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Building Infrastructure for Surveillance of Adverse and Positive Childhood Experiences: Integrated, Multimethod Approaches to Generate Data for Prevention Action

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Abstract

Adverse and positive childhood experiences have a profound impact on lifespan health and wellbeing. However, their incorporation into ongoing population-based surveillance systems has been limited. This paper outlines critical steps in building a comprehensive approach to adverse and positive childhood experiences surveillance, provides examples from the Preventing Adverse Childhood Experiences: Data to Action cooperative agreement, and describes improvements needed to optimize surveillance data for action. Components of a comprehensive approach to adverse and positive childhood experiences surveillance include revisiting definitions and measurement, including generating and using uniform definitions for adverse and positive childhood experiences across data collection efforts; conducting youth-based surveillance of adverse and positive childhood experiences; using innovative methods to gather and analyze near real-time data; leveraging available data, including from administrative sources; and

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integrating data on community- and societal-level risk and protective factors for adverse childhood experiences, including social and health inequities such as racism and poverty, as well as policies and conditions that create healthy environments for children and families. Comprehensive surveillance data on adverse and positive childhood experiences can inform data-driven prevention and intervention efforts, including focusing prevention programming and services to populations in greatest need. Data can be used to evaluate progress in reducing the occurrence of adverse childhood experiences and bolstering the occurrence of positive childhood experiences. Through expansion and improvement in adverse and positive childhood experiences surveillance—including at federal, state, territorial, tribal, and local levels—data-driven action can reduce children's exposure to violence and other adversities and improve lifelong health and well-being.

INTRODUCTION

Adverse childhood experiences (ACEs) are preventable,[1] potentially traumatic events that occur in childhood (age 0–17 years), including experiencing neglect or experiencing or witnessing violence. Also included are aspects of a child's environment that can undermine their sense of safety, stability, and bonding, such as growing up in a household with substance use; mental health problems (including having a family member attempt or die by suicide); or instability owing to parental separation or incarceration of a parent, sibling, or other members of the household. The landmark Centers for Disease Control and Prevention (CDC)–Kaiser Permanente ACEs Study first identified the associations between 10 types of ACEs and adult health outcomes.[2] Since then, ACEs have been linked to toxic stress responses that negatively impact healthy brain development, leading to increased risk for adverse health outcomes, violence victimization and perpetration, and reduced economic and life opportunities.[3–5] Unfortunately, ACEs are common. Almost 2 in 3 adults report experiencing 1 type of ACE, and nearly 1 in 6 reports having experienced 4 types of ACEs.[4] Positive childhood experiences (PCEs) include children having nurturing, safe relationships with parents and other adults and living in safe environments that help children to learn, play, and thrive. PCEs are another important—but less recognized—construct that may have a notable influence on healthy brain development and positive health and behavioral outcomes across the lifespan.[1,6] In addition to their direct effect on positive health and well-being, PCEs may prevent ACEs from happening in the first place[1] and could mitigate the health consequences of ACEs if experienced.[1,6]

Despite the documented impact of ACEs and PCEs on lifelong health, their incorporation into ongoing population-based surveillance systems has been limited. Data on the duration, frequency, and severity of ACEs have not been routinely collected in population-level surveillance,[7] and data proximal to the time when ACEs and PCEs occur—in childhood and adolescence—are less available. ACEs definitions have not been revised in recent decades—making their re-examination a priority to ensure that inclusion of ACEs and their measurement is consistent with recent scientific evidence[7–13]—and measures of PCEs are limited. There are also limited near real-time data available, and data to aid in the identification of disparities in ACEs and PCEs across demographic groups and geographic locations that are owing to conditions in which people live, work, and play are sparse.

Contextualizing ACEs and PCEs in the individual, relational, community, and societal environments within which they occur is a challenge.

