines. Among participants allocated to the intervention group, 75% received the intervention during the 6-month study period.

number generator with 1:1 allocation to the 2 groups. The RA then conducted a structured interview with the parent or caretaker at the time of enrollment. Baseline interviews included sociodemographic and health information about the child and family, questions about parental concerns related to child development or behavior, and items from the Promoting Healthy Development Survey (PHDS)²¹ to measure families' experiences with primary care. For control families, the RA also conducted the PEDS, PEDS: Developmental Milestones, and MCHAT-R screens (the MCHAT-R is validated for children ages 16–30 months and was only administered to children in that age range at baseline). Baseline screening was conducted by the RA for the

control group and by 211LA (as part of the intervention) for the intervention group. When screening results suggested that control families had developmental or behavioral concerns, the RA encouraged parents to raise those concerns with their health providers, but results were not shared directly by the RA with health providers. This was done to ethically address needs of control families without unduly influencing usual care. Both control and intervention families received care as usual from their primary care providers.

The Intervention

Intervention procedures are summarized in Fig 2. For families in the intervention group, the RA attempted to connect the parent to the 211LA care coordinator. Whenever possible, this connection

was made by using a “warm hand-off” immediately after the baseline interview, calling the 211LA care coordinator directly and connecting the parent over the phone. If that was not immediately feasible, the RA shared the care coordinator's phone number with the parent and sent the parent's contact information to the care coordinator.

When the care coordinator and family were able to speak by phone, the care coordinator administered the PEDS Online screening tools, entering parent responses into the PEDS Online and 211LA data systems, sharing results with the parent, and making referrals on the basis of developmental risk. Detailed screening and care coordination protocols and procedures were developed and tested before this study.¹⁷ Typically, children with high or moderate developmental risks were offered referrals to their local EI (for children <3 years old) or ECSE (for children ≥3 years old) programs for developmental evaluations and services. When parents indicated behavioral concerns, additional referrals were made for behavioral health services. All families were also offered referrals to ECE programs and social services if parents expressed a need.

Whenever possible, the 211LA care coordinator made 3-way calls to connect the parents to local service agencies directly. When a 3-way call was not possible, the 211LA care coordinator completed referral forms and sent these securely to the service agencies or called agencies on the parent's behalf. Parents were also given agency contact information so they could contact them directly. Results of screening and referrals were summarized in a care plan and sent to the primary care provider to be scanned into the child's medical record.

Finally, the 211LA care coordinator made follow-up calls with parents

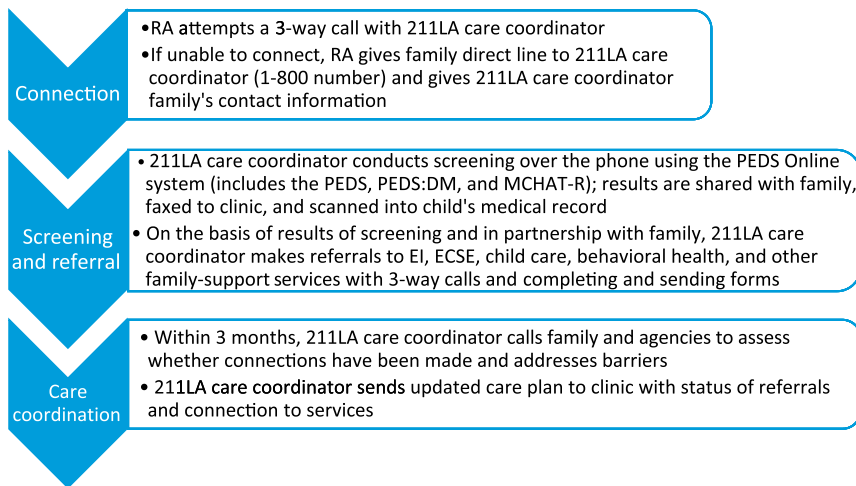


FIGURE 2

Summary of intervention procedures. The figure is used to summarize the intervention protocol used by the study team to connect families in the intervention group to 2-1-1 and by the 2-1-1 care coordinator to conduct screening, referrals, and care coordination for the intervention group. PEDS: DM, Parental Evaluation of Developmental Status: Developmental Milestones.

and service agencies, typically ~15, 30, and 60 days after their initial contact, to determine the status of referrals and address any barriers. As part of the Los Angeles County health and social services safety net, 211LA care coordinators also connected families with other services, such as transportation, housing, food, and utility assistance, as needed to address barriers and ensure timely interventions for children. Families received between 4 and 30 calls, as needed, to complete care coordination. Six months after each intervention-group family's enrollment in the study, a follow-up document was sent to the clinic to describe final outcomes of each referral, including whether a child was evaluated, whether he or she was found eligible for services, and, if receiving services, what specific services (eg, speech therapy, physical therapy, behavioral therapy, or ECE).

