

# **Screening Adolescents for Adverse Childhood Experiences (ACEs): INCORPORATING RESILIENCE AND YOUTH DEVELOPMENT**

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# INTRODUCTION

**A**pproximately half of all adolescents ages 12-17 in the United States have experienced at least one Adverse Childhood Experience (ACE).<sup>1</sup> These experiences can have profound detrimental effects, including increased risk for poorer physical health and learning and behavioral issues during childhood and adolescence, and depression, substance abuse, chronic illness and shorter lifespan in adulthood.<sup>2</sup> Adolescence provides a key window of opportunity to ameliorate the short- and longer-term impacts of trauma and adversity, positively altering the life course trajectory. However, despite high prevalence rates of trauma and an increasing awareness of the importance of addressing ACEs, screening for ACEs in adolescent health care settings remains inconsistent.<sup>3</sup>

In this practice paper, we examine the current literature on ACEs and ACE screening with adolescents and summarize findings from qualitative research conducted with adolescent health providers and adolescents to understand their perspectives on this topic. Based on this examination, we provide recommendations for adolescent health providers to effectively implement ACE screening with adolescents.



# BACKGROUND

## What Are ACEs?

Adverse Childhood Experiences (ACEs) are adversities experienced in childhood and adolescence that have also been linked to serious health and social challenges in adulthood, including chronic illnesses and decreased life expectancy. ACEs were initially identified in a landmark 1998 study by the Centers for Disease Control and Prevention (CDC) and Kaiser Permanente.<sup>4</sup> ACEs identified in the landmark study included physical or emotional abuse or neglect, sexual abuse, households with intimate partner violence, substance misuse or dependence, mental illness, parental separation or divorce, and an incarcerated household member.<sup>5</sup>

## Prevalence of ACEs Among Adolescents

ACEs are prevalent in the United States, yet current data on national estimates of prevalence among adolescents (ages 10-19) are limited.<sup>6</sup> According to the 2019 National Survey of Children's Health, an estimated 42% of youth ages 6-11 and 50% of adolescents ages 12-17 have experienced at least one adverse event from a list of nine childhood adversities.<sup>1</sup> Additionally, the data and literature regarding ACEs in youth indicate that the prevalence is higher among certain sub-groups, including those who identify as female; non-Hispanic Black and Latinx; lower household income; and lesbian, gay, bisexual, and transgender.<sup>1,7-11</sup>

## ACE Screening Tools for Adolescents

Medi-Cal, California's Medicaid program, covers 40% of all children in California, and one in three individuals overall.<sup>12</sup> Half (50%) of all individuals covered by Medi-Cal are Latinx, 19% are white, 10% are Asian and 9% are Black. Among beneficiaries, 62% speak English and 32% speak Spanish. Children and youth ages 0 to 20 comprise 42% of Medi-Cal enrollees.<sup>12</sup> In California, all children and adolescents who qualify for Medi-Cal benefits by income (up to 226% of Federal Poverty Level) are eligible, regardless of citizenship or immigration status.<sup>12</sup> Health care providers screening adolescents for ACEs need to respond to the rich cultural and linguistic diversity of young Californians.

To receive Medi-Cal payment for conducting ACE screenings, clinicians in California must use the Pediatric ACEs and Related Life-events Screener (PEARLS) with children and adolescents ages 0-18.<sup>13</sup> The PEARLS tool includes a screening for ACEs (Part 1) as well as a screening for additional adversities (Part 2). For adolescents, two versions of the tool are available: 1) [PEARLS adolescent tool](#), for ages 12-19, to be completed by a parent/caregiver; and 2) [PEARLS for adolescent self-report tool](#), for ages 12-19, to be completed by the adolescent. Clinics can be reimbursed for yearly screening of children and young adults under age 21. Either the PEARLS or the Adult ACE screener may be used for 18- and 19-year-olds and the Adult ACE screener should be used for





20-year-olds.<sup>14</sup> The Adult ACE screener is based on the landmark study by Kaiser Permanente and the CDC.<sup>4</sup> Both the adult and pediatric versions of the screener contain the 10 questions about ACEs from the landmark study. The PEARL screener has an additional section with nine questions about community violence, discrimination, and other social determinants of health (SDOH).

### **Screening Adolescents for ACEs: Provider Perspective**

Screening adolescents for ACEs and providing appropriate interventions for the “dysregulated biological stress response and the concomitant long-term changes in physiology” of toxic stress can improve child and family health and wellbeing, reduce the transference of intergenerational adversity, and reduce long-term costs of the health impacts of ACEs.<sup>2,15</sup> Pediatric and family practice providers (physicians, nurse practitioners, physicians assistants) are well suited to screen for ACEs yet most clinicians do not routinely screen for ACEs due to perceived barriers.<sup>16-18</sup> According to results from the American Academy of Pediatrics (AAP) Periodic Survey, only one-third (32%) of pediatricians ask about any ACEs during visits and even fewer (11%) reported being familiar with the original ACEs study.<sup>16</sup> Pediatricians who believed

in the influence of positive parenting skills on child wellbeing, that they themselves could positively impact the parenting skills of their patients’ parents, and that the screenings were within their scope of practice were more than twice as likely to screen for ACEs.<sup>16,17</sup> The most common ACEs inquired about included maternal depression and parental separation/divorce.<sup>16</sup>