Comprehensive ACEs and PCEs surveillance strategies that address these limitations could aid in more effective data-driven prevention and intervention efforts, including focusing prevention programming and services to populations in greatest need. Through the expansion of ACEs and PCEs surveillance—at all geographic levels—data-driven action can reduce children's exposure to violence and other early adversities and improve lifelong health and well-being. This paper's aim is to outline the steps for building a comprehensive approach to ACEs and PCEs surveillance (see Appendix Figure 1, available online), provide examples from the Preventing ACEs: Data to Action (PACE:D2A) cooperative agreement (CDC-RFA-CE20-2006; described in this supplement[14]), and describe improvements needed to optimize surveillance data for action.

DEFINITIONS AND MEASUREMENT: A CONTEMPORARY REVIEW OF THE SCIENCE

The landmark CDC–Kaiser ACEs Study[2] formed the foundation for ACEs definitions and measurement over the past few decades. The 10 types of ACEs included in the original study were developed using items from pre-existing scales.[2,7,8] ACEs literature supports that these 10 types of ACEs are, individually and cumulatively, associated with numerous poor health outcomes and risk behaviors.[3–5,15–17] However, published literature does not provide a theoretical or empirical rationale to explain why these specific types of ACEs were included in the original ACEs Study,[8] despite being widely considered impactful and important. Notably, however, these 10 types of ACEs do not comprise a comprehensive view of childhood adversities and may not adequately include some adversities—such as experiences of discrimination or poverty—that disproportionately impact some communities and contribute to health inequity.[8–13,18,19] Yet, the original ACEs comprise most ACEs measured in surveillance or research efforts.[19]

Critical to the success of improving surveillance is a commitment to a continual re-evaluation of the science to ensure that the most impactful ACEs are included in ACEs definitions and measures in the most scientifically valid, rigorous manner possible.[7–13,19] Researchers have delineated the importance of re-examining and updating how ACEs are defined and measured[7–13,19–21] and have called for more nuanced approaches to ACEs quantification.[8,13] Although individuals with more ACEs often have a greater risk for adverse outcomes,[3,4] simply counting the number of ACEs a person experienced accounts for less variance in outcomes than examining the individual contribution of specific ACEs.[22] Therefore, scientists have advocated for a host of different approaches in quantifying ACEs measures beyond the ACEs score.[7,22–27] In line with these calls, in 2021, CDC's National Center for Injury Prevention and Control funded the American Public Health Association to partner in undertaking an extensive process to update how ACEs are defined, measured, and quantified. In line with recommendations in the literature,[8] the process of re-examining what constitutes an ACE will begin by identifying conceptually relevant candidate-expanded ACEs that have been posited to be potentially traumatic experiences that undermine a child's sense of safety, stability, and bonding. The American Public Health Association will hold expert panel meetings, and together with their partners, conduct an extensive scoping

literature review that will examine the strength of the evidence between individual candidate ACEs, toxic stress, and health outcomes. Key to this process will be a careful examination of the conceptual framework related to ACEs and how these experiences differ from the social determinants of health (also often called adverse community environments).[18,19,28] Ultimately, this information will be used by CDC to identify the most impactful core ACEs (i.e., those most strongly, consistently associated with toxic stress and adverse health). Efforts will also be made to examine the evidence for how to best quantify ACEs. Re-evaluating how ACEs are defined, measured, and quantified will increase the field's rigor and comprehensiveness and have positive implications for policy and prevention.

Re-evaluating and expanding the list of ACEs and reconceptualizing ACEs measurement are not without challenges. Increasing the number of ACEs measured by surveillance systems could increase respondent burden and may have notable cost implications.[8,29] The ideal list of core ACEs would balance comprehensiveness with practicality to capture the most impactful ACEs with minimal conceptual or theoretical overlap. In addition to efforts to re-examine a core set of ACEs, the work undertaken by CDC, the American Public Health Association, and other partners as outlined for ACEs includes a similar process to create a core set of PCEs. Although some conceptual frameworks[30,31] and measures[6,32,33] of PCEs exist, more work is needed to identify the most impactful, culturally appropriate PCEs at each childhood developmental stage for inclusion in surveillance and research that are rooted in promoting safe, stable, and nurturing environments for all children and families. It is also important to recognize that re-evaluating ACEs and PCEs definitions and measurement is not a one-time activity but a continual process to ensure that measures reflect current research.

