

Developmental and Autism Screening Through 2-1-1

Reaching Underserved Families

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Background: Developmental disorders, including autism spectrum disorders (ASDs), are increasing in prevalence. Early identification is necessary for early intervention, which is critical for reducing challenges and lifetime costs, especially for ASDs. Because not all children have equal access to developmental and autism screening through primary care settings, nontraditional methods are needed to reach underserved populations.

Purpose: In this proof-of-concept study, the 2-1-1 Los Angeles County Developmental Screening Project (2-1-1 LA Project) provided developmental and autism screening by telephone in a population of low-income and racially and ethnically diverse children.

Methods: Aggregate data were reviewed for 2845 children who were screened for developmental delays using the Parents' Evaluation of Developmental Status (PEDS) instrument and/or autism using the Modified Checklist for Autism in Toddlers (M-CHAT) instrument between September 1, 2009, and October 31, 2011.

Results: Data analysis was conducted December 2011 through February 2012. A majority of children (56%) screened with the PEDS had a moderate to high risk of developmental delays, including 28.2% classified as high-risk, which indicates need for further evaluation. Among 1605 children screened with the M-CHAT, 21.2% had an elevated risk of ASDs. Follow-up care coordination was provided for 2625 children to facilitate completion of referrals for diagnostic evaluation, early childhood education, and other developmental or behavioral needs.

Conclusions: The project's approach enhanced access to screenings and referral uptake in a population of children that may have difficulty accessing primary care. Findings suggest the potential of nontraditional developmental screening models.

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Introduction

Approximately one in six children in the U.S. today has a developmental disorder.¹ One in 88 meets the diagnostic criteria for an autism spectrum disorder (ASD), a group of neurodevelopmental

disorders affecting communication, behavior, and social skills across a wide range of severity.² Early intervention can reduce challenges and lifetime costs, particularly those associated with ASDs,^{3–9} but a lot depends on early diagnosis. Children who are poor or racial/ethnic minorities tend to be diagnosed later and underdiagnosed.^{1,10–13}

The American Academy of Pediatrics (AAP) recommends universal autism screening at ages 18 months and 24 months in addition to periodic developmental screening.^{14,15} Both are critical as general developmental screening can catch broad concerns but may not identify nuanced early warning signs of ASDs, including difficulty with social communication, imitation, and pretend play.¹⁶ Efforts are underway to improve the delivery of these screenings within primary care settings,^{17–19} but

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reaching the goal of universal developmental and autism screening will be challenging if primary care is the sole delivery mechanism.

There are at least four major barriers to implementing universal developmental and autism screening in medical settings: inconsistent access to preventive care and a medical home^{20,21}; low prevalence of developmental and autism screening by healthcare providers (especially for non-English speaking families)^{22–25}; frequent use of nonstandardized screening procedures^{26,27}; and inconsistent referrals for further evaluation when screening indicates potential problems.^{20,28–30} Given the magnitude of these barriers, a broader menu of strategies is needed for reaching underserved children.

This paper describes the origins and operation of the 2-1-1 Los Angeles County Developmental Screening Project (2-1-1 LA Project), a proof-of-concept study that explored the feasibility of providing developmental and autism screening for young children in low-income and racially and ethnically diverse populations in Los Angeles County through 2-1-1. It reports on the intervention approach, evaluation methods, evidence of participation and outcomes from the project's first 2 years. Implications of the project's findings for research and practice are discussed.

Methods

Study Setting

In California, 60% of children with special healthcare needs (CSHCN) do not have a medical home.³¹ Only 14% of California's children receive standardized developmental screening within healthcare visits.²⁴ Nearly one third of California's children live in Los Angeles County, and 15% (approximately 400,000) of the county's children are identified as CSHCN.³² Reported prevalence of CSHCN varies widely by income, language, and race/ethnicity, possibly because of differences in screening and diagnostic testing rates.