Additional Data Collection

Other data sources included medical record abstraction for each child at baseline and at 3 and 6 months after enrollment. The RA and medical-student volunteers conducted these abstractions, noting any

documentation in the medical record about developmental screening, developmental-behavioral concerns, or referrals to intervention services in addition to general health information, such as health conditions, medications, clinic use, and vaccination status. The RA then conducted a follow-up structured interview with all study participants 6 months after enrollment, which included the previous PHDS items and follow-up questions about developmental-behavioral concerns, referrals, connection to services, and experiences with 211LA, if applicable.

A trained medical-student volunteer also conducted retrospective medical record reviews of an entirely separate cohort of children of similar age who were seen for well-child care at CMOAR during the 6 months before the intervention began to assess clinician practices before the study and to determine if the study might have altered clinician practice with respect to developmental screening and referrals among control patients.

Outcomes and Analyses

All of the data collected were entered into the Research Electronic Data

Capture system at University of California, Los Angeles.²² Analyses were conducted by using Stata software (version 14; Stata Corp, College Station, TX). Primary outcomes were dichotomous and included (1) referral to EI or ECSE and (2) receipt of intervention services. Each of these outcomes was considered a "yes" if documented in the medical record, reported by the parent in the baseline or follow-up interview, or included in the 211LA care plan. Additional outcomes, including whether developmental surveillance (asking developmental milestone questions without using a structured screening tool) was performed by the health provider, whether the primary care provider conducted developmental screening with a validated tool, and whether a developmental or behavioral concern was noted, were taken from the abstracted medical records. Because medical records typically do not document whether a child has been evaluated or found eligible for services by an EI or ECSE program, these variables were measured by parent report and 211LA data only. A comparison of the percentage of children with each of these outcomes between intervention and control groups was performed by using a 2-sided Fisher's exact test. To measure differences in family experiences with primary care over time, we analyzed the following domains from the PHDS at baseline and at the 6-month follow-up: percentage of recommended anticipatory guidance topics discussed, percentage of family-centered care items reported as "usually" or "always," assessment of parental smoking and substance use, and assessment of parental well-being. We built difference-in-differences models, with clustered SEs and controlling for child age, sex, and primary home language, to determine if there were statistically significant differences in change over time on the basis of group assignment.

RESULTS

Retrospective Medical Record Review

Medical records were reviewed for all children ages 12 to 42 months who were seen in the clinic for well-child care during the 6 months before the start of the study and included 142 records. These abstractions revealed that although almost all children (99%) had documented developmental surveillance performed during well-child visits, only 4% had been screened by using a structured, validated screening tool, 11% had developmental-behavioral concerns noted in the medical record, and 8% had documentation of a referral for EI or ECSE.

Prospective RCT Study Results

Recruitment for participation in the RCT resulted in 182 children being assessed for eligibility and 152 children enrolling in the study after 12 were excluded for not meeting eligibility criteria and 18 declined to participate (Fig 1). Of the 152 children enrolled at baseline, 77 were randomly assigned to receive the intervention, and 75 were randomly assigned to receive usual care alone. Baseline sociodemographic characteristics of the children and families participating in the study are in Table 1. Average child age was 24.5 months, and child sex was evenly split between boys and girls (50%). Families predominantly self-reported as Latino or Hispanic (97%), mostly Spanish speaking (68%) or bilingual, having low annual household income, and having parental education at the high school level or lower. None of these family characteristics revealed a statistically significant difference between the intervention and control group. In terms of developmental-behavioral concerns, 38% of parents reported having a concern in the previous 6 months. This percentage did not differ between groups and is similar to previous national

TABLE 1 Sociodemographic and Developmental Characteristics of Study Participants at Baseline