Establishing and using uniformly defined and measured ACEs and PCEs not only enables comparability of findings across studies but also facilitates the monitoring of trends over time. Optimal core surveillance would also include measures of lifetime and annual prevalence of selected ACEs and PCEs. Measuring the annual prevalence of select data elements would allow public health officials and researchers to monitor trends in core ACEs and PCEs and plan for and evaluate the impact of intervention and prevention activities. Furthermore, optimal surveillance includes detail on the age of onset, frequency, duration, and severity of experiences for certain ACEs—such as physical and sexual abuse—to enable a better understanding of how timing and severity impact health and opportunity.[13,20] Given the scope of prevention and intervention activities that may address ACEs and bolster PCEs, ideal ACEs and PCEs surveillance would collect data at multiple geographic levels (e.g., school district, county, state, national). Inclusion of ACEs and PCEs in surveillance at multiple geographic levels would not only facilitate a better understanding of these experiences in various communities but also enable effective monitoring of the impact of evidence-based prevention strategies or policies that are enacted at multiple levels.

MOVING TOWARD PROXIMAL ADVERSE AND POSITIVE CHILDHOOD EXPERIENCES SURVEILLANCE DATA COLLECTION

Although the frequency of data collection varies, all 50 states and the District of Columbia have collected retrospective data on ACEs from adults at least once between 2009 and 2020

using the Behavioral Risk Factor Surveillance System (BRFSS) ACEs module. BRFSS data have been instrumental in building momentum for ACEs science, policy, and practice across the country and in establishing an understanding of how commonly ACEs occur—and their associations with long-term health outcomes and risk behaviors. Over the past decade, the BRFSS ACEs module has delivered representative, state-level retrospective data on ACEs among adults. However, the retrospective design requires adults to report on childhood experiences—which may have occurred 30, 40, or 50 years in the past—introducing the potential for recall bias.[7,34] The BRFSS design, namely the retrospective data collection among adults when ACEs may have occurred decades before, limits the understanding of the current prevalence and incidence of ACEs, trends over time, and the ability to monitor the impact of prevention efforts in the present.[13] In addition, PCEs have not been widely collected in the BRFSS. Future surveillance efforts that focus on data collection of respondents more proximal to the experiences in question (i.e., children and adolescents) would counteract the problems of recall bias common in retrospective studies of adults[7,34] and ensure that data are more useful to inform current prevention activities. Adolescents represent an ideal population for ACEs and PCEs surveillance because they are able to consent or assent to, understand, and participate in surveys and more accurately recall and report experiences that occurred in childhood to date.[35] Adolescents may also be more accurate reporters of sensitive topics, including child abuse, neglect, and other experiences of violence, than parents.[36–41] Although there are distinct benefits to assessing ACEs and PCEs among adolescents, this youth-based type of surveillance presents challenges. It is critical to ensure that the ACEs and PCEs asked of children and adolescents are aligned with agreed-upon uniform definitions and are elicited using age-appropriate measures. This requires cognitive testing and assessment of reliability and validity of core ACEs and PCEs measures in these populations. Chief among the challenges of youth-based data collection, are those related to disclosure of contemporary experiences of child abuse and neglect, which are reportable to local authorities and have health and safety implications. Considerations for confidentiality, ethical participation, legal reporting, and safety should be integrated into any system that monitors the experiences and behavior of children and adolescents.[42]

