

# Addressing Social Context in Adverse Childhood Experience Screening Policy: Implications for Children With Special Health Care Needs

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Adverse childhood experiences (ACEs) disproportionately affect children with special health care needs, especially racial and ethnic

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minority children whose ACEs may be less likely to be identified. As awareness and understanding of the health impacts of ACEs have increased, heightened by the COVID-19 pandemic, several areas of the United States have initiated policy efforts to screen for and address ACEs. However, these policies do not always include mechanisms to account for context-specific adversity or contemporary stressors in the lives of children. Stressors most significant in a child's life may include adversities beyond those included in common ACE screening instruments. ACE policy in California will be discussed relative to addressing the social context in ACEs screening. By taking a holistic view of ACEs and thinking beyond deriving ACE scores alone, clinicians can ensure that ACE-related policies are implemented with maximum benefit to diverse children with special health care needs. *J Pediatr Health Care.* (2022) XX, 1–4

## KEY WORDS

Adverse childhood experiences, Health policy, COVID-19, Children with special health care needs

## INTRODUCTION

In the United States (U.S.), an estimated 1 in 5 children has a special health care need, defined as children who have or are at elevated risk for a physical, developmental, behavioral, or emotional disorder that may be chronic and require health services across the life course (McPherson et al., 1998). This population of children is affected uniquely by adverse childhood experiences (ACEs), which are traumatic or stressful events that occur before 18 years old in a child's household (Felitti et al., 1998). There is a dose-response relationship

between the number of ACEs a child experiences and risk for developing a special health care need, as well as a greater risk for accumulating additional ACEs among children who already have a special health care need (Kan et al., 2020).

ACEs are strongly predictive of morbidity and mortality across the life course, as they may result in toxic stress that dysregulates biopsychosocial function and increases the risk for disease (Grummitt et al., 2022; Shonkoff et al., 2012). Racial and ethnic minority (herein minoritized) youth with special health care needs may be more likely to go without treatment despite reporting high levels of ACEs (Finkelhor et al., 2021). Given the growing interest in addressing ACEs in policy in the U.S., it is essential to ensure that policies are responsive to the changing context in which children with special health care experience adversity, including the context of the COVID-19 pandemic (Finkelhor, 2018). We provide an overview of contemporary social context considerations for ACE screening, an example of policy efforts in California to address ACEs, and recommendations for clinical management of ACEs in light of existing ACE policy.

### WHY CONTEXT MATTERS FOR ACE SCREENING

In recent years, racial and or ethnic disparities in COVID-19 illness and mortality and high-profile police killings of unarmed Black individuals have shed light on unique ACEs that children from diverse communities might encounter (Claypool & Moore de Peralta, 2021; Loe et al., 2021). These adversities may include exposure to police violence, increased xenophobic racism, and immigration-related trauma or forced parental separation (Cheng, 2020; Choi et al., 2019; Loe et al., 2021). In addition, children from communities that disproportionately experienced COVID-19-related mortality may have unaddressed grief and traumatic loss (Fitzgerald et al., 2021). These contextual ACEs related to racism and emerging societal inequities may be especially relevant to children with special health care needs, as these youth are also more likely to identify as non-Hispanic Black and live in poverty, which may exacerbate the number and types of ACEs (Ghandour et al., 2022). Racial and ethnic minority communities of children with special health needs may be more likely to be underidentified for treatment, perpetuating well-documented disparities in health service access for minoritized youth (Alegria et al., 2010; Lau et al., 2012). It is critical to implement ACE screening with attention to a child's social context to capture the range of adversities experienced by children with special health needs and identify children needing intervention.

### EMERGING SCREENING POLICIES FOR ACES

Given the known burden of ACEs on public health, health care providers have a growing interest in identifying and addressing ACEs in childhood to mitigate the long-term harm of adversity and toxic stress (Pardee et al., 2017). Several states have even legislated policies to screen for ACEs among children to address a preventable cause of illness (Cooper & Hanlon, 2020). Although there are efforts in

multiple states to implement trauma-informed care and trauma response resources for children, the State of California has been the most direct in developing policies for ACE screening. Under SB 428, California's Medicaid program reimburses ACE screening for children, adolescents, and adults when approved screening instruments are used (e.g., Pediatric ACEs Screening and Related Life Events Screener [PEARLS]) and providers are appropriately trained (California Legislative Information, 2021). California has invested significant resources in developing trauma-informed care systems and resources to support ACE screening and response. The Nation Governors Association and the National Academy for State Health Policy have recommended the development of a common, statewide language and lens for approaching ACEs and increasing access to ACE screening in a trauma-informed, coordinated manner (Haldar et al., 2021). As such, several states are now following the lead of California as it pertains to ACE screening or has considered adopting the PEARLS as a state-supported screener (Haldar et al., 2021).