Perceived barriers to screening among pediatric clinicians include time constraints during visits, lack of relevant training, challenges with reimbursement, discomfort discussing trauma, the view that screening for ACEs is beyond their expertise and should be conducted by mental health professionals, and feeling underprepared to address positive screens and provide resources for effective interventions.<sup>18-20</sup> However, recent research suggests that screening for ACEs is not typically a time-consuming process and, when offered training on trauma-informed care, providers’ willingness and comfort with screenings increase.<sup>18,19</sup> Additionally, research shows that ACE screening is associated with high patient satisfaction.<sup>21-24</sup> However, this research has not been conducted with adolescents, and adult studies do not specify whether results for younger adults (through early 20s) differ from those for older adults.

## Screening Adolescents for ACEs: Adolescent Perspective

For adolescents, a primary concern about ACE screenings is confidentiality. The importance of confidentiality to adolescents has been well documented,<sup>25,26</sup> and is supported by California law for behavioral and sexual health services. Assurances of confidentiality from health care providers are critical for increasing adolescents' willingness to disclose information about their mental health, sexual health, substance use and comfort in seeking health care in the future. Teens are more willing to disclose sensitive information if screening occurs apart from their parents/guardians.<sup>27</sup> However, in a recent study only half of adolescents had time alone with primary care providers (PCPs) and discussed confidentiality with those PCPs.<sup>28</sup> Percentages of adolescents whose visit included time alone with a PCP are highest for white females (62%) and African American males (53%), and are lower for Latinx females (50%) and males (41%), and African American females (55%) and white males (51%).<sup>28</sup>

Adolescents have expressed confusion about the purposes of ACE screening, expressed beliefs that ACEs primarily impact mental health, and report receiving little information on the association of ACEs with physical health problems.<sup>29</sup> Studies suggest that aggregate-level reporting of ACEs, in which a summary score option is provided to allow the adolescent to avoid disclosing specific traumas, may also increase adolescents'



acceptance of screening while posing a separate challenge in reducing providers' ability to provide targeted interventions in response to specific experiences.<sup>30,31</sup>

## Rationale for Adolescent-Focused Screening Practices and Further Research

Given the potential for positive impact on health throughout the lifespan,

early screening and detection of ACEs can be an important part of comprehensive care.<sup>32</sup> Adolescents have unique perspectives and experiences that must be addressed during clinical visits. Research indicates that caregivers (parents, guardians, etc.) respond positively to screening of their younger children for toxic stress and adversity, and discussing results with them.<sup>33</sup> However, less is known about the acceptability to adolescents and providers of such screenings and best practices for conducting them.<sup>3</sup>

Presently, there is limited evidence to direct ACEs data collection in primary care practices that serve adolescents, such as pediatrics, adolescent medicine, and family practices, and further research is needed to identify screening approaches that are feasible, acceptable, accurate, and actionable for this age population.<sup>34</sup> This paper aims to identify ways to implement developmentally and culturally responsive ACE screenings and follow-up using feedback from adolescents and adolescent health care clinicians.

# QUALITATIVE STUDY TO INFORM ADOLESCENT SCREENING

## Methodology

**T**he aim of our study was to obtain feedback from health care providers and adolescents on how to implement developmentally and culturally appropriate ACE screenings and follow-up. We conducted individual interviews with providers and focus groups with adolescents. Our study was approved by the Institutional Review Board of the University of California, San Francisco.



### Health Care Provider/ Administrator Interviews

We conducted Zoom interviews with 14 adolescent health care providers (10 in California and four in other states) who were considering their organization's ACE screening efforts. Our recruitment letter specified that we were interested in talking with providers working with low-income and immigrant adolescents. Participants were recruited through postings on listservs of adolescent health care providers, referrals by providers to other potential study participants, and other word-of-mouth strategies. We recruited more than one provider per institution, when possible, to capture a range of viewpoints within each setting. Each interview participant received

a \$25 gift card for their time. All interviews were recorded through Zoom, with permission of the participant, and transcribed.

Of the 14 stakeholders interviewed, nine had been screening for ACEs between three months and 10 years, and five (including two outside California) were not currently screening adolescents for ACEs. Four were designated site champions for implementing ACE screening in their respective institutions. We included a variety of providers who were or were not yet screening for ACEs to increase the usefulness of this study for those just beginning their efforts to implement ACE screening. We aimed to incorporate insights from providers and sites with ACE screening experience, including those who have provided trainings (champions), while also developing a set of recommendations



that respond to perceived barriers among those providers who previously have hesitated to engage in screening.

Most health care practices that screened for ACEs used the PEARLS. The others used the traditional ACE screen,<sup>4</sup> with their own additional questions about social determinants of health (SDOH). Many practices incorporated pre-existing questions about resilience that they had created themselves or borrowed from other settings.



### Adolescent Focus Groups

Two focus groups were conducted with adolescents and young adults in English via Zoom. Each focus group was ethnically and racially diverse and included adolescents from immigrant families. Participants ranged in age from 13 to 21 and were recruited through referrals from individuals working in adolescent health care and social service settings. We obtained verbal permission from all adolescents and, for those under age 18, their parents or guardians. We recorded the focus groups with permission of all participants. All participants received \$30 gift cards for their time.