Improving ACEs and PCEs surveillance does not necessitate the invention of a new, dedicated surveillance system. In fact, utilizing existing surveillance systems can be cost effective and efficient and ensure stability of data collection efforts. Existing surveillance systems can be adapted to collect rigorous data about ACEs and PCEs as well as relevant risk and protective factors for ACEs, including social determinants of health. CDC's Division of Violence Prevention strategy for improving ACEs surveillance includes collaborating with partners on existing federal surveys, such as the Youth Risk Behavior Surveillance System, National Health Interview Survey, National Survey of Children's Health, National Survey of Family Growth, and BRFSS. For example, the Division of Violence Prevention has begun bolstering youth-based surveillance of ACEs and PCEs by collaborating with CDC's Division of Adolescent and School Health, which manages the Youth Risk Behavior Surveillance System. In 2021, a total of 19 states, school districts, or tribal organizations applied for and received supplemental funding from CDC to add either 8 or 16 ACE and PCE questions to their local Youth Risk Behavior Surveys (Appendix Table

1, available online, and Appendix Figure 2, available online). CDC's National Center for Health Statistics, in collaboration with the Division of Violence Prevention, is cognitively testing ACE and PCE questions among middle- and high-school students to ensure that questions are valid for these populations. Fortifying ACEs and PCEs surveillance does not need to be a uniquely federal effort. State, local, territorial, tribal, and academic partners may add ACE and PCE questions to local systems. Local collection of data on ACEs and PCEs is critical given that many evidence-based prevention and policy activities take place at the state or local level.

IMPORTANCE OF TIMELY DATA COLLECTION METHODS

Although the expansion of youth-based surveillance efforts will improve the ability to monitor the burden of ACEs and PCEs proximal to their occurrence, these methods are not without limitations owing to the time lag between data collection and availability. Data on ACEs and PCEs in these data sources are often not available for analysis for 1–2 years after data collection. For some childhood experiences that are stable over time, this time lag may not hinder the ability to utilize data for prevention action or intervention service allocation. However, recent public health crises—including the coronavirus disease 2019 (COVID-19) pandemic—highlight the importance of obtaining more timely data to better understand the immediate impact of these crises on ACEs.[43,44] For example, in addition to the trauma associated with the loss of a parent or caregiver,[45] the social, educational, and economic challenges associated with the COVID-19 pandemic have been posited to be associated with a likely increase in ACEs.[46–48] In addition, early evidence from the COVID-19 pandemic suggests that—despite stressors—parents and children may feel very close to one another owing to the additional time spent together during quarantine or other COVID-19 mitigation measures (e.g., working or going to school from home).[49,50] However, there are few timely data sources available to test hypotheses about the impact of public health or other crises on ACEs and PCEs.

Although historically, the use of surveillance methods that generate near real-time data has been limited in injury epidemiology, there are examples of newer data collection mechanisms that have proven useful in recent years for timely data collection and decision making. For example, data collected as part of emergency department syndromic surveillance,[51] emergency medical services,[52] and hotline help service providers[53,54] include information that can be used to understand emergent trends in various ACEs, such as child abuse and neglect[44,53] and adult substance use or mental health problems.[43,55] Although these data sources are not ideal for robust, multifaceted surveillance or research, they can provide near real-time signals of increases or decreases in ACEs. Other timely data collection mechanisms used in public health include web panels,[56] with particular emphasis placed on those using probability-based sampling methods.[57,58] Novel methods that can synthesize complex or voluminous text, including from social media, medical records, or other administrative records, can aid in more timely, rich use of surveillance data.[59] Although not a replacement for understanding the experience of ACEs among population-based samples, innovative surveillance methods can provide additional information about current trends in ACE indicators and are an important part of comprehensive ACEs surveillance systems.

ENHANCING DATA ON THE RISK FACTORS FOR ADVERSE CHILDHOOD EXPERIENCES, INCLUDING THE SOCIAL DETERMINANTS OF HEALTH

Building an effective, comprehensive surveillance strategy should include data collection on critical risk factors for ACEs, in addition to protective factors and other PCEs, to ensure that populations with heightened ACEs burden can be identified and that disparities can be addressed through prevention and policy efforts. Expanding data collection to include the risk factors for ACEs, including social determinants of health[28] (e.g., systemic racism; economic instability; and access to quality health care, housing, and education), will provide an opportunity to contextualize ACEs and PCEs. At present, there are limited data on the unique burden of ACEs and PCEs across communities. A few studies have described the differential rates of ACEs by racial and ethnic groups, with Hispanic, Black, and other communities of color experiencing a greater burden of ACEs.[4,60–62] These disparities exist because of the economic and societal structures in which people live, work, and play.[1,3,28] Expanding surveillance infrastructure to contextualize the risk factors for ACEs and PCEs— including at state, territorial, tribal, and local levels—will ensure that data are available to understand and focus on prevention strategies to reduce inequities for all children.