	Overall	Intervention Group	Control Group
Total, <i>n</i> (%)	152 (100)	77 (51)	75 (49)
Child age, mo, mean (SD)	24.5 (8.8)	25.7 (9.5)	23.3 (7.9)
Boys, <i>n</i> (%)	76 (50)	44 (57)	32 (43)
Race and/or ethnicity, <i>n</i> (%)			
Latino or Hispanic	143 (97)	72 (95)	71 (99)
White, non-Hispanic	1 (1)	1 (1)	0
African American	3 (2)	3 (4)	0
Other	1 (1)	0	1 (1)
US-born parent, <i>n</i> (%)	44 (29)	22 (29)	22 (29)
Primary home language, <i>n</i> (%)			
Mostly English	34 (23)	18 (24)	16 (21)
Mostly Spanish	102 (68)	55 (72)	47 (63)
English and Spanish equally	13 (9)	3 (4)	10 (13)
Other	2 (1)	0	2 (3)
Annual household income, \$, <i>n</i> (%)			
<20 000	86 (66)	42 (63)	44 (69)
20 000–34 999	31 (24)	16 (24)	15 (23)
35 000–69 999	11 (8)	6 (9)	5 (8)
70 000–99 000	2 (2)	2 (3)	0
100 000+	1 (1)	1 (1)	0
Parent education, <i>n</i> (%)			
Less than HS	75 (49)	39 (51)	36 (48)
HS graduate or GED	43 (28)	21 (27)	22 (29)
Some college or 2-y degree	26 (17)	13 (17)	13 (17)
≥4-y college degree	8 (5)	4 (5)	4 (5)
Parent reported developmental-behavioral concern in past 6 mo, <i>n</i> (%)	57 (38)	28 (36)	29 (39)
Developmental risk, ^a <i>n</i> (%)			
Low	77 (55)	36 (54)	41 (57)
Moderate	44 (32)	26 (39)	18 (25)
High	18 (13)	5 (7)	13 (18)
Failed MCHAT-R (<i>n</i> = 140), ^b <i>n</i> (%)	11 (8)	4 (6)	7 (10)

GED, general equivalency diploma; HS, high school.

^a Developmental risk was measured by using the PEDS Online system.

^b The MCHAT-R was administered to children older than 16 months.

estimates.²³ Although there were more children in the control group scoring in the high-risk developmental category on the basis of the PEDS Online screening system (18% vs 7%), the difference was not statistically significant, and the combined number in the high- and moderate-risk categories (the criteria for EI or ECSE referral) was similar in the 2 groups. Overall, 8% of children who were tested failed the MCHAT-R, with no statistically significant difference between groups.

Descriptive statistics showing the primary study outcomes for the intervention and control groups are in Table 2. The percentage of children in the intervention group screened

with a validated tool indicates the percentage that reached 211LA and received the intervention during the 6 months between enrollment and follow-up. None of the children in either group had documentation of a clinician-performed validated screening tool in their medical records. Developmental surveillance (milestone questions from the electronic medical record) conducted by the health providers in primary care, along with documentation of developmental-behavioral concerns by clinicians, was similar in the 2 groups. However, we found a large and statistically significant difference between groups in terms of referrals to EI and ECSE programs for evaluation

TABLE 2 Screening and Referrals, Connection to Services in 6 Months

	Overall (<i>n</i> = 152), % (<i>n</i>)	Intervention (<i>n</i> = 77), % (<i>n</i>)	Control (<i>n</i> = 75), % (<i>n</i>)	<i>P</i> ^a
Developmental screening and surveillance				
Developmental surveillance done by PCP in primary care encounter	92 (140)	91 (70)	93 (70)	.77
Screened with validated tool by PCP in control group and 211LA in intervention group	38 (57)	74 (57)	0 (0)	.00
Developmental concern noted in medical record	13 (19)	13 (10)	12 (9)	.99
Primary study outcomes: referrals and services				
Referred for evaluation and/or services (EI or ECSE)	21 (32)	32 (25)	9 (7)	.001
Receipt of services	9 (13)	16 (12)	1 (1)	.002

PCP, primary care provider.

^a *P* values obtained with 2-sided Fisher's exact test.

(32% intervention versus 9% control, $P = .001$), completed evaluations (19% intervention versus 1% control, $P < .001$), eligibility for services (16% intervention versus 1% control, $P = .002$), and receipt of services (16% intervention versus 1% control, $P = .002$). These differences remained statistically significant after adjustment for child age, sex, and primary language in multivariable logistic regression models (Supplemental Table 4). Other referrals made by 211LA to families in the intervention group included child care and preschool programs, family literacy programs, and behavioral health and social services. We did not see any documentation in medical records about referral to these other programs and services and did not hear from parents in the control group that their child health providers made such referrals.

Parents' reports about primary care experiences, based on PHDS items at baseline and at the 6-month follow-up, are in Table 3. The results for our

sample are comparable to those found in other clinics and other studies.²⁴ These indicators of primary care components did not change significantly over time or show statistically significant differences between groups.

We also examined whether there were any differences in demographic characteristics between children who followed-up at 6 months and those who did not and found only that children in the group lost to follow-up were 5 months older on average, possibly because these older children were not as likely to return to the clinic for well-child care.

DISCUSSION

To our knowledge, this study was the first used to test telephone-based early childhood developmental screening and care coordination in an RCT. We found that children assigned to the intervention group had significantly higher odds of being screened with a validated tool, being

referred for evaluation, being found eligible for services, and receiving services compared with those receiving usual care alone, even after adjusting for other variables. Families working with 211LA were also connected to community services beyond EI and ECSE programs, including ECE and behavioral health and family-support services. The intervention did not seem to significantly affect components of primary care received.

