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Data-Driven Primary Prevention Strategies for Adverse Childhood Experiences

As states address multiple and multi-faceted challenges such as the current opioid crisis, many are realizing the need to invest in upstream evidence-based prevention strategies. Preventing adverse childhood experiences (ACEs) is a critical place to start. ACEs include childhood experiences that have the potential to inflict emotional, intellectual, and physical harm. The common denominator of all ACEs is their ability to have a profound detrimental impact on a person's long-term health and wellbeing. ACEs can increase one's risk for problems relating to behavioral health (e.g., substance use and unsafe sex), mental health (e.g., depression and suicide) and chronic disease (e.g., heart disease, cancer, and liver disease), that compound and can lead to premature death. States and territories can help prevent ACEs by enhancing protective factors and reducing risk factors through activities that support safe, stable, nurturing relationships and environments.

In this report, we define primary prevention interventions as those that prevent ACEs from occurring in the first place, rather than those that prevent problems from worsening (secondary prevention) or keep problems from inflicting long-term harm (tertiary prevention). Data-driven primary prevention approaches in public health are those that use state monitoring and surveillance data to determine which ACEs are most prevalent and, consequently, which conditions and/or outcome(s) states should target using evidence-based, primary prevention interventions.

State health leaders play a critical role in this process by promoting and facilitating ACEs data surveillance and monitoring. Surveilling and monitoring data is key to informing the state's programmatic and policy work, documenting progress and impact, setting relevant ACEs-related state priorities, and influencing policy to address ACEs prevention.

Building on the ASTHO brief "Adverse Childhood Experiences: Primary Prevention," this report:

- Highlights ACEs-related data sources.
- Provides examples of how states can use these data to inform their primary prevention work.
- Offers resources for states considering crafting data sharing agreements.
- Identifies challenges in collecting ACES-related data.



Overview

The data sources discussed below may be used independently or woven together to enhance a state's scope on ACEs and ACE-related measures. Figure 1 is a visual crosswalk of ACE-related measures cross-referenced with data sources to illustrate how states may use the sources to fill in gaps in their ACEs monitoring and surveillance and to inform their ACEs prevention programs. The green denotes ACE measures, as defined from the original CDC-Kaiser ACEs study. The core YRBSS comments discuss health behaviors that may indicate ACEs. The yellow denotes ACE-related measures, such as social determinants of health measures. This crosswalk is current as of May 2019.

Figure 1. Crosswalk of Data Sources

| ACE indicators /ACE-related indicators | ACEs BRFSS | PRAMS | YRBSS | NCANDS | NSCH | NatSCEV | Kids Count |
|--|---------------|-------|---|--------|------|---------|---------------|
| Physical abuse | | | Physical fight with parent | | | | |
| Sexual abuse | | | | | | | |
| Emotional abuse | | | | | | | |
| Physical neglect | | | | | | | |
| Emotional neglect | | | | | | | |
| Caregiver treated violently | | | | | | | |
| Household substance use | | | Youth substance use | | | | |
| Household mental illness | | | Youth mental health | | | | |
| Parental separation/divorce | | | | | | | |
| Incarcerated household member | | | | | | | |
| Caregiver financial issues/poverty | | | | | | | |
| Caregiver physical health | | | | | | | |
| Caregiver employment issues | | | | | | | |
| Housing stability/high cost burden/crowded housing | | | | | | | |
| Family or child insurance status | | | | | | | |
| Neighborhood safety/violence | | | Physical fights, bullying, carrying a gun | | | | |
| "Treated unfairly because of race" | | | | | | | |
| Food insecurity | | | | | | | |
| Head Start enrollment | | | | | | | |
| Dating abuse | | | | | | | |
| Risky sexual behavior | | | | | | | |

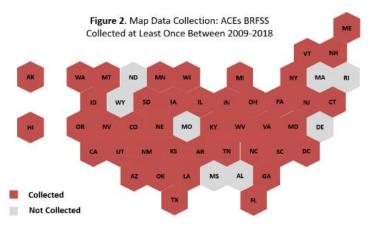


Data Sources

Adverse Childhood Experiences Behavioral Risk Factor Surveillance System Module

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual random-digit dial survey that <u>collects</u> data on individuals' health-related risk behaviors, chronic health conditions, and use of preventive services. BRFSS collects data in all 50 states DC, and three U.S. territories. vi

States may opt to add one or more optional BRFSS modules, such as the ACEs module, which includes 11 questions adapted from the original 1993 CDC-Kaiser ACE study on child abuse and neglect and household challenges. Since 2009, 42 states and the District of Columbia have included ACE questions for at least one year on their surveys (see Figure 2).