The 2-1-1 Los Angeles County Developmental Screening Project

This project is the largest information and referral agency in the nation, serving the most populous county in the U.S. Of the 500,000 annual callers to 2-1-1 LA, 22% are families with children aged <5 years. Callers who have young children are overwhelmingly female (91%), with only a high school education (37%) or less (25%). Sixty-five percent of parent callers are Hispanic, compared to 48% of the LA population, and 25% are African-American, compared to 8% of the LA population.³³ Two of five speak Spanish as their primary language. Few are white non-Hispanic (4%) or Asian (1%) compared to the county's white non-Hispanic (28%) and Asian populations (14%).

The project reaches populations with the most risk factors and the fewest resources. More than half (52%) of callers with young children have monthly incomes of ≤\$1000 and are publicly in-

sured or uninsured. Most children (80%) qualify for Medicaid funding. Almost half (45%) of parents do not have use of a car.

Intervention

The 2-1-1 LA Project was initiated in 2009 in response to a recommendation from the Early Identification and Intervention Collaborative for Los Angeles County to improve low screening and early detection rates for developmental disabilities. The project provides early developmental and autism screening for vulnerable families and is the first program in the nation to conduct such screenings by phone through a 2-1-1 call center. This paper reports the protocol and results of the first 2 years of this ongoing project.

After receiving standard 2-1-1 service, a portion of parent callers of children aged 0–5 years were invited by the 2-1-1 information and referral specialist to complete a questionnaire regarding their child(ren)'s development. Information and referral specialists were given a monthly performance goal for referrals to the project but given discretion regarding how to meet that goal. Selection into the project was nonrandomized, and parents who voiced developmental or behavioral concerns were automatically referred for screening. When a parent consented, the call was transferred to a trained Care Coordinator who administered the Parents' Evaluation of Developmental Status (PEDS Online)³⁴ for all children aged <5 years and the Modified Checklist for Autism in Toddlers (M-CHAT)³⁵ for children aged 16–48 months. Results were shared immediately in terms understandable to the family.

If parent responses indicated having a child at elevated risk for a developmental disorder or an ASD, the care coordinators provided referrals to publicly available services based on protocols suggested by the PEDS screening tool (Table 1). Referrals for diagnostic evaluation or medical specialty care were provided when indicated. Children were referred to early education programs (including Head Start and Early Head Start) if not already enrolled, and families were linked back to primary care whenever possible. Those with low risk were scheduled for annual follow-up screening through the project. Referrals were made with the parent present on the phone to teach the parent how to best advocate for the child's needs. An action plan was developed with each family using a care coordination model designed to maximize health outcomes in at-risk populations.³⁶ Care coordinators continued to regularly check in with families until assistance was no longer needed.

Measures

The present study, conducted December 2011 to February 2012, utilized aggregated data reports, survey data, grant materials, and interviews with the project director and consultants. The Washington University Human Research Protection Office determined that this study did not involve activities subject to IRB oversight.

Data collection timelines are depicted in Table 2. Parent interest level, defined as voluntary acceptance of the invitation to participate in screening, was measured across a 6-month period (May 2011 through October 2011). These dates were selected based on consistent documentation of screening offerings during this period, providing for accurate calculation of acceptance rate. Screening completion rates were reviewed for a 10-month period (January through October 2011). Data collected included number of referrals for screening, screenings completed immediately via live transfer to a care coordinator versus screenings completed by calling the parent back, and number of missed screenings due to

Table 1. Description of PEDS and M-CHAT screening outcomes and referral examples^a

Screening outcome ^b	Description of concerns	Typical referrals
PEDS Path A High risk of developmental disability	Multiple developmental and frequent behavioral concerns	Further evaluation Specialty referrals if warranted (medical, mental health) Early intervention (age 0–2 years) or early childhood special education (age 3–5 years)
PEDS Path B Moderate risk of developmental disability	At least one developmental concern and other behavioral concerns	Further evaluation if warranted Early intervention or early childhood program
PEDS Path C Elevated risk for behavioral or mental health problems	Behavioral or mental health concerns but no developmental concerns	Further evaluation if warranted Specialty referrals if warranted (medical, mental health) Early intervention program
PEDS Path E Low risk of developmental disability	No concerns of any type	Early childhood program such as Head Start Annual rescreening
M-CHAT: Fail	Shows possible signs of an autism spectrum disorder	Refer to state's developmental disability regional center for autism diagnostic evaluation Follow PEDS referral pathway per developmental screening results
M-CHAT: Pass	No signs of an autism spectrum disorder. Other developmental concerns may still be present.	Follow PEDS referral pathway per developmental screening results

^aAs a standard, all referrals included vision, hearing, and lead screening as well as recommendation of early childhood education programs.