### Data Analyses and Reporting

We analyzed the interview and focus group data using Atlas ti version 9 software. Coding was conducted using grounded theory methods<sup>35</sup> and emerging themes identified.<sup>36</sup> Preliminary analysis informed continuing data collection, and individual interviews were discontinued when data saturation was reached—that is, when no new themes or codes emerged. Codes and emerging themes were compared and discussed among investigators and research associates.

We have not identified individual providers or adolescents in the quotes below in order to preserve their confidentiality. In sections with multiple quotes, each quote is from a different participant unless noted. We did not identify health care providers by role (such as nurse practitioner or physician), as we found that opinions and insights about screening for ACEs did not differ across disciplines. We occasionally report the kind of setting a participant works in to help with context.



# QUALITATIVE STUDY FINDINGS

## Provider Perspectives

### Provider Experiences Can Impact Screening Implementation

Providers' own experiences and training impacted their attitudes about and openness to incorporating screening in their practices, particularly among those who had not yet started screening adolescents for ACEs. Those who were not screening for ACEs noted greater concerns about adolescent acceptance of the screening, especially if questions were felt to be too invasive, or if they were seeing a highly traumatized population:

*"I think that with screening, we miss opportunities for universal education. We also do not acknowledge that for many, many of the young people I serve, they have had to narrate their stories in a particular way in order to get services."*

The providers who were not screening for ACEs expressed additional concerns. First, they anticipated that adolescents' parents might find some of the SDOH-related questions invasive. Additionally, providers were worried that ACE screening would disrupt the organization and flow of the clinic schedule, adding extra time to each visit. They also expressed reluctance to conduct screenings in the clinic setting, if good referrals or back-up services were not available.

*"If there were evidence-based measures for what to do with the positives and the scales that are higher, that would be great. I would love to send that referral or do that modality or whatever. I know it's not one size fits all. I wish money was thrown at that, the response. If this will be part of that, that'll be great."*

Third, some resisted incorporating screening into practices when they felt that they had inadequate input into how screening would occur and how to deal with issues raised (once the "Pandora's box was opened"). They all emphasized the importance of training all staff—from front-line intake workers to providers—in trauma-informed care and the purpose of screening before beginning to implement ACE screening.

Direct provider experience with ACE screening offers insights regarding how to best incorporate screening to maximize acceptability and safety. First, stakeholders across all types of health care providers and settings who are screening for ACEs and SDOH are generally positive about the changes that screening has brought to their clinical care.

*"I think over time I've come to realize that just administering the screening and having that conversation is a form of addressing it. Creating the space to have a discussion with the patient is, in a lot of cases, most of what is needed."*



This provider, who worked in a county health system, went on to say that it was “challenging” to institute the SDOH part of the PEARLS. “We’re administering that in places where we don’t have social work and some other supports. That remains a challenge, but not the actual ACE screener itself. I think just the conversation that opens up with the provider is 90% of the therapeutic value of it.”

Despite this belief in the power of creating a supportive space to discuss adversity with adolescents and families, some providers did have concerns about screening without having adequate behavioral health or community resources to address responses to screening.

“I do think that’s actually an issue somewhat with the social determinants of health part of the PEARLS as well. That’s not really [our pediatric clinic’s] problem per se, it’s a much larger societal problem. We don’t have good infrastructure for resources for families who are socio-economically disadvantaged.”

Second, developing skills for transforming screening into trauma-informed care cannot be done without adequate provider capacity. Overall,

providers stressed the transformative nature of incorporating trauma-informed approaches and the importance of fully training the entire clinic staff and all clinicians in principles of trauma-informed care.

“What I will share with you is that our trauma-informed care program really started out as a workforce training program, where we wanted our workforce to interact with our patients in a more empathetic way. Particularly, when there’s difficult patient interactions, patients becoming upset, angry, frustrated, showing up late, or things like that.

What I quickly learned is that it was insane of us—as in leadership—to think that our workforce can deliver this highly empathetic, very caretaking type of care to our patients if they didn’t feel that leadership was treating [our workforce] in an empathetic and caretaking way. We call that ‘parallel process’ in the mental health world. We really shifted to having to change the environment of our practices to make them more trauma informed...for our patients, but also for our employees.”

Stakeholders also stressed that training staff and rolling out an ACE screener was a slow process that required significant time investment. Some clinics applied for grants to support the training time. Many clinics designated “champions” on their staff to assist with the rollout. These champions coordinated and sometimes provided the trainings, then followed up with emails containing videos and other resources that could be shared with patients about the impact of ACEs. They worked with front-desk staff and medical assistants to develop scripts to explain the screening procedures. Many started small with one clinic pod, or one age group, or even one or two providers, and checked in with providers, medical assistants, and front desk staff at least every week to see how the rollout was going. One provider, who was not a champion herself, stated:

“I was really impressed because we’ve rolled out plenty of screeners before, that are very heavily dependent on our medical assistants. The particular people in charge of that training are excellent, they’re great and super well organized. I think they knew where other rollouts had failed, so they really tried to make this work.”

