

Barriers and Facilitators to ACEs Screening in a Medicaid Serving Pediatric Clinic

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Abstract

Background

"Adverse Childhood Experiences" (ACEs) capture childhood adversities related to abuse, neglect, and household dysfunction. Many experts have advocated for the integration of social risk screenings alongside ACEs in primary care settings. In California, the Pediatric ACEs and Related Life Events Screener (PEARLS) expands on the original ACEs screener by incorporating social risk factors. The PEARLS screener has been implemented in Medicaid-serving institutions as part of the "ACEs Aware" initiative in 2021. Despite these advancements, the ACEs screening process, including key components like service referrals and referral utilization, remains poorly understood. This study aimed to explore the facilitators and barriers for screening, referring, and utilizing referrals for ACEs.

Method

Qualitative research conducted with eight focus groups (four in Spanish, four in English; N = 40) with caregivers of pediatric patients who completed the PEARLS screener and received an external or internal referral at an urban safety-net clinic. Transcripts were evaluated using thematic analysis.

Results

Three main themes were identified: 1) Collaborative Communication and experiences with caregivers, indicating that caregivers prioritized empathetic, bidirectional communication. 2) Structural referral barriers, and 3) timely Service Connection and Care Coordination. Caregivers do not perceive the screening process itself as significant; their primary concern was access to referrals and resources.

Introduction

Adverse Childhood Experiences (ACEs) comprise acute and chronic traumatic events, adversities, and household dysfunction experienced in childhood that compromise health and well-being into adulthood (Felitti et al., 1998). Data collected from 2015 to 2017, estimated that 61% of adults have experienced at least one type of ACEs and 15.6% experienced four or more ACEs (Bethell et al., 2014; Merrick et al., 2019). During the COVID-19 pandemic, close to 73% of youth experienced at least one ACEs with 8% reporting four or more (Anderson et al., 2022). Studies indicate that throughout the pandemic, children and youth experienced exposure to various toxic stressors such as loss of loved ones, illness, parental job and financial instability, social isolation, parental substance use, mental health, intimate partner violence, and other traumatic events (Araujo et al., 2021). Racial and ethnic minority children and adolescents bore the brunt of the pandemic as they faced the aforementioned exposures along with unique stressors related to racial and socioeconomic disparities (Camacho & Henderson, 2022). In the aftermath of the pandemic, pediatricians' roles are evolving and going beyond their traditional roles as

clinicians to now include referrals and resource linkages to mitigate the effects of the pandemic on ACEs.

In response the American Academy of Pediatrics (AAP) and Centers for Disease Control and Prevention (CDC) have recommended social risk screening be done alongside early detection for ACEs within primary care settings (Bethell et al., 2017; Hughes et al., 2017; Loveday et al., 2022; Shonkoff & Garner, 2012). In California, the Pediatric ACEs and Related Life Events Screener (PEARLS) screener was implemented in Medicaid serving health systems to measure original ACEs domains along with social risk factors as part of the “ACEs Aware” initiative during the COVID-19 pandemic (Koita et al., 2018). The underlying principle behind the administration of the PEARLS in a Medicaid-serving pediatric clinic was to connect families to resources given the substantial demand for social determinants of health (SDH) and mental and behavioral services.

However, studies have shown challenges with patient-to-provider communication and low referral uptake following positive ACEs screenings (Dumke et al., 2024; Loveday et al., 2022). While ACEs screening may improve how well clinicians identify ACEs, further research is needed to understand the process of screening for ACEs in Medicaid serving institutions. This study aims to explore the facilitators and barriers for screening, referring, and service utilization for ACEs in safety-net settings. Findings will provide recommendations to address the ACEs among vulnerable populations in Medicaid-serving clinics.

Methods

Research Design

This qualitative research conducted eight focus group discussions within a Medicaid-serving, pediatric clinic to explore experiences with ACEs screening, service referrals process, and service utilization as part of the California’s ACEs Aware initiative between February and July 2021. Focus groups were selected because collective dialogues foster a supportive environment for discussing sensitive, stigmatized topics such as trauma, family stress, and economic insecurity among safety-net patient populations. Each focus group lasted about 60 minutes.