^bOral administration of the PEDS eliminates use of Path D which records questionable results for parents who have difficulty understanding the printed version of the PEDS.

PEDS, Parents' Evaluation of Developmental Status; M-CHAT, Modified Checklist for Autism in Toddlers

inability to reach parents in the latter group. The relationship between missed screenings and overall volume of referrals for screenings was examined.

The PEDS and M-CHAT screening results were tracked over the first 2 years of the project (September 1, 2009–October 31, 2011). Referrals made by care coordinators were tracked for this same period, as well as outcomes of these referrals as reported by parents. A “successful link” occurred when the child received at least one new referred service. A distinction of “new” was made because some children were already enrolled in programs such as Head Start, but may have needed additional referrals for unmet needs. An outcome of “pending services” indicated that an application for service enrollment or eligibility determination was in process, or that the child qualified but was waiting for services. Care coordinators recorded a referral for “annual rescreening” for low-risk children.

Screening Instruments

The PEDS and M-CHAT screening tools are often administered in tandem. These instruments are brief, appropriate for administration by telephone, and immediately identify levels of risk (or “pathways”) for developmental problems including autism. Definitive diagnosis requires further evaluation.

The PEDS is a 10-item parent interview tool used to screen for developmental concerns in children aged 0–8 years. Standardization included children from diverse racial, ethnic, and socioeconomic backgrounds, and the tool has moderate sensitivity (0.74–0.79) and specificity (0.70–0.80).³⁷ PEDS screening results are translated into pathways indicating level of risk for different types of delays (Table 1).

The M-CHAT is a commonly used parent questionnaire that identifies elevated risk for ASDs or other serious developmental

Table 2. Measurement operationalization and data review periods

Measurement	Definition or instrument	Data review period
Parent participation rate	Acceptance of invitation to take screening	May 2011–October 2011
Screening completion rate	Completion of screening following acceptance of invitation	January 2011–October 2011
Screening outcomes	PEDS and M-CHAT screening tools	September 2009–October 2011
Referral outcomes	Parent report of successful linkage to service referrals, pending services, or referral for annual rescreening	September 2009–October 2011

PEDS, Parents' Evaluation of Developmental Status; M-CHAT, Modified Checklist for Autism in Toddlers

Table 3. PEDS and M-CHAT screening and referral outcomes by level of risk, %^a

	Identified risk	Linked to services	Pending services	Referred for annual rescreen	Other ^c
PEDS (n=2845)					
High developmental risk: Path A (n=803)	28.2	45.2	33.9	<1	20.5
Moderate developmental risk: Path B (n=782)	27.5	47.6	34.4	<1	17.4
Very low developmental risk: Path E (n=797)	28.0	1.2	<1	97.9	<1
Behavioral/mental health risk: Path C (n=463)	16.3	23.5	11.2	59.8	5.5
M-CHAT (n=1605)^b					
Risk for autism: fail (n=341)	21.2	51	23.2	5.3	20.5
Limited risk for autism: pass (n=1264)	78.8	—	—	—	—

^aRefer to Methods for complete description of outcomes.

^bOverlap exists between the M-CHAT and PEDS pathways, because referrals were made according to PEDS pathway protocols in conjunction with M-CHAT results. M-CHAT Fail results are broken out independently for reporting purposes only.

^c“Other” included families who could not be reached after several attempts or whose records were missing data.

PEDS, Parents' Evaluation of Developmental Status; M-CHAT, Modified Checklist for Autism in Toddlers

problems. It typically is administered with parents of children aged 16–30 months, but trends in the literature suggest it is appropriate for use with children aged ≤48 months.³⁸ Parents answer 18 *yes/no* questions and scoring yields pass/fail screening results. The M-CHAT standardization included children with and without ASDs. Tool sensitivity approaches 0.91 as an upper bound, and true specificity is still being established.³⁹ Positive predictive value varies between 0.36 for the M-CHAT alone, and 0.59–0.80 with follow-up interview.^{38,39} A follow-up interview increasingly is being used to improve the accuracy of M-CHAT results but was not in use at the time of this data collection.