Third, in addition to training staff and clinicians, some clinics also developed handouts for adolescents and their families, explaining ACEs and their impact, linking to videos about ACEs and stress-reduction as well as related apps. They noted that practices needed to consciously make decisions regarding whether to screen the teen only, the parent only about their adolescent’s experience, or both.

Several different viewpoints were expressed among champions who were interviewed regarding where to place the emphasis in screening:

### **Screening adolescents only:**

“The question is really, ‘Is the person impacted by what’s happened to them?’ I think it’s more powerful coming from the person who had the experience than a parent making an assumption about the person (their adolescent).”

### **Screening parents only:**

“The reason we ultimately decided to have the parent do it is because according to the biology of toxic stress, there are experiences that particularly infants and young children before the age of three may have been exposed to, which actually have a disproportionate impact on the development of their brain, and potentially on their long-term trajectory, but that they may not remember, because they were too little, but it actually had a physical impact on them. In part for those reasons, we chose to have parents complete the ACEs [screener], even if the child was an adolescent.”

### **Screening adolescents and parents:**

“We had a lot of back-and-forth discussion about this, the reason being that if we screen just the teen and there’s a positive screen, something comes up on that, then how do you go back and explain to the parent, ‘Oh, by the way, we did the screening, this came up, your child has been abused, et cetera, et cetera’? That puts both the teen and the parent and us in a very difficult position.”

Seven of the nine providers who had experience screening for ACEs used the PEARLS. The others used the original ACE screener,<sup>41</sup> including one institution outside California that used the Health Leads toolkit<sup>37</sup> to screen for SDOH and a mental health clinician in California, who was screening before the PEARLS was available.



## Challenges and Advantages of Implementing the PEARLS during the COVID-19 Pandemic

At the height of the COVID-19 pandemic, study stakeholders reported that many clinics prioritized in-person visits for younger children who needed vaccines and surveillance of rapid developmental changes, rather than in-person adolescent visits. This meant that they saw few adolescents face-to-face in clinics, but also that they had more time to spend in planning how they were going to incorporate the PEARLS into subsequent adolescent visits when these visits were made available again.

Before COVID-19, adolescents and parents in several health care organizations would both fill out confidential screeners in the waiting room, which raised concerns that parents had viewed or even filled out the adolescent's screener. However, because of social distancing protocols during COVID-19, teens were roomed immediately without their parents, and filled out PEARLS and other screeners by themselves.

Some clinics screened for ACEs only at in-person visits, while others assigned a medical assistant to call the adolescent for all psychosocial screenings, including the PEARLS, and enter the responses into the medical record. Then the provider would call for a follow-up telehealth visit within 30-60 minutes. De-identified ACE screening was preferred, but stakeholders acknowledged that it was difficult to do via telehealth. By Spring 2021, most clinics had returned to a regular in-person clinic schedule. Ironically, providers are struggling to incorporate the PEARLS into a regular 20-minute adolescent visit, as compared to the far longer telehealth visits allocated during the pandemic. One provider and screening champion stated, "We did get positive feedback from parents. I think they appreciate being asked about this. It's doable when we don't have 26 patients on our schedule." But even she was concerned with how to balance the value of screening and educating parents and teens with the stress it would put on a full schedule.



## Challenges Incorporating the PEARLS into Busy Clinic Schedules

Providers struggled to incorporate ACE screening into their regular clinic schedule. Several voiced the same concerns as the provider below:

“The way our visits are structured is basically all visits are 20 minutes, including well-child checks, which is pretty challenging. I struggled to get through our teen visits pre-ACEs in 20 minutes unless they have absolutely no health problems and are not sexually active. Unless they say no to absolutely everything I ask, there’s going to be something that’s going to push us past the 20 minutes, so it’s hard to incorporate [ACE screening] into an already packed visit without it feeling like an afterthought, and it often opens discussions that really require some time and some care and thoughtfulness.”

Others reflected that even before ACE screening, adolescents would often bring up issues that required extra time, and that it was “worth it to go ahead and invest that time to spend with that particular patient.”

Some providers had issues with the questionnaires themselves. Although she understood the rationale for de-identified screening of adolescents in allowing respondents more autonomy to disclose traumas, the provider below found that the de-identified screen was harder to address efficiently.

“... you don’t know what they’ve scored on. All you know is that they have some ACEs. I’m like, ‘Everyone has ACEs. How is this at all helpful?’ You can’t really negotiate. Then you have to have a bigger conversation, which is fine, but it is just time-consuming that you don’t know like, ‘Well, are they ACE because they’re having food insecurity or because there’s mental illness in the home?’ I don’t know what their ACEs are and so you have to pry to get that out or you do a blanket, ‘Okay, well, we have services.’ It just feels a little bit more generic.”

The same provider expressed frustration at what she called “screening fatigue.”

“I have so many questions that at the end they’re like, ‘No. No. No. I’m fine. I’m fine. Let’s just get to this visit.’ That’s more of what I’m worried about. I’m worried more about the validity of the self-report because of so many screens.”

Her concerns were echoed by several providers, including an ACE screening champion in another institution:

“I think the biggest barrier with the tools that we have right now is that there’s so much overlap, there’s so much repetition. I wish there was one standard screen that we could do that addresses everything in a thorough way.”