Study Participants

The researcher team consisted of bilingual (Spanish-English) facilitators, predominantly comprising racial and ethnic minority women with personal or professional experience with safety-net and Medicaid serving health system. This shared background facilitated cultural attunement, rapport and linguistically responsive facilitation during focus group discussion. Researchers accommodated monolingual Spanish speakers by conducting four focus groups in Spanish and four in English, with a total of 40 participants across both languages. To maintain methodological integrity investigators maintained reflexive field note, documented analytic decisions and conducted peer debriefing sessions after each focus group.

Participant Selection And Recruitment

Utilizing purposive sampling, a pediatric primary care clinic serving Medicaid patients was selected to administer the PEARLS screener prior to annual wellness examinations in Spring 2021. Caregivers were eligible to participate in this study if they were: 1. the parents or legal caregivers of children ages 0–17 seen for a wellness checkup at a Pediatric primary care clinic at an urban safety net teaching hospital in southern California, 2. received and completed the PEARLS Screener for their child (or the child completed it themselves if ages 12–17), and 3. the primary care provider referred the family to a resource external to the clinic to address the child's social, mental, developmental, or behavioral needs. Caregivers received a \$60 gift card in exchange for their participation.

A discussion presentation and guide were developed by the lead PIs and research team. The discussion presentation explained the ACEs screening process when the PEARLS screener was completed. The PEARLS screener is a 17-item pediatric ACEs screening tool developed for use in primary care settings (Thakur et al., 2020; Ye et al., 2023). The screen included the ten original ACEs categories, plus related life events, including bullying, community violence, discrimination, family separation, low family cohesion, caregiver death or physical illness, food insecurity, and housing instability. Each of the 17 items was dichotomized as yes (score = 1) or no (score = 0). The presentation included images and questions to assist in recalling experiences, explained key concepts—Stress, Trauma, and Coping—and provided time for questions. The next steps involved having caregivers recall the time they completed the PEARLS screener, the discussion they had with the health provider, and the referrals they received to see healthcare professionals in the hospital or to external agencies. The last step reminded caregivers that their child might have had a follow-up appointment with a healthcare professional or an external agency. After reviewing the PEARLS screening process completed by participants during their primary care clinical visit, the focus group facilitator used the discussion guide to facilitate a deeper conversation about the facilitators and barriers related to the ACEs screening process, service referrals, and how referrals are utilized (Table 1). To ensure accuracy of statements, the facilitator summarized main points and repeated them back to caregivers.

Data Collection

The PEARLS screener was provided in English and Spanish. As part of routine clinical care and quality improvement, independent of this study, the clinic ACEs lead generated a monthly report of families eligible to participate. After receiving the IRB approval, families who consented to be contacted and met the eligibility criteria (n = 112) were invited by telephone to participate in the study approximately 0 to 4 months subsequent to their initial referral. Of the 112 individuals invited, 40 participated in the focus group. (Fig. 1).

Analysis

Before conducting the focus groups and analyzing the data, Principal Investigator J.M. provided research assistants (A.M. & M.G.) with comprehensive training on qualitative research methods. This training covered key aspects, including note-taking during focus groups, qualitative data analysis using Braun and Clarke's thematic analysis, and navigating the qualitative data analysis software, Dedoose. The data was transcribed, organized and analyzed using Dedoose (Dedoose, www.dedoose.com).

Following the completion of all eight focus groups and several weeks of training, the research team independently reviewed an initial transcript to familiarize themselves with the content and identify meaningful data. This process allowed research assistants to ask clarifying questions and refine their analytical approach. Given that most coders were bilingual in Spanish and English, each coder was responsible for analyzing at least one translated transcript. After analyzing the Spanish transcriptions, the team generated an initial set of codes to enable cross-validation across transcripts. This facilitated discussions to identify both established concepts and emergent, unanticipated patterns within the data.

