

Position Statement:

Social Equity In New Jersey Demands Appropriate Use of The ACE Study

The New Jersey ACES Collaborative¹ is committed to pursuing a standard of excellence in the engagement, partnering, and servicing of New Jersey residents and communities. This commitment demands we continuously review and assess the unique and comprehensive ways we provide that service. In 2019, the Collaborative released Adverse Childhood Experiences: Opportunities to Prevent, Protect Against, and Heal from the Effects of ACEs in New Jersey. This report identified five areas of opportunities for further investigation and action which include: *supporting parents and caregivers, providing training and professional development in trauma-informed care, promoting community awareness of ACEs, advancing policies and practices that help children and families thrive, and collecting, analyzing and sharing data and findings from research and practice.*²

In alignment with the findings in the ACEs report and the state's key initiatives of social justice, strength, family support, and innovation, the New Jersey Statewide ACEs Action Plan was released by the Department of Children and Families on February 4, 2021, as a framework inspired and guided by the community of people most impacted by ACEs. As implementation of the plan began, a complex question was raised: Should New Jersey conduct ACE's screenings? This question warrants a thorough evaluation of the origin, intent, and expected outcomes of the original ACEs study and ACEs questionnaire. Moreover, there is a fundamental responsibility to evaluate New Jersey's position alongside the initiatives set forth by the administration, the goals of our community, and the statewide ACEs Action Plan.

The NJ ACEs Collaborative supports the use of ACE scores for population surveillance, public health promotion, and prevention strategies. However, despite its usefulness in research and surveillance studies, the ACE score is, according to Dr Anda, a relatively crude measure of cumulative childhood stress exposure that can vary widely from person to person³. Unlike recognized public health screening measures, such as blood pressure or lipid levels that use measurement reference standards and cut points or thresholds for clinical decision making, the ACE score is not a standardized measure of childhood exposure to the biology of stress⁴. Furthermore, the ACE Study presents both strengths and limitations that require careful consideration when used outside of public health surveillance.

¹ Center for Health Care Strategies. (2019, May). Mobilizing for New Jersey's Children and Families: Preventing, Protecting, and Healing from Adverse Childhood Experiences. https://www.chcs.org/project/mobilizing-for-new-jerseys-children-and-families-preventing-protecting-and-healing-from-adverse-childhood-experiences/.

² The Burke Foundation ACEs Report. (2018, July). The Burke Foundation ACEs Report. aces-report.burkefoundation.org/.

³ Anda, R. F., Porter, L. E., & Brown, D. W. (2020). Inside the Adverse Childhood Experience Score: Strengths, Limitations, and Misapplications. American journal of preventive medicine, 59(2), 293–295. https://doi.org/10.1016/j.amepre.2020.01.009

⁴ Finkelhor D. (2018). Screening for adverse childhood experiences (ACEs): Cautions and suggestions. Child abuse & neglect, 85, 174–179. https://doi.org/10.1016/j.chiabu.2017.07.016

Unintended Consequences of Screening

In considering the question of "screening" it is important to clearly define what this means. In medicine and public health, "screening" is done to identify underlying conditions or diseases. Others use the term "screening" to refer to obtaining a history of exposure to ACEs to facilitate better relationships and trauma-informed approaches to interactions in the community. We believe that ACEs screening should not be used as diagnostic tool but to support those who have experienced ACEs⁵⁶. The Collaborative supports the latter approach for the following reasons:

- ACEs are neither a disease nor a condition but rather an intimate personal history.
 Screening risks stigmatizing certain population groups and may generate fear and reluctance to participate in services or initiatives.
- Individual ACE scores have the potential to be used for discriminatory practices, such as in employment decisions.
- The methods for obtaining ACE scores (various ACE questionnaires modeled after the original CDC Kaiser Permanente study) that are being widely promoted for assigning risk for "toxic stress" or ACE related health and social problems, cannot accurately assign risk at the individual level.
- "Assignment" of individuals into services using ACE scores will necessarily mislabel some individuals as high risk for ACE related outcomes and others low risk, leading to confusion, unnecessary interventions, fear, wasted resources, and missed opportunities for supporting individuals affected by ACEs.

These concerns have been extensively published by experienced researchers in the field. Conversely, the ACE screening protocols that have been popularized on the internet and by journalists have not been properly researched for their safety and efficacy. Issues of systemic inequities, social inequalities, and unaddressed structural racism should also motivate us to pause and reflect upon the deeper challenges faced by the individual. Considering these flaws and challenges, the Collaborative discourages the use of ACEs scores for screening or diagnosing individuals or assigning individual risk for decision making about need for services or treatment.