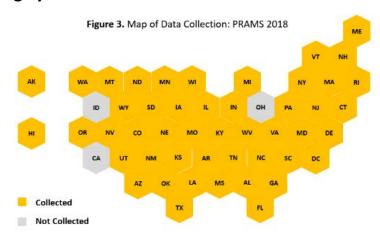


State Highlights: ACE Disparities

A Florida study <u>revealed</u> that youth in the state's juvenile justice system had much higher rates of ACEs than the original CDC-Kaiser study had predicted. Most of the surveyed youth (66%-97%) reported experiencing at least one ACE between 2007-2012, and half experienced four or more ACEs, compared to only 13 percent in the original study. The Florida study demonstrates the need for more primary prevention methods to prevent ACEs, especially with at-risk populations. It also acknowledges that current policies in child welfare and juvenile justice focus on secondary prevention and trauma-informed care rather than on primary prevention.

Pregnancy Risk Assessment Monitoring System

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a CDC surveillance project that collects state-specific data on maternal attitudes and experiences before, during, and after pregnancy. It is the only surveillance system that provides data during pregnancy and after birth. Figure 3 shows a map of current PRAMS participants. Forty-seven states, Puerto Rico, DC, and the Great Plains Tribal Chairmen's Health Board currently collect PRAMs data The PRAMs data portal includes data sets from 2000-2011. The questionnaire comprises a set of core





questions along with state-selected questions from a CDC-developed list. PRAMs core topics <u>include</u> attitudes about the most recent pregnancy, preconception care, prenatal care, Medicaid and WIC participation, breastfeeding, substance use, health insurance coverage, physical abuse, infant healthcare, and contraceptive use.

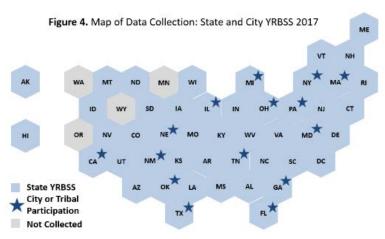
Data to Action State Highlight: Supporting Breastfeeding in the Workplace

Emerging research on breastfeeding suggests it has positive physiological effects for the mother, such as reduced maternal stress, higher-quality sleep patterns, and a reduced likelihood of postpartum depression, thus influencing maternal mood, affect, stress, and overall maternal care. Vii Secondly, supporting breastfeeding in the workplace promotes family financial stability, another protective factor against ACEs. Viii Mothers who work at organizations that promote breastfeeding are also more likely to remain employees, return to work more quickly after childbirth, and miss fewer work days from a sick child, among other benefits for the organization and family. According to the National Conference of State Legislatures, 29 states, the District of Columbia, and Puerto Rico have laws related to breastfeeding in the workplace.

CDC <u>highlights</u> PRAMS data-to-action success stories from Oregon on supporting breastfeeding in the workplace. Oregon's state health agency used PRAMS data to identify barriers to breastfeeding and worked with building managers to allow state employees to breastfeed at work. They then took the findings to the state legislature to help create a state bill that requires employers to provide space and time for breastfeeding. Breastfeeding in the workplace is one example of how to promote protective environments to prevent ACEs.

Youth Risk Behavior Surveillance System

The Youth Risk Behavior Surveillance System (YRBSS) <u>surveys</u> middle school- and high school-aged youth on six categories of health risk behaviors and experiences. These behaviors include substance use, unhealthy dietary and physical activity behaviors, mental health factors, sexual behaviors related to unintended pregnancy and sexually transmitted infections, behaviors related to unintended injury and violence, and sexual identity and the sex of sexual contacts. YRBSS includes data from 46 states, including 21 major cities (see Figure 3).



Data to Action State Highlight: Wisconsin School Wellness

School districts in Wisconsin used YRBSS data to implement school wellness initiatives. The district's coordinated school health model includes skill-based health education, staff wellness, and establishing wellness rooms in each building. The wellness rooms will be linked to positive behavioral interventions and supports as well as assist students and staff with mindfulness techniques to self-regulate and cope with stress. One school district conducts an emotional wellness screening program to detect symptoms of depression, anxiety, suicidal thinking and behavior, attention problems, disruptive behavior, and substance use.