Through this iterative process, a codebook was developed that underwent multiple iterations to refine codes, revise, compare and reduce themes. To assess its reproducibility, interrater reliability was evaluated, revealing a 90% agreement across all identified themes. The finalized codebook provided a foundation for confirmability and facilitated transferability of the findings as illustrated in Table 2.

Results

Over a 6-month period, we conducted eight focus group discussions. Each group consisted of five participants, for a total of 40 participants in the study. Based on the discussions, we identified three major thematic domains: facilitating collaborative communication and experiences with caregivers, managing service referrals, and ensuring timely service connection and care coordination. Most themes captured consistent codes related to facilitators and barriers in the ACEs screening process within a Medicaid-serving institution (Table 2).

Collaborative Communication and Experiences with Caregivers

Caregivers did not consider the ACEs screening significant; rather, they prioritized meaningful conversations with healthcare providers. Caregivers reported being more likely to engage in referrals and resources when their interactions with providers were positive. These conversations were characterized by compassionate and easily digestible information regarding their child's health. This process involved providers and clinical staff establishing bidirectional communication, allowing caregivers to ask questions, collaboratively explore solutions to their child's health, and engage in service referrals. Receiving information or materials in their preferred language contributed to building rapport between caregivers and providers. *"The medication classes that was totally different quite enlightening okay all medication versus new medications and I was quite impressed with the information that I got out of there."*

"There's a special program that's free for everyone its called [Pullums] -poems- music program in [Leimert]- Limerick- park and the kids can do dance, theatre, singing, learn how to play an instrument, and they also travel.

Caregivers appreciated when the clinical staff took that extra step to ensure their social needs were met. *"If you're struggling financially there's programs to help you financially"*

A respondent noted that *"one day the doctor asked us what we needed other than --independently of the health services and all of this. He said if we need anything else at home or if everything is fine. And I told him we needed assistance at home, she sent an email or something like that to the resource office and they contacted me to tell me specifically where the food banks were, the specific place where I was going to go, and that was a great help."*

With my son's pediatrician, he is always attentive and he tries to help and make everything easier for us, with the pharmacy. He has always tried to help me, in addition to what refers to, well, to the medical situation, he has also asked questions and wanted to know if we are okay in the other aspects.

There are also certain barriers pertaining to the communication process, particularly concerning linguistic differences: *"Since I don't speak English it's also a bit frustrating because sometimes like when you go to the consultation they give you one -- I mean, it's more difficult when you talk through the phone to a physical person not being there. And it is true that sometimes it does help you because you don't understand English, but it's a little frustrating when sometimes your doctor doesn't speak your language".*

Service Referrals Barriers

Caregivers expressed greater interest in accessing resources and being connected to referrals rather than focusing solely on the ACE screening process. Caregivers showed a preference for being linked to resources within the medical center rather than being referred to external resources. Most caregivers felt that the familiarity with the facility and the communication with doctors better facilitated the referral process internally. Caregivers noted that when medical staff dedicated time to helping them schedule appointments, establish a warm handoff, and provide reminders, they were able to successfully connect with service referrals and resources.

However, a source of frustration was the lack of referral follow-up. The majority of caregivers voiced frustration over inconsistencies in follow-up for referrals, both internally and externally. A caregiver explained that *"[Doctor said] "I am going to refer her to have an electro," and they never made an appointment for her and they gave me an appointment back with her pediatrician but they never made her the electro until one day my daughter got sick and I had to take her to the emergency room and that was the way they did it."*

Another participant expressed: *"my baby was born premature, and I was keeping up with my baby's speech. The doctor made -- I don't know if they made a referral. I don't know if they contacted the Regional*

Center, but all they did was give me a website where I could search the organization. I don't know if that's the procedure that has to be followed or if the doctor has to send something to the organization that has to help my son"

Several factors contributing to the lack of follow-up included: Instances where a referral or appointment was promised but never materialized, referrals being lost or overlooked, resulting in no subsequent follow-up, delays in the delivery of referrals, leading to prolonged periods between submission and scheduling of services by referral agencies, and providing parents with contact numbers for referral agencies without offering assistance or coordination in accessing care.