We recommend that the ACEs questions be part of an information dialog between the service provider and client. This allows for the development of:

- 1. A deeper relationship between client and practitioner.
- 2. A better understanding of possible additional reasons for the engagement; and
- 3. A foundation for deeper trust.

As New Jersey aims to forge an innovative way of community-healing through sustainable systems, we encourage the larger work that requires identifying solutions based on community input and addresses the root cause rather than the symptoms.⁷

⁵ State of Indiana Commission on Improving the Status of Children (Children's Commission). Position Statement on the Appropriate Use of Adverse Childhood Experiences (ACE) Scores. http://www.in.gov/children/files/ACEs-Position-Statement.pdf

⁶ McLennan, John & McTavish, Jill & MacMillan, Harriet. (2020). Routine screening of ACEs: Should we or shouldn't we?. 10.1016/B978-0-12-816065-7.00008-2.

⁷ McLennan, J. D., MacMillan, H. L., Afifi, T. O., McTavish, J., Gonzalez, A., & Waddell, C. (2019). Routine ACEs screening is NOT recommended. Paediatrics & child health, 24(4), 272–273. https://doi.org/10.1093/pch/pxz042

Goals of the Collaborative

A predominant goal of the Collaborative is to generate a shift in culture for which trauma and ACE awareness is immersed into the social constructs of residents, communities and professionals in New Jersey. The void identified in the absence of the ACE screening in practice is then filled by the calculated revolution of visualizing and implementing creative primary prevention within our social systems, which is inclusive of careful and sensitive gathering of information about ACEs for individuals that will promote healing, diminish shame, and empower individuals to engage in community in a way that reduces the transmission of adversity to the next generation.

Established in the arena of epidemiology, the original intent of the ACE score was to inform through public health surveillance the discovery of the impact ACEs has on the collective community. "Epidemiological research is not for diagnosis: we can't assume we know anything about an individual epidemiological finding like those in the ACE study." (https://www.aceinterface.com/). More importantly, the study created a compelling demand for innovative thinking, a shift from secondary and tertiary prevention to primary prevention in early childhood. Primary prevention requires a reflective examination of methods to reduce or eliminate factors that negatively impact health and lead to disease. Accordingly, the most appropriate way to respond is in reflecting on the systems that can reduce or eliminate childhood abuse, neglect and other adverse experiences. Considering that the ACE score does not reflect the frequency, severity, timing (age of occurred experience), or other important risk and protective factors, two individuals with the same ACE score may have extremely different experiences and subsequent needs. ACE scores can provide useful information about grouped (average) risk for many public health outcomes but projecting those values onto any individual's ACE score to make inferences about health, educational, or social consequences may lead to significant underestimation or overestimation of actual risk.8

In New Jersey, like the rest of the country, a high percentage of children have been exposed to adversity, and the impacts of ACEs are significant. In 2016, more than 40% of children (younger than 18 years) in the state had experienced one or more ACEs, and more than 18% of children had experienced at least two. Among the state's youngest children (under five-years-old), 33% had experienced one or more ACEs. These numbers do not reflect the present-day traumas our communities have experienced as a result of the COVID-19 pandemic, the implications thereof, and the explicit displays of systemic racism in our nation and communities. Therefore, we believe it is safe to say all New Jersey residents have experienced some level of trauma in the recent years.

Edward Verne Roberts⁹ was a great leader and activist, a true pioneer who effectively advocated through the disability rights movement for actionable changes that made life easier for all

⁸ Dube S. R. (2018). Continuing conversations about adverse childhood experiences (ACEs) screening: A public health perspective. Child abuse & neglect, 85, 180–184. https://doi.org/10.1016/j.chiabu.2018.03.007

⁹ Elliot, M. J. (1995, March 16). Edward V. Roberts, 56, Champion of the Disabled. Retrieved from https://www.nytimes.com/1995/03/16/obituaries/edward-v-roberts-56-champion-of-the-disabled.html.

Americans. Inspired by Roberts' inclusive thinking, we seek to collaborate with advocates and stakeholders to identify and implement primary prevention methods through a lens that sees New Jersey as one community that will collectively benefit as a result of ACEs prevention in our interconnected systems.

Additional Reading

Anda RF, Brown DW. (n.d.) Root Causes and Organic Budgeting: Funding Health from Conception to the Grave. *Pediatric Health*. 2007;1(2):141-143. [Editorial].

Merrick MT, Ford DC, Ports KA, Guinn AS. Prevalence of Adverse Childhood Experiences From the 2011-2014 Behavioral Risk Factor Surveillance System in 23 States. *JAMA Pediatr.* 2018;172(11):1038–1044. doi:10.1001/jamapediatrics.2018.2537