LEVERAGING EXISTING DATA THROUGH THE USE OF ADMINISTRATIVE DATA SOURCES AND DATA LINKAGE

Administrative data are a rich source of information to access when building comprehensive ACEs and PCEs surveillance strategies. These data can contain substantial information about many indicators of ACEs and PCEs, with substantial cost and time efficiencies.[63] For example, many jurisdictions collect data on substantiated or reported cases of child abuse and neglect, mental health or substance abuse treatment services utilized, and contact with the justice system. It is important to recognize that these data sources often represent only a subset of people affected by an ACE (e.g., adults needing inpatient mental health or substance use treatment); however, they remain useful indicators to understand the broader burden within a community.

When feasible, information on ACEs and PCEs could be formally linked (i.e., by direct identifiers or probabilistic matching algorithms) or visually overlaid with some administrative data to provide context for risk and protective factors related to these experiences. For example, the U.S. Census Bureau's American Community Survey[64] could be linked with available data on ACEs or PCEs at multiple geographic levels to better contextualize how risk factors, including social determinants of health,[28] impact ACE or PCE exposure. American Community Survey data contain information on state- and community-level financial, housing, and health characteristics.[64] Other state and local administrative data sources may also be available that contain indicators on access to quality child care, education, health care, and social services; food stability and quality; and neighborhood safety. Administrative data that contain information on the risk and protective factors for ACEs can be linked or visually overlaid with ACEs or PCEs data to identify the geographic or demographic subpopulations at greater risk for ACEs. ACEs and PCEs data linked or visually overlaid with data on social determinants of health will better elucidate the structural inequities contributing to disproportionate ACEs burden and pave the way for evidence-based prevention strategies that address inequities.

BUILDING COMPREHENSIVE ADVERSE AND POSITIVE CHILDHOOD EXPERIENCES SURVEILLANCE: ILLUSTRATIONS FROM PREVENTING ADVERSE CHILDHOOD EXPERIENCES: DATA TO ACTION

Comprehensive surveillance strategies that include the types and sources of data illustrated in this paper can provide a compelling picture about the wide-ranging burden of ACEs, their underlying risk and protective factors (including PCEs), and insights on how to focus prevention strategies to impact those experiencing a disproportionate burden of ACEs (Appendix Figure 1, available online). However, critically important is the ability to obtain and utilize data to inform prevention strategies at the levels where they occur. The PACE:D2A cooperative agreement[14] provides examples of how surveillance strategies could be implemented to obtain the data needed to understand ACEs burden and inform prevention action. PACE:D2A recipients[14] are adding ACE and, in some cases, PCE items to the 2021 administration of their state Youth Risk Behavior Survey (or equivalent youth-based survey), which will bolster states' understanding of the prevalence of select ACEs and PCEs among adolescents. These findings will inform statewide strategies for preventing ACEs. Recipients are also tailoring prevention strategies to the needs of specific communities while maintaining alignment with the statewide strategic plan. To support data-driven decision making at the county and regional levels, county-level data are being used from other youth-based surveys, hotlines, syndromic surveillance systems, and cross-sector administrative sources as part of surveillance strategies. In addition to informing prevention, surveillance data can be used to monitor prevention strategy impact. For example, if a jurisdiction is focused on building economic supports for families through the expansion of earned income or child tax credits,[1] including data elements that monitor family economic stability can provide indications as to whether prevention efforts or policy changes have had an impact on financial stability and, subsequently, reductions in ACEs burden.