Timely Service Connection and Care Coordination Key for Referral Utilization

The utilization of referrals improved when timely connections to services were established, and appointment reminders were provided. Caregivers highlighted various effective strategies, such as reminder phone calls, texts, or communications before appointments, follow-up checks to confirm successful referrals, proactive outreach from health staff, facilitating coordination of multiple visits in one day or one location, and expediting referrals. For instance, for one family that recently experienced a traumatic event found value in receiving appointment reminders via text messages. They particularly appreciated a single comprehensive visit to the hospital, during which they consulted with an endocrinologist, psychologist, and nutritionist. They explained that they *"ended up getting a notification in the mail notification via email and through my phone and this was for the nutritionist and also...they ended up having us meet the nutritionist, the diabetes doctor and everyone all at the hospital and we were able to meet with all three of them that same visit. And it was really nice, because each of them came and started talking with my daughter..."*

However, caregivers voiced frustration over extended wait times before their children could see a provider at the Pediatrics clinic or the lack of referral services. *"I once asked in Harbor but they told me they don't give therapy to children So then I asked them to please if they knew of any other hospital, clinic where I could take her, they said yes but they have never called me."* Caregivers noted that the clinic's operations did not consider their work schedules and other commitments. *"I've missed appointments only because of that I there's i'm a mother of three and it's really hard to sometimes work last minute around the schedule"*

Some parents suggested that the medical center could enhance its scheduling system by arranging staggered appointments for multiple children within the same day or for a child with diverse needs.

Discussion

Although caregivers did not perceive the ACEs screening process to be significant, their primary focus was on being connected to referrals and resources. Communication between health providers and

caregivers facilitated the uptake of referrals. Studies have seen an increase in accessing referred services when health providers engage in positive discussions with caregivers following an ACEs screening (Bodendorfer et al., 2019; Garg et al., 2019). Research has consistently shown that effective communication between providers and patients enhances health outcomes. However, despite the expansion of ACEs screening across healthcare systems, there is no consensus on its clinical use, including how to interpret results. This represents a significant gap in the patient-provider relationship that requires more rigorous research, as communication style, trust, and relational safety influence how patients disclose traumatic events (Finkelhor, 2018; Kim et al., 2020; Sharkiya, 2023). Additionally, the provider-patient or family relationship is a critical factor in developing trauma-informed care interventions. Strong, trust-based communication is essential for implementing trauma-informed strategies, which have been shown to improve outcomes related to adverse childhood experiences (Azamar-Alonso et al., 2019). Therefore, enhancing provider-patient interactions is crucial in the pathway of improving healthcare outcomes through the adoption of trauma-informed care systems and referral services. Research has repeatedly shown that effective communication between provider and patient improves health outcomes (Sharkiya, 2023). More rigorous research is required to examine the impact of the provider-patient relationship on the ACEs screening process.

Issues due to follow-up prevented connections to dire resources. Effective ACEs screening is valuable because follow-up and linkage to services happen after the initial screening. While screening can detect risks, many patients do not access necessary behavioral health and social support due to barriers at structural, organizational, or relational levels (Bodendorfer et al., 2019). These follow-up failures are caused by mechanisms such as fragmented services, workforce shortages, and limited time in primary care settings, which hinder follow-up processes, as well as poor coordination between clinical and community partners that reduces opportunities to connect families with needed support after screening (Dumke et al., 2024). One aspect of these inefficiencies involves the inability to deliver services and resources in a timely manner (Machtinger et al., 2024). Recent studies have shown that referral uptake is low after screening for ACEs, in particular, for referrals related to social determinants of health (SDH) like housing and food (Ticknor et al., 2026).

The underlying principle behind the administration of the ACEs in a Medicaid-serving pediatric clinic was to connect families to resources given the substantial demand for SDH and mental and behavioral services. In general, there is no clear direction on the timing and strategies for referring families to resources following a positive ACEs screening (Machtinger et al., 2024; Ticknor et al., 2026).