### MOVING BEYOND ACE SCORES

Although these policy efforts represent a major step forward, California's ACE screening policies have received criticism, such as insufficient provider training on how to assess and respond to ACEs appropriately; insufficient mental health system capacity for evidence-based trauma treatment; and a lack of consensus on how to screen, what to screen for, and what constitutes a positive screen (Campbell, 2020; Finkelhor, 2018). In addition, there is limited consideration for contemporary stressors that may be relevant to the diverse racial and ethnic demographic makeup of Californian youth. The PEARLS, used in California for Medi-Cal reimbursement for ACE screening, assesses 10 types of abuse, neglect, and stressful household experiences derived from the original Centers for Disease Control and Prevention-Kaiser ACE study conducted in the 1980s (Thakur et al., 2020). It also includes items screening generally for bullying, discrimination, housing instability, food insecurity, parental separation, death of a parent/caregiver, and serious physical illness/disability of a parent/caregiver. These adversity items are counted and summed into an overall ACE score that is then used for clinical risk stratification and behavioral health referrals (Thakur et al., 2020). However, there are several key potential issues regarding the screening process and classification scores for ACEs with the PEARLS. Although all ACE items in the PEARLS are counted the same, evidence suggests that not all trauma or adversity experiences are equivalent (Amaya-Jackson et al., 2021). Trauma and adversity are related and can overlap, but they are clinically distinct constructs that become conflated in the ACE scores, which do not give us information about the severity, frequency, harm, developmental timing, or impact of events. They also do not capture traumatic stress or behavioral symptoms related to adversity or functioning (Amaya-Jackson et al., 2021).

One key area in which clinicians may build on ACE scores derived from instruments supported in policy, such as the PEARLS, is by considering the cultural context for marginalized youth. Although the PEARLS asks broadly regarding experiences of discrimination, this is not the only form of race-based traumatic events and stressors. Examples of ACEs that are not captured in the PEARLS include vicarious experiences through witnessing police killings of Black individuals in the U.S., detainment of families at the border, and in-transit immigration trauma among Latino youth (Perreira & Ornelas, 2013; Tynes et al., 2019), all of which may lead to increased, unaddressed psychiatric comorbidity.

Given the disproportionately high levels of COVID-19 morbidity, disability, and mortality in Black and Latino communities in the U.S., assessing COVID-19-related adversity may be a priority for marginalized youth, similar to ACE screenings including HIV-related adversity in high-HIV burden countries (Alcendor, 2020). However, the inclusion of ACEs relevant to diverse communities is complicated by several challenges, such as (1) limited awareness of validated measures to assess for culturally specific adversities, (2) limited focus on cultural responsiveness and sensitivity in ACE training for clinicians, and (3) restriction of ACE screening insurance reimbursement to screening with specific instruments. Despite these challenges, the assessment and documentation of context-specific ACEs is an important endeavor. Health services use is notably lower for racial and ethnically-diverse adolescents, partially because of inadequate identification of clinical risk factors and clinician biases (Ngu & Flores, 2007). Including culturally- and contextually congruent ACEs and items assessed by the PEARLS or other ACE screeners could help mitigate this disparity.

## CONCLUSIONS

ACE screening must be congruent with the lived experiences of all individuals living in the U.S. and thus account for the growing demographic diversity of youth. Screening must also account for the reality of the profound adversity some children experienced as a result of the COVID-19 pandemic. ACE scores alone cannot give clinicians a complete picture of a child's stress and trauma experiences or point conclusively to evidence-based or contextually congruent interventions. Resolving issues around best practices for ACE screening and ensuring the cultural and contextual sensitivity of screening instruments is critical as more states adopt ACE policies and codify screening practices for which the evidence base is uncertain into law. It is important for clinicians conducting ACE screening to be aware and prepared to communicate about ACEs relevant to diverse communities and understand that deriving an ACE score from a pre-established, policy-defined set of adversities is not the end goal of screening. Rather, ACE scores may be used as a starting point to assess the most significant stressors in a child's life, which may include stressors beyond those included in common ACE screening instruments. By taking a holistic view of ACEs and thinking beyond scores alone,

clinicians can ensure that ACE-related policies are implemented with maximum benefit to diverse children with special health care needs.

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