Results

Participation

Nearly 11% (n=4137) of callers with children aged 0–5 years (n=37,955) were invited to participate in screening during the 6-month parent participation review period. Of these, 70% (n=2896) accepted the invitation to participate in screening. The number of parents invited to participate in screening was determined by the capacity of dedicated project staff.

Ten months of screening-completion data were reviewed, which included the parent participation data review period. Of parents who accepted an invitation to participate in screening (n=3305), 20.8% were transferred directly from a 2-1-1 information and referral specialist to a project care coordinator for immediate screening. Others (38.8%) were called back to complete the screening because a care coordinator was not available at the time of transfer. The need to call families back resulted in an inability to reach 40.4% of callers who initially indicated interest in screening. As the volume of screening referrals increased over the first 2 years of the project, the number of missed screenings increased because of lack of capacity to handle increased volume.

Screening

During the first 2 years of the project, developmental screening was completed for 2845 children (Table 3). In all, 55.7% of children screened were at moderate to high risk for delays: 28.2% at high risk, indicating strong need for further evaluation, and 27.5% at moderate risk. For children whose parents completed the M-CHAT, 21.2% had a positive screening result, indicating an elevated risk for an ASD or other serious developmental problems. It was unknown whether children had received prior screening through a school or medical setting. However, one third of families who participated in screening reported prior developmental concerns. Of these, half had been concerned for at least 6 months, and another third had been concerned for more than 1 year.

Referrals

Based on identified needs of all children screened, 92.2% of children (n=2625) received at least one new referral (Table 3); only 5% (n=123) were connected to some type of educational program or service already. Follow-up tracking of referral linkages revealed that 45.2% of children with high risk for delay received at least one referred service and an additional 33.9% had services pending. Among children at risk for ASD, more than half (51%) received at least one of the referred services, and 23.2% had services pending. Although outcome data are reported separately for developmental and autism screening results, care coordinators took both PEDS and M-CHAT results into consideration when making referrals.

Discussion

In a convenience and purposive sample of 2-1-1 LA callers with young children, levels of voluntary parent participation and family interest were high. The percentage of children identified as having moderate to high risk for delays (55.7%) was approximately double that for same-age children nationwide (26.4%) or in California (30.5%).²⁴ The percentage of failure on the M-CHAT (21.2%) was higher than a recent finding that 8.8% of children have positive M-CHAT screens.⁴⁰ The prevalence of high risk for developmental disorders and ASDs identified through the screenings, prevalence of pre-existing developmental concerns, and large numbers of children who were not receiving any early education programming all signal unmet needs and underscore the utility of universal screening in this population.

The 2-1-1 LA Project reached a low-income population of high-risk children who are less likely to receive screenings through primary care settings. The model used in this project appears to facilitate access to screenings and referral uptake. The project utilizes an established institution to provide a new service and capitalizes on 2-1-1's volume in order to reach many children. It further adds standardized screening tools, a structured care coordination model, and data systems for tracking and reporting outcomes. It leverages an extensive information and referral database and improves it by adding resources specific to early development.

The project is similar to nationwide projects targeting cancer risk assessment and referrals utilizing the 2-1-1 system.⁴¹ The administrators of 2-1-1 LA consider screening and care coordination the next generation of information and referral services. A recent recommendation for updates to the American Association of Pediatricians (AAP) screening guidelines also highlighted the need to include care coordination as a component of the screening process.⁴² Finally, the high level of caller interest and willingness to participate provides evidence of community demand and acceptability—both key indicators of feasibility.⁴³

Program Resource Demands

Although the 2-1-1 LA Project offers a replicable model for early detection of developmental issues in high-risk, difficult-to-reach populations, obstacles remain. Replication in other 2-1-1 call centers would require staff to conduct community-based needs assessments, establish community partnerships, add information about local service systems to their referral databases, and establish referral relationships. Having adequate numbers of highly trained staff is also critical, as evidenced by missed

opportunities for screening when care coordinators were not immediately available.