Our study has several limitations. First, the sample of 152 children enrolled is relatively small, comes from a single clinic system, and was fairly homogeneous in terms of race and ethnicity, primary language, and other sociodemographic variables. Therefore, it is unclear that our findings would be generalizable to other patient populations or other clinic settings. Also, the large effect of the intervention seen in this study may be related in part to the low baseline rates of screening and referral done at our partner clinic.

TABLE 3 Changes in Primary Care Experiences Between Baseline and 6-Month Follow-up

	Intervention Group		Control Group		Difference-in-Differences Estimator <i>P</i>
	Baseline, %	6 mo, %	Baseline, %	6 mo, %	
Recommended anticipatory guidance topics discussed	61.0	68.1	55.1	54.6	.14
Family-centered care (usually or always)	87.2	84.9	89.2	83.1	.55
Assessment of smoking and substance use	88.2	89.0	87.7	83.6	.52
Assessment of parental well-being	60.3	67.2	50.4	56.6	.92

Percentages are restricted to participants with a parent interview at both baseline and the 6-mo follow-up. Difference-in-differences models are adjusted for child's age, sex, and primary home language, and clustered SEs are used to account for within-group correlation.

The intervention might reveal smaller effect sizes in other settings. However, the rates of screening and enrollment in services among families in the intervention group were also substantially higher than those reported nationally in previous studies.^{8,9,25,26} Finally, we were limited by available data sources, including parent report and medical record review, both of which may have omissions or inaccuracies, as well as a substantial loss to follow-up of parents in both groups over time.

Despite these limitations, this study has important implications for clinical practice and future research. Many studies have revealed that child health providers struggle to achieve recommended practices in developmental screening and connection to services for families with developmental-behavioral concerns. Families and providers face multiple barriers limiting the numbers of children enrolled in appropriate interventions, and these barriers are even more pronounced for children from low-income families or families of racial and ethnic minority, families with low levels of parental education, and families for whom English is not a primary language. 211LA has developed a care coordination program that appears to be more effective than a primary care clinic in connecting children with developmental-behavioral concerns to intervention services and has the potential to address barriers for these vulnerable families. 2-1-1 call centers around the United States have

comparable resource directories and data tracking systems and have the potential to replicate this program with training of existing staff. This model could potentially be implemented at relatively low cost as a centralized utility that could be shared among multiple clinics in a region, reducing the burden of care coordination for clinic staff and more effectively linking families with services. Future studies are needed to test whether this program can be scaled up and replicated in other clinic sites, with different patient populations, and ultimately in other 2-1-1 call centers.

In addition to these demonstrated improvements in connecting children with developmental delays to intervention services, partnerships between primary care and 2-1-1 may have the potential to benefit children and families who have psychosocial risks associated with developmental-behavioral concerns and poor school readiness.²⁷⁻³⁰ Because 2-1-1 call centers and resource directories are designed to address basic needs and connect families to social services, they have the potential to support vulnerable families well beyond linkages to developmental services. The initial description of the 211LA Developmental Screening and Care Coordination Program demonstrated that families are willing to engage in screening even when in crisis and that the young children of families calling 2-1-1 have a higher risk of developmental-behavioral concerns.¹⁷ This current study

suggests that 211LA may also be an exceptionally effective partner for primary care clinics struggling with their own developmental screening and care coordination. Future research should examine whether this model can improve long-term child health, development, and educational outcomes.

CONCLUSIONS

Telephone-based early childhood developmental screening and care coordination through a 2-1-1 call center has the potential to improve screening rates, referrals, and connection to services compared with usual pediatric primary care alone. This is a model that could be scaled up through a national network of 2-1-1 call centers.

ABBREVIATIONS

211LA: 2-1-1 Los Angeles County CMOAR: Clínica Monseñor Oscar A. Romero
ECE: early care and education
ECSE: Early Childhood Special Education
EI: early intervention
MCHAT-R: Modified Checklist for Autism in Toddlers, Revised
PEDS: Parental Evaluation of Developmental Status
PHDS: Promoting Healthy Development Survey
RA: research associate
RCT: randomized controlled trial

and interpretation and development of tables used to describe results and revised the manuscript draft; Ms Arriola Zarate assisted with implementation of the intervention, collected data, assisted with data analysis and interpretation, and revised the manuscript draft; Ms Estrada assisted with implementation, data collection, data interpretation, and revising of the manuscript draft; Drs Chan and Orantes collected data, assisted with analysis and interpretation, and revised the manuscript draft; Dr Chung oversaw the study design and implementation and data collection and analysis and revised the manuscript draft; and all authors approved the final manuscript as submitted.

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