One overlapping tool brought up by several providers was the Staying Healthy Assessment (SHA), which is a yearly requirement for patients who are covered by Medi-Cal.<sup>38</sup> Like the PEARLS, the SHA asks about exposure to community violence, parental substance abuse, and histories of physical and sexual abuse.

## Providers' and Adolescents' Concerns Regarding Assuring Medical Record Confidentiality

Recent policy changes, including the 2021 implementation of the Cures Act Final Rule and its requirement of open notes in the electronic medical chart, have raised additional concerns about maintaining adolescent confidentiality about sensitive disclosures.<sup>39</sup> The Cures Act was originally written to ensure that patients, their various health care providers, and health researchers would have access to electronic medical records across institutions. Little attention was paid to its impact on adolescent privacy and confidentiality rights.<sup>39</sup> California has among the most robust confidentiality protections in the nation, giving adolescents not just the right to consent to sexual, reproductive, and mental health care without their parents, but also the right to control the release of their confidential records.<sup>40</sup> However, with the opening of the medical records of children and adolescents under age 18 to their parents, health care providers have to actively protect documentation of confidential care during each confidential visit, in order to comply with California Law.<sup>39</sup> “My Chart” is a portal through which adolescents could potentially message their providers securely. However, a recent study at Stanford found that in over half of the teen applications for My Chart, the email given to Stanford was the parent’s, not the adolescent’s.<sup>41</sup>

In addition to the concerns about release of sensitive records to parents, providers report that adolescents expressed worries that the information placed in their chart would follow them for years to come, impacting future interactions, even if they have been resolved. This includes not only confidential issues, such as mental health diagnosis, past abuse, or sexual behavior, but other health status, such as their weight. In response, some stakeholders reported that in their practices

the ACE screen is hidden and not available on Open Notes, and that the “My Chart” function is turned off for adolescents ages 12-17. Several providers reported that they were concerned about the potential impact on the provider-adolescent relationship if patient information is inadvertently disclosed.

One provider, interviewed shortly after her clinic instituted Open Notes, stated that clients asked her, “Can you take the child abuse code out of the chart?” The provider agreed that the ongoing presence of a history of child abuse in the chart was stigmatizing.

*“They don’t want it in there. It’s what we’re going to do with that information that I just want to protect it for them, and not let it become this big thing that becomes flagged and put in people’s chart and passed on from whoever to whoever. As much as we try to protect health information, I don’t think we can.”*

Providers also expressed that it was important to set the stage for the screening, “normalizing” the idea of screening for ACES to help their patients feel that they were not specifically pulled out for this type of screening. One champion stressed how important it was to discuss this issue with clinic staff and to provide scripts for talking with families about the screening.

*“Because if the parent or the teen asks the MA [medical assistant], why are we are asking these questions, they can say, ‘Oh, we want to ask, we ask everybody. This is part of your checkup,’ and they can just normalize it instead of saying, ‘Why are you just asking me?’ Training up your workforce, I think, really helps.”*

Finally, it is important to recognize that confidentiality can go both ways. One clinic that was screening both parents and teens for ACEs found that the parental scores were in some cases higher than the teen's, due to early childhood family issues that parents had not shared with their adolescent.

## **Importance of Focusing on Resiliency Along with ACE Screening**

Many providers expressed the need to ask teens and parents about strengths and coping mechanisms, as they felt uncomfortable asking only about past traumas and risk factors. They felt that the lack of resilience questions within the PEARLS was problematic. As one provider put it, “We lose the opportunity to tell them that this isn’t just all bad. You can overcome these ACEs. The purpose of the screening is not just to identify, but to help improve, to help you overcome these, and we lose that without the resilience questions.”

Noting that there were no standard resilience questions, they either asked parents and teens open-ended questions about the teens’ strengths, or used some of the questions below:

- “Does your child bounce back easily when something doesn’t go their way?”
- “What are your favorite qualities about your child?”
- “Do you feel like your child handles stress well?”
- “Do you feel like you can bounce back easily after illness?”

Observing that parents and teens often don’t write anything in a questionnaire about the teen’s strengths, they might add in conversation something like, “You didn’t write anything here and I know you must be good at something or feel proud of something about yourself. Let’s talk about that.”

In addition to talking about strengths, a few providers from larger health organizations talked about the importance of addressing toxic stress to mitigate its impact on the developing brain of children and adolescents. One organization developed extensive handouts with QR code links to videos about toxic stress and mindfulness for both parents and adolescents. Others noted that addressing social determinants of health with resources and referrals could help reduce adolescent and family stress levels.

Overall, most providers who are screening for ACEs feel that the screening allows them to deliver trauma-informed care, even if limited resources exist for providing or referring for mental health and other services.

## Adolescent Perspectives

**E**ach focus group had four participants. One group had a mix of youth from Northern and Southern California, and one was a group of Northern California youth who participated in the same after-school program. Most of the youth in the focus groups had spent time with their providers during a health visit without their parents in the room (“time alone”), except for one 13-year-old in each focus group, who had not yet experienced confidential time during a health visit. The Zoom format did not allow for confidential demographic questionnaires. However, we learned through consent discussions with youth and their parents that each focus group contained at least one immigrant youth.