As we reconsider strategies for optimizing the administration of ACEs screenings in Medicaid-serving institutions, establishing an efficient referral system with a feedback loop becomes not only essential but also an urgent priority. This multifaceted system should be incorporated in the electronic health record (EHR) system, so health professionals get prompted to provide intervention. Part of this system should include various communication channels, such as appointment reminders via text messages or phone calls in multiple languages, to enhance care coordination and ensure timely access to services.

This will ensure that those with high ACEs scores are immediately connected to services and resources without any unnecessary delays.

Study Limitations

It is important to acknowledge the limitations of our study. We specifically focused on caregivers whose children attended Harbor-UCLA medical center, which introduced a selection bias. The sample was further limited to those with internet access and technological literacy, adding to the selection bias. The sample size was small, with only forty participants attending eight focus groups, averaging about five participants per group. Most caregivers reported being unable to participate due to the lack of focus group availability. One limitation of online focus groups is that they may reduce the amount of information shared by participants. Additionally, technical issues like sound delays with online platforms and internet connectivity can disrupt the flow of the discussion. There was a significant waiting period between the time the ACEs screener was administered and when caregivers were invited to participate in focus groups. This could have potentially affected the caregivers' ability to recall the ACEs screener when questioned about the assessment process. These limitations underscore the need for additional research to explore parents' attitudes and experiences with the ACEs screening process. The PEARLS screener relied on self-reported responses, which are prone to social-desirability bias. Finally, given that this study was primarily focused on generating a hypothesis, future research is needed that focuses on hypothesis testing with more rigorous designs.

Conclusion

This study demonstrated the importance of having resources available when screening for ACEs. When providers established open lines of communication, caregivers were more receptive to engage in referrals and resources. However, issues with referral processes and inefficiency contributed to caregivers limited engagement with these resources. As we prepare for the post-pandemic mental and behavioral needs of children and youth, establishing an efficient and effective referral system becomes not only essential but also an urgent priority in Medicaid serving healthcare systems.

Abbreviations

ACEs

Adverse Childhood Experiences

PEARLS

Pediatric ACEs and Related Life Events Screener

SDH

Social determinants of Health

Declarations

Consent to Participate and Consent to Publish

The study protocol was reviewed and approved by the appropriate Institutional Review Board (IRB) from the Lundquist Institute at Harbor-UCLA Medical Center. Written informed consent was obtained from all participants before participation in the focus groups. Participation was voluntary, and participants were informed that they could withdraw from the study at any time without consequences. Caregivers received compensation for their participation.

All participants provided informed consent for the publication of de-identified data. No personally identifiable information is included in this manuscript.

Competing Interests

The authors declare that they have no known financial or non-financial competing interests that could have appeared to influence the work reported in this paper.

Author Contributions

Author 1 conceived the research question and designed the methodology.

Author 1, Author 2, Author 3 conducted the data collection.

Author 1, Author 2, Author 3, and Author 4 conducted the thematic analysis.

Author 5 reviewed and edit the manuscript

All authors reviewed the manuscript and approved its final version

Availability of Data and Materials

Due to ethical restrictions and participant privacy, the full interview transcripts supporting this study are not publicly available. Anonymized excerpts are available from the corresponding author upon reasonable request and completion of a data access agreement.

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Tables

Table 1
Focus Group Presentation Stages and Discussion Guide Questions

Steps	Discussion Guide Questions
1. Presentation of the PEARLS tool and screening conducted during the clinical visit	"We want to know about your experience as a parent who cares for a child that sees a doctor at primary care clinic. We want to know what some barriers and challenges are you face when speaking with to your child's doctor during the process of taking the PEARLS Survey". Was it easy? Challenging? Why? Did you get stuck in any step? What happened? What went well?
2. Evaluation of experiences with the health provider	"You discussed the info with your child's doctor (and possibly a social worker or psychologist) in the same clinic": What has been your experience taking your child to primary care pediatrics clinic? Was it easy? Challenging? Why? What could have gone better? What support you wish you would've received from your medical doctor?
3. Evaluation of the referral process navigation	Your child's doctor referred your family to another person or organization (for example, a mental health organization) What happened? What could have been done differently to improve the outcome?
4. Follow-up and appointment with a healthcare professional or an external agency	"You may have set up an appointment with another person or organization". What happened?
5. Evaluation of family resources and needs	You or your child may have met with someone from another organization to help your family cope with stress. I will now show you a list of helpful resources. Please choose 2 or 3 that would help your family cope with stress and tell us why you made the selection. "What do you think would get in the way of your family using these helpful resources and why?" "Money, transportation, language, lack of childcare, work hours, location hours, stigma, etc.?"