The project currently employs a director, two bilingual care coordinators, and a care coordinator assistant for administrative tasks. Contract consultants include a program evaluator, a policy and systems advisor, and child developmental research specialists. The care coordinators have training in child development, and the project director is a mental health professional with extensive experience in California's service system for individuals with developmental disabilities.

Technologic infrastructure and expertise are essential to develop and manage secure data systems to track screening, referrals, and quality control processes. In particular, 2-1-1 LA found it necessary to develop its own software to track care coordination activities and data collection, integrating this component into its existing web-based, telephony-synched information and referral database system. An online web-based system is needed for tracking referrals across partner organizations, as parents do not always understand and report this complicated information accurately. The sharing of informed consent information also can be cumbersome but is necessary to enable communication with other providers.

Because proactive, systematic screening falls outside traditional 2-1-1 system tasks, supplemental and sustainable funding is necessary to implement this strategy in addition to typical information and referral services. Physicians warn that we cannot rely on primary care for all routine identification and follow-up needs given the increasing complexity of demands on the medical system.⁴⁴ In contrast, funded partnerships between primary care, 2-1-1s, and community organizations could have a substantial impact on health outcomes by facilitating well-child care, educating parents, and delivering time-intensive care coordination.

Cross-organizational relationships are a critical component of the project's broader goal of supporting integration of care, effective communication, and collaboration within the community-wide support system. The project has established partnership agreements for services with community-based organizations and government agencies, including area early childhood education programs, Head Start and Early Head Start, and local programs serving CSHCN.

The implications of this program must be considered in the context of the growing prevalence of developmental disorders and ASDs, the expanding diversity of the nation's population, and the increasing financial frailty of families who rely on systems such as 2-1-1. Few published studies describe similar solutions for increasing developmental and autism screening in underserved populations. In order to further explore the potential of this

nontraditional developmental screening model, research is needed to determine effectiveness of implementation within other call centers, accuracy of developmental screenings conducted by phone, and benefits relative to costs.

Limitations

There are several limitations to the current study. First are the practical limitations of analyzing data collected by a community-based agency for nonresearch purposes. This study demonstrated feasibility of an innovative intervention but would benefit from more-rigorous evaluation.

Second, several factors may have contributed to the elevated rates of developmental and autism risks observed in the population of children whose parents called 2-1-1 LA. Selection bias was likely because, by design, participants with stated developmental concerns (approximately 30% of callers) were more likely to be referred for screening. However, stratification of findings revealed that a moderate to high risk of delay was identified in 44% of children whose parents had no stated concern—a proxy for referring callers at random for participation—as compared to the 56% rate of identification for all children screened. Thus, rates of identification remained high despite the nonrandomized selection process. Use of the M-CHAT follow-up interview tool might improve autism screening results by reducing false-positive results. Accuracy of referrals was likely improved, however, by considering the PEDS and M-CHAT results together.

It is not surprising to observe a high rate of developmental concerns in a population with elevated psychosocial risk factors. In one follow-up study of children who failed the M-CHAT, 50% were ultimately diagnosed with an ASD, whereas the majority of the other half were diagnosed with significant developmental delays.²⁷ Some researchers voice concerns about overburdening systems with referrals. Others have suggested that screening over-referrals in high-risk populations are not inherently harmful, as these children tend to exhibit a higher need for remediation in cognitive, language, and academic skills.⁴⁵ Further investigation is needed, but early referrals for enrichment activities may ultimately help to increase school readiness. The reach of 2-1-1 to poor and minority populations creates a promising avenue for further exploration of developmental risk in these children and subsequent development of interventions.

Conclusion

Children with the greatest social disadvantage often do not receive early detection and intervention. This project demonstrates that even families in the midst of economic

crises are vitally interested in their children's developmental progress, willing to engage in screening, and able to follow through with recommendations for early intervention with support from a care coordinator. The findings from this research should encourage further evaluation of developmental-behavioral screening and care coordination through non-emergent crisis call centers.

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