When asked at the beginning of the focus group if they had heard about ACEs, all stated that they had not. All focus group participants, except one, had filled out questionnaires in their primary care visits, but only two youth in the second focus group had filled out the PEARLS, which they did not know by name, but recognized once the PEARLS was shared on a Zoom screen. Youth in one focus group liked the directness and clarity of the PEARLS, but youth in the other group found the questions intrusive and in one instance “triggering.” Two youth who had filled out the PEARLS in their check-ups stated that they were not told in advance why they were being given the questionnaire, and the primary care providers who saw them did not ask them about their results on the screener.

*Areas of agreement* between the focus group participants included:

- Youth need to feel trust in a provider and safety in the setting in order to fill out the screener “completely.”

- Adolescents noted that providers engender trust and safety through a variety of behaviors, including showing genuine interest in the adolescent, rather than trying to just “check the boxes” with a questionnaire:

“Then I also think sometimes when you’re filling out a questionnaire, some kids might want to avoid a question because they’re like, ‘I don’t want to talk to my provider about that,’ or ‘I don’t want to deal with the provider being insincere’ ... It depends on your provider and how comfortable you are with them, but I know my primary healthcare provider, doctor, it’s awkward when she talks about mental health because it feels very insincere, social, like, ‘You’re feeling sad sometimes?’ Like that. It’s patronizing, and so sometimes, I don’t want to bring that up with her, I don’t want to deal with that.”

They noted that having a provider who is willing to reveal something about themselves helps to build a level of trust so that the adolescent has some idea of the person they were engaging with during the visit.

“What I’m trying to say is that sometimes I don’t want to tell my mom something, but I can tell my doctor because with my doctor I’ve established a relationship, and where we can just like talk about like, ‘Oh, how was your day? How was your week? What did you do? How was your trip?’ Just normal things like that.”

Another useful strategy suggested by youth was having the provider explain in advance the purpose of the questionnaire and asking permission to give the questionnaire. Furthermore, providers were seen as more respectful and authentic when they asked the adolescent if they wanted to talk about the results, as well as responding to the content of the questionnaire.



All youth who had experienced any kind of psychosocial screening agreed that “time alone” with a provider was important and an essential element for feeling comfortable in the visit. Some youth talked about preferring to be screened for ACEs in schools, as they had enough contact with school and school clinic personnel to know whom they would trust and whom they would seek out if they were having a problem, versus a primary care provider they saw once a year or less.

One of the strengths of qualitative research is the ability to elicit multiple voices and explore disparate answers. Areas in which youth across and within the two focus groups *did not all agree* regarding completing a PEARLS screening in a health care setting include:

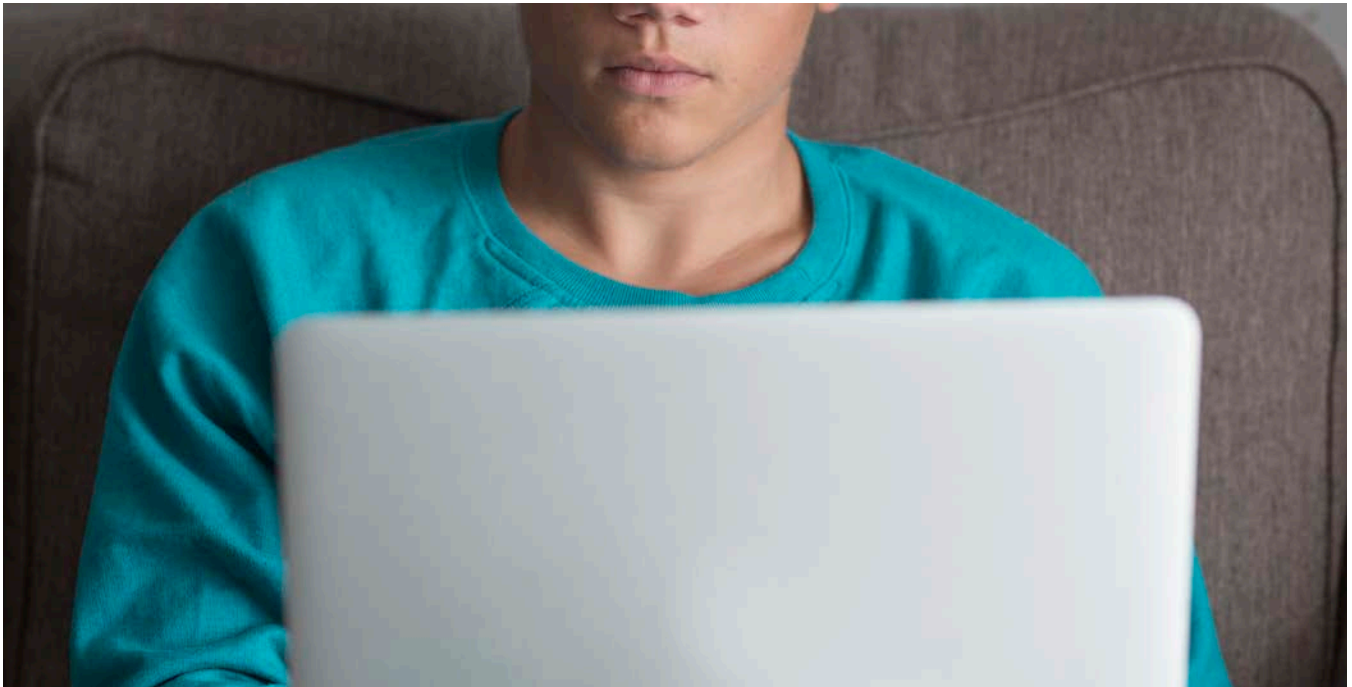
- **Screening preferences:** Some youth prefer to complete a paper or form on a computer screen, while others prefer to have someone read it to them, perhaps reflecting a literacy and comfort level with paperwork, which some youth said they did not enjoy.
- **Perceptions regarding whether they find the questionnaire clear and direct (positive) or intrusive (negative):** Youth in one focus group found the question about having an incarcerated parent invasive and worried about being judged: “That question, I feel like that would make them, I don’t know, probably have a different opinion about you or something. They’d probably think a different way like how you were raised or something or stuff like