National Child Abuse and Neglect Data System

The National Child Abuse and Neglect Data System (NCANDS) <u>collects</u> child protective services agency data from 50 states and the District of Columbia. This includes case-level data, such as characteristics of the abuse and neglect, demographics of the children involved, Child Protective Services findings, services provided, risk factors of the child and caregivers, and characteristics of the perpetrators.

National Survey of Children's Health Data

The National Survey of Children's Health Data (NSCHD) <u>provides</u> data on children's health, including social and community determinants of health, such as mental and physical health, access to healthcare, family health, neighborhood safety, and school experiences. NSCHD is funded and directed by HRSA's Maternal and Child Health Bureau and collects data from all 50 states and the District of Columbia.

Annie E. Casey Foundation: Kids Count Data Center

Kids Count is an Annie E. Casey Foundation project with sites located in all 50 states, Puerto Rico, the U.S. Virgin Islands, and the District of Columbia. The Kids Count Data Center <u>includes</u> an amalgamation of local data from each of the Kids Count state organizations, as well as state-collected data and national data sources affecting children and family well-being. (Examples of national data sources available include U.S. Census data, data from the Administration for Children and Families, and data from participants in the Supplemental Nutrition Assistance Program.) Indicators include demographics and family nativity, family economic well-being, education and test-scores, family and community indicators, health indicators, and safety and risky behaviors indicators.

National Survey of Children's Exposure to Violence

The National Survey of Children's Exposure to Violence (NatSCEV) is <u>conducted</u> by the Office of Juvenile Justice and Delinquency Prevention, with support from CDC. It documents the incidence and prevalence of children's exposure to violence. Survey topics include crime, child maltreatment, victimization (via internet, by peer or sibling, or sexual), and indirect victimization, such as witnessing violence, exposure to community violence, and school violence.

National Data Archive on Child Abuse and Neglect

Since 1988, the National Data Archive on Child Abuse and Neglect (NDACAN) has been <u>promoting</u> data exchange regarding child maltreatment. NDACAN compiles data from national sources, large-scale longitudinal data, state administrative data, and microdata from leading research and makes them available for secondary analysis. Available data sources include longitudinal studies of child abuse and neglect, national surveys on child and adolescent well-being, and the Adoption and Foster Care Analysis and Reporting System.

Data Sharing Agreements

Data sharing agreements are one way to strengthen partnerships between the state agencies that collect and analyze data. The agreements can help document how data is exchanged, merged, and managed between partners, including dealing with confidentiality issues, custodial responsibility of the data, and disposition of the data. One partnership that can benefit from a bi-directional data sharing agreement is the state home visiting program and state and county child welfare system to track home visiting participant child maltreatment outcomes. In the Pew Home Visiting Data for Performance



<u>Initiative</u>, only two of the five pilot states, Oklahoma and Kansas, were able to negotiate a data sharing agreement between their child welfare agencies and home visiting programs, partially because of preexisting memoranda of understanding. The following are available resources below may help guide states in creating data sharing agreements:

- <u>Collaboration and Cross-Sector Data Sharing to Create Healthier Communities</u> (2018): This
 toolkit aims to help states create a community information exchange to strengthen
 collaboration between health, human, and social services to address social determinants of
 health and improve population health.
- <u>Data Sharing: Courts and Child Welfare</u> (2018): This guidance document from the HHS'
 Administration for Children and Families aims to help support courts and child welfare agencies
 to create two-way data exchanges.
- <u>Intersegmental Partnerships and Data Sharing: Promising Practices from the Field</u> (2018): This
 resource is meant to improve collaboration and communication between K-12 public school
 districts and institutes of higher education.
- The Pew Home Visiting Data for Performance Initiative: Phase II Final Report on Feasibility Study (2017): This report details lessons learned and barriers for states looking to create memoranda of understanding between state home visiting programs and state/local child welfare systems.

State Data Sharing Highlights

Massachusetts State Legislation- Chapter 55

In 2015, Massachusetts established data sharing between more than 20 partners, including the state government, state agencies, academia, healthcare stakeholders, and private industry. The legislation's goal was to link, analyze, and visualize data that would guide policy decisions for responding to the opioid epidemic. The data was used to develop a <u>report</u> analyzing fatal and nonfatal opioid overdoses.

New Jersey State Legislation- Chapter 193

The <u>New Jersey Integrated Population Health Data</u> project was launched in 2015 to facilitate public health and safety data sharing between state agencies and academia. The act also established data stewardship measures that includes protocols for securely receiving, maintaining, and transmitting data.