BUILDING ADVERSE AND POSITIVE CHILDHOOD EXPERIENCES SURVEILLANCE DATA FOR ACTION: IMPLICATIONS FOR PRACTICE

Although comprehensive ACEs and PCEs surveillance strategies have substantial potential to improve understanding of and ability to prevent ACEs and adverse health outcomes across the lifespan, challenges to the successful implementation of these strategies remain. In addition to broad acknowledgment and investment in ACEs and PCEs surveillance and commitment to include ACEs and PCEs in youth-based and other surveillance at local, state, and national levels, other activities are also needed to build comprehensive surveillance infrastructure capacity.

Once jurisdictions identify ACEs and PCEs surveillance as a priority, it is critical to first identify data infrastructure gaps. First, programs should conduct a surveillance capacity assessment that identifies what ACEs, PCEs, and risk and protective factor data–including social determinants of health—are available and where they are housed. They should also investigate their ability to link and integrate data and develop an understanding of the existing infrastructure for analysis, dissemination, and visualization of the data to identify the next steps for improvement.

It is important to recognize that many data sources related to ACEs and PCEs are collected by disparate agencies as part of their unique mission, which highlights the importance of building cross-sector coalitions to improve data access and sharing to bring together data across a host of ACEs, PCEs, and associated risk and protective factors. As part of PACE:D2A, recipients are required to foster cross-sector collaboration across partners to enhance surveillance and prevention capabilities. To achieve this, several jurisdictions have founded statewide ACEs data strategy workgroups with representatives from diverse state agencies. The goal of these workgroups—composed of the data owners for various data sets —is to identify gaps in available data and determine how to effectively collaborate, share, and disseminate data for the mutual benefit of the communities they serve. Data owners are present in data-use decision making to ensure that the data they maintain are used with fidelity and in accordance with their privacy and security standards. Although this is just one way to facilitate sharing of ACEs and PCEs data, it highlights the importance of cross-sector collaboration across departments of health, education, child and family services, mental health and substance use, and justice, among others, to utilize data for preventive action most effectively.[14] PACE:D2A cross-sector collaborations can serve as a model for data sharing and partnership for other states if resources are available. Jurisdictions interested in creating data strategy working groups may also consider including others who prioritize ACEs prevention within academia and school- or community-based organizations. These institutions, which may not have collaborated previously, can serve as a structural base to guide the types and sources of data needed; foster collaborations; and ensure wide and appropriate data use, dissemination, and sharing for effective data for action.

Efficient data sharing is the basis of an actionable surveillance program. A comprehensive, multisectoral surveillance strategy for ACEs and PCEs necessitates strong, broad data-sharing agreements between various agencies within a jurisdiction and between the jurisdiction and external partners. Moreover, opportunities to make data widely available and accessible should be investigated. It is important to recognize the critical need to use data and interoperability standards for efficient integration of data sources, incorporate data quality feedback loops to data providers, routinely assess needs with respect to data infrastructure, and identify mechanisms to link or visually overlay data. State health departments and other agencies would benefit from having the epidemiologic, data management, data dissemination, and health communication capacity to carry out key surveillance functions. Successful data dissemination will require data integration and visualization tools and expertise to communicate data to varied audiences, including opportunities to triangulate across data sources to tell digestible data-driven stories about the burden and impact of ACEs and PCEs and how prevention strategies may be employed to reduce risk factors in the environments in which children and families live, work, and play.

CONCLUSIONS

The comprehensive data approach to ACEs and PCEs surveillance outlined in this paper will provide an important advancement in the monitoring and prevention of ACEs by offering the ability to simultaneously assess trends and prevalence, PCEs, and contextual factors that contribute to disproportionate burdens of ACEs in some communities. Collective efforts to prevent ACEs using comprehensive ACEs and PCEs surveillance to ensure effective,

focused prevention strategies could prevent a wide range of adverse behavioral, health, and social outcomes,[1,3,4,20] reducing a large public health burden.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS

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