that basically. They will see you differently.” Additionally, youth in that group talked more about their worry about themselves or their family being judged for what they said. One participant also felt that she wouldn’t necessarily answer the question about sexual abuse to a “regular person.”

Youth in the other focus group thought that the questions in Part 2 about SDOH would be easier to fill out and would reflect community issues rather than issues in the family.

“I do feel that these questions are not better, but they don’t cause the same amount of concern as the other ones. As you mentioned, this is for a community. This isn’t ‘What is your household like?’ To these questions, I think that there will be no problem with these. But again, just asking the patient or whoever it is like, ‘What would you like to do? Do you want me to be in the room? Do you want anyone to be in the room, or how much time do you need?’”



→ **Who should be the appropriate screener?:**

Some youth think only therapists should ask these questions, as they see primary care providers as taking care of their body and therapists as taking care of their minds. This opinion may reflect a gap in knowledge about the impact of stress on physical health and may also reflect an issue with the quality of primary care that they have previously experienced.

→ **Trust in how collected information would be used:** Teens in one group expressed more concern about what providers would do with the information they had disclosed. In our diverse focus groups, teens who were particularly concerned about this issue were from immigrant families.

“They ask you basically the troubles and stuff that you went through in your life, and stuff that you currently have problems with or had problems with. I think that if you had been through most of those things, they may not treat you differently, but have a different opinion on you. You could have a certain type of personality. After they find out all the stuff about you, they’ll be like, ‘Oh, that’s why you got that type of personality.’”

When asked what providers could do to help them feel better, several young people suggested that clinics should help establish and encourage peer support groups. They also suggested the health care providers “should keep a positive attitude.”

“Maybe try to keep them in a positive mentality first. Also, keep reassuring them that it’s completely okay for that to have happened to you. Keep reassuring them that it’s okay for them to feel those emotions. They shouldn’t feel weak or put down in any way because of what they feel.”

# LINKING THE PERSPECTIVES OF PROVIDERS AND ADOLESCENTS

## Summary and Recommendations

**A**s reflected in the perspectives of providers and adolescents captured in this study, a variety of strategies will likely help set the stage for more effective and youth-centered ACE screening, particularly for ethnically and racially diverse adolescents. Both groups pointed to the importance of assuring confidentiality and emphasizing the value of setting the stage for why the screening is occurring, how the information may be used, and having the opportunity to discuss screening findings. Providers were particularly sensitive to the importance of capacity building across all individuals working in clinics, so that every staff member is attuned to the importance of trauma-informed care. Providers and adolescents noted the importance of time alone opportunities in which communication could occur more openly. While there was some disagreement regarding whether the teen or the teen's parent or both should complete the screen (given that some ACES may have been experienced long before the adolescent could be aware of it), there was strong agreement that the screening should occur separately and privately.

Providers tended to be more sensitive about the potential burden of screening, particularly if resources are not readily available for any needed follow-up services and referrals. They did note that even if these services were not available, just identifying the presence of an issue and bringing it into the open had therapeutic value. Others noted that some of these issues do come up even without formal screening and need to be responded to as part of quality care. There was also strong commitment to emphasizing the strengths and assets of the adolescent along with identifying any trauma as part of screening. Providers were also sensitive to adolescents who were concerned about how information in their electronic medical chart would “follow them,” even if the issue was resolved.

Based on the findings of our qualitative study, we offer the following recommendations for providers implementing ACE screening with adolescents in health care settings:

✓ ***Assure active engagement of providers in providing input into screening protocols and determining ways to assure successful integration into clinic/practice flow.***

Providers felt that it was important for them to have a voice in shaping how the screening would take place, how it would be introduced to the adolescent and their family, and how the information would subsequently be used.

✓ ***When providing clinician and staff training, emphasize the importance of addressing toxic stress.***

The purpose of ACE screening is to open a conversation with adolescents and families about trauma and toxic stress that they may have experienced, and to offer interventions to mitigate potential changes to neuroendocrine, epigenetic, immune, and metabolic systems. *The Roadmap for Resilience: The California Surgeon General's Report on Adverse Childhood Experiences, Toxic Stress, and Health* recommends supportive relationships, quality sleep, balanced nutrition, physical activity, mindfulness practices, experiencing nature, and mental health care as needed.<sup>2</sup> Even when providers do not have adequate referral resources, they can play an important role in treating toxic stress through supportive conversations, handouts, and web links about these strategies. Providing these strategies to all adolescents and families does not necessitate knowing which specific ACEs the adolescent has experienced and can be helpful even when the adolescent or their caregiver is reluctant to disclose past or ongoing adversity.