Additional Examples of Data Use for Primary Prevention

New York State Health Improvement Goals

<u>Incorporating</u> ACEs into state health improvement priorities, strategies, measures, and benchmarks for success is one strategy state health leadership can use to prevent ACEs. In New York state's health improvement plan, preventing and addressing ACEs is a goal under the priority area of promoting well-being and preventing mental and substance use disorders. Plan objectives include:

- 1. Establishing a baseline in 2019 and increasing the reach of community resilience programs by 10 percent using data from the New York State Office of Alcoholism and Substance Abuse Services and Office of Mental Health, along with data from the New York State Department of Health.
- 2. Continuing to monitor ACEs in New York state using the ACEs BRFSS module.
- 3. Reducing reports of child abuse and maltreatment by 9 percent by 2024, as indicated by the NCANDS data.



The plan includes enhancing collaboration and establishing new partnership at the community and state levels. The state also has a related goal under child and adolescent health that focuses on enhancing children's and adolescents' social-emotional development and relationships.

Data Use Example: The Lifelong Effects of Childhood Protective Factors

In addition to using the ACEs BRFSS module, Wisconsin used a team of experts in poverty and early childhood adversity to add ACEs questions to its 2014 and 2015 BRFSS. The questions touched on topics related to child poverty and neglect and discussed factors promoting child and youth resilience. Questions included measures of positive family experiences and measures of positive relationships with friends and other adults. An analysis of Wisconsin's BRFSS data <u>found</u> that the protective factors in childhood had a lifelong effect, decreasing the impacts of child adversity.

Challenges in Data Collection

Although ACEs data collection has become more commonplace, there are still challenges related to standardization and consistency of state and local surveys and data collection methodology. There is also a lack of real-time understanding of ACE incidents. The following are challenges that states face in ACEs data collection, followed by suggestions for how states can work toward solutions.

Challenge 1: There is a lack of uniformity in the use of federally-provided survey questions like the ACEs BRFSS module, YRBS, or PRAMS. States are free to use or leave out the survey questions according to their needs; therefore, the whole module may not be used, questions asked each year may be inconsistent, and states may reword questions and, consequently, alter their validity.

• **Consideration**: Federal partners and national organizations can provide guidance and technical assistance to states, helping to clarify and guide question selection.

Challenge 2: One of the primary methods of survey collection is random-digit-dial on landline telephones, a method of communication that is becoming obsolete.

Consideration: Federal, state, and local partners may investigate relevant survey collection
processes to determine the method that is the most cost-efficient and reaches the greatest
number of participants. (For example, CDC will be testing out web-based survey collection
methods.)

Challenge 3: Most ACE data collection is retrospective. Adults are asked to recall past childhood events, which are then reported in aggregate. This method of data collection makes understanding the incidence of ACEs difficult and does not allow for real-time map creation.

• **Consideration**: Federal, state, and local partners can consider methods of collecting ACE incidents in real time, including generating timely hot spot maps. This will allow states to better understand where to focus their resources.

Challenge 4: The ACEs BRFSS module only collects data from non-institutionalized U.S. adults, leaving out institutionalized populations who may have experienced higher rates of ACEs, as was shown in the example of Florida's juvenile justice population.

 Consideration: The juvenile justice system should consider <u>screening</u> or ACEs and work in conjunction with child welfare services to provide adequate trauma-informed care and resources.



Conclusion

State health leadership has an important role to play in prioritizing the primary prevention of ACEs and ensuring that collected data is being used to guide decisionmaking to select primary prevention programs, target interventions, and develop new measures to better capture ACEs data. All 50 states, the District of Columbia, Puerto Rico, and some territories are collecting ACEs data. States are using their data in a variety of ways beyond typical surveillance and monitoring to identify health disparities, encourage wellness and protective environments in schools, improve child abuse and neglect data systems, highlight the lifelong benefits of ACEs prevention, and prioritize ACEs as a social determinant of health in state health improvement plans. As states work toward preventing ACEs, ensuring that their efforts are data-driven is a necessary first step.

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^{iv} CDC. "Picture of America: Prevention." Available at

^v WHO. "Public Health Surveillance." Available at

viCDC. "BRFSS ACE Data." Available at

vii Kathleen M. Krol and Tobias Grossman. "Psychological effects of breastfeeding on children and mothers." Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6096620/. Accessed 6-1-2019.

viii ASTHO. "Worksite Wellness: Breastfeeding Promotion." Available at

ix ibid