Table 2
Facilitators and Barriers from the Thematic Analysis

Themes	Facilitators	Barriers
Collaborative communication and experiences with caregivers	● Bidirectional communication ● Asking questions and exploring solutions together ● Use of caregiver language ● Evaluation of social needs	● Financial support to assist to the screening process. ● Language barriers
Service referrals barriers	● Assistance with scheduling appointments and reminders	● Lack of referral follow-up and coordination of services ● Culturally and Linguistically Inappropriate ● Discrimination/stigma ● Financial restrictions
Timely service referrals and care coordination for referral utilization	● Verification of successful referrals ● Ability to arrange several visits in a single day or location	● Long wait times at the pediatric clinic before their kids could see a provider. ● Transportation ● Work hours restriction: Clinic appointments conflict with work schedules

Figures

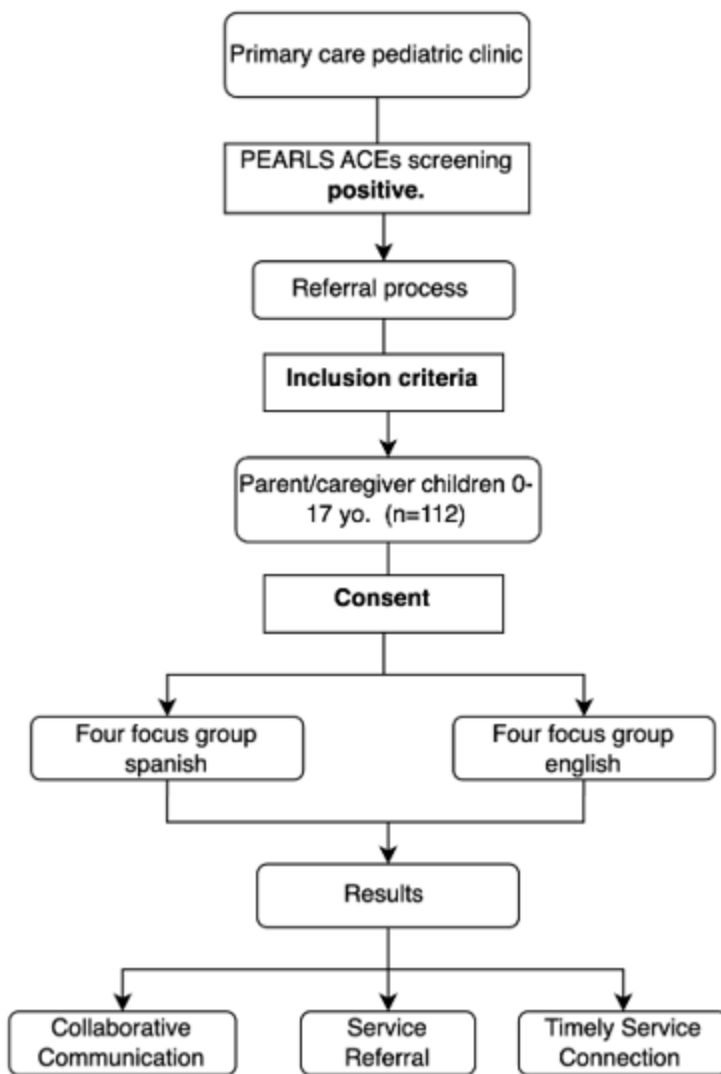


Figure 1

Screening process and selection.