✓ ***Engage in capacity building of direct providers and all other staff members who interact with adolescents.***

Interview participants all emphasized the importance of training all staff, from front-line intake workers through providers, in trauma-informed care and the purpose and utility of screening. They also acknowledged that providers and staff themselves may have experienced ACEs, thus needing an opportunity to address their own trauma reactions and contribute to creating a healing-centered work environment.

✓ ***Integrate ACE screening into clinic flow with other mandated screens, such as depression, substance use, SDOH and the Staying Healthy Assessment.***

A benefit of ACE screening can be opening up a trauma-informed discussion and increasing alliances between families and their primary care providers.<sup>42</sup> The timing of screening and its integration into the clinic workflow may also need to be considered if the provider is establishing a trusting relationship with the adolescent that may help them feel more comfortable in disclosing personal information. Overall, there is also a need to ensure that the information gathered is not a burden on the adolescent, their parent or guardian, or the provider themselves, while also committing to using the information gathered as part of the visit. Although previous literature has indicated that screening for ACEs is not typically a time-consuming process, providers in this study reported mixed perspectives on this aspect. Thus, implementation of screening needs to take into account the perceptions regarding provider and practice setting. It may also be useful for funders, such as the State Health Department, to help assure that screening tools being used are aligned and not duplicative in effort (e.g., PEARLS and Staying Healthy Assessment).



✔ ***Establish a clinic protocol for introducing and explaining the purpose of the screening.***

Assess whether the adolescent prefers to fill out a written or computer format or have the screening be read aloud as a means of assuring that the adolescent's level of literacy is not an additional data collection burden. The Center for Community Health and Evaluation (2019) recommended investing in patient relationships as a key element to assure more successful ACE screening: "Clinics should invest in training staff on how to administer the assessment and developing scripts." The report also recommended "pairing ACE screening with efforts to assess patient strengths and resiliency factors."<sup>43</sup> As a means of increasing adolescent acceptance, both adolescents and their caregivers should have the opportunity to complete screenings, if possible, as there can be differences in responses.<sup>30</sup> It may also be important to provide the adolescent with sufficient privacy to enable them to disclose personal information without sharing it with their parent or guardian.

✔ ***Maintain adolescent confidentiality and share with the adolescent any limits to confidentiality, given the Cures Act and open files.***

Ensure that adolescents can fill out the de-identified screen and develop an adolescent handout that has confidential resources. Providers generally need to affirmatively sequester confidential discussions in the electronic records as they write, so they will not be released in an after-visit summary or appear in Open Notes. Advocate for these protections to help the clinic comply with California's robust adolescent privacy protections.

✔ ***Ensure that sensitive information collected during ACE screening is not used to stigmatize youth and families.***

Provider, family, and adolescent concerns about access to sensitive information—ranging from Child Protective Service reports to parental or teen histories of incarceration, and immigration or foster care status—will remain barriers to effective screening unless all are assured of the rationale for collecting this information, any potential repercussions of this information, and control over its release. As ACEs disproportionately affect Black and Brown communities, it is particularly important that screening is a way to combat rather than add to structural racism.<sup>44,45</sup>

✔ ***Engage in an assets-based discussion of screening results, the long-term impact of toxic stress, and healing measures with adolescents, incorporating each of these issues into trauma-informed care.***

Teach adolescents healing, resilience, and coping skills in developmentally appropriate terms. Providers have an opportunity to help the adolescent identify personal strengths and resilience that have helped them cope with the ACEs they might have experienced. The AAP recommends asset-based adolescent psychosocial screens, rather than risk-based discussions, to engage teens.<sup>46</sup> Thus, as part of or complementary to PEARLS, providers should identify a consistent approach for helping their clients identify strategies that have shaped, and can continue to shape, their recovery from ACEs-related experiences.



✓ **Identify clinic and community resources available for follow-up if needs are identified.**

Given that there may be a variety of needs, it is important for clinics to review and assess how appropriate and youth-friendly referral sources in the community are and to assist the adolescent and their family in accessing care. An important part of the referral strategy is following up to ensure that visits have occurred, adequate funding mechanisms exist, and other barriers, such as transportation and childcare for younger siblings, have been dealt with.

✓ **Engage parents/caregivers in supporting their adolescents' healing and growth, particularly in light of inter-generational transmission of ACEs and the trauma experienced by the adolescent and their parent.**

While providers are first and foremost concerned about their adolescent patients, they also need to recognize that adolescents' families continue to play an important role in the lives of their patients. While the providers may play a secondary role, they can be a trusted ally to support a family dealing with a variety of trauma-related experiences. Use of telehealth or other types of interactions by telephone may also be helpful supplements to face-to-face visits. Clinic resources, such as written materials and videotapes, may also be useful and informative for both the adolescent and their family.

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