Adverse childhood experiences and developmental disabilities: risks, resiliency, and policy

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ABBREVIATION
ACE Adverse childhood experience

Thanks to the seminal work of Robert Anda and Vincent Felitti, it is now widely accepted that adverse childhood experiences (ACEs) can have lifelong effects on physical, behavioral, and mental health and that many adult diseases can be considered developmental disorders that began early in life. Genomics has advanced the neurobiological understanding that underpins ACEs, wellness, and disease, which are modulated through stress pathways and epigenetic modifications. While data are currently limited, children with developmental disabilities have an increased ACE risk compared to typically developing peers. This recognition has important ramifications for health and policy interventions that address the root causes of ACEs, especially in this vulnerable population. With increased societal recognition, advances in policy will lead to medical, financial, and public benefits in years to come, hopefully changing healthcare models from ‘sick care’ to ‘well care’.

An old aphorism states that ‘what is learned in the cradle is carried to the grave’. Modern neuroscience has extended this to understanding that human life has no precise beginning or end, with both genetic changes and actual cells persisting through generations.1,2 Furthermore, adverse events in life, beginning even before conception, during in utero development, and into childhood can have deleterious consequences on physical and mental health in adulthood.

While physiological stresses, such as severe malnutrition, have been associated with long-term consequences,3 it was the pioneering work of Vincent Felitti, Robert Anda, and colleagues which demonstrated that early adverse childhood experiences (ACEs) can have lifelong effects on adult mental and physical health,4 with subsequent studies pointing to explanatory effects on gene expression, the immune system, and stress responses supporting this concept of delayed consequences. For many adult disorders, from hypertension to depression, this changed the fundamental question from ‘What is wrong with you?’ to ‘What happened to you?’5,15

The clinical implications of ACEs are linked to the importance of how these events are handled, through complex neurobiological mechanisms involving stress-related circuits.5,6 With the assistance of caring family members, other responsible adults, and a supportive environment, stress can be managed successfully. Resilience can be built, with mitigation of the long-term consequences through increased self-confidence and self-efficacy.

Resilience includes both internal factors and external supports as the means to overcome stressful events. When external supports are not present stress can become toxic,7 with dysregulation of the immune and neuroendocrine systems mediated by the hypothalamic–pituitary axis, leading to both short- and long-term physical and mental health problems.

Neuroscience now provides an understanding of the molecular mechanisms by which stress affects the brain and body. Some of these mechanisms are epigenetic.8 Epigenetic changes affect which, when, and where genes are turned on and off during development. Some epigenetic switches are rapidly turned on and off, others are programmed early in life and remain stable across the life span, and some may be passed on to the next generation.

This review presents an overview of this complex topic, drawing on many studies that have been conducted to address the long-term consequences of ACEs and the underlying mechanisms, with attention to children with developmental disorders/disabilities. The need to develop effective policies and programs to prevent and ameliorate the detrimental effects of ACEs is also discussed.

ACE OVERVIEW

ACEs initiate a chain of events which affect later childhood development and have deleterious effects extending to adult health status, behavior, and disease.4 ACEs were originally described by Robert Anda and Vincent Felitti in the ‘ACE Study’, initiated by the Centers for Disease

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Control and Prevention and Kaiser Permanente in 1995. Felitti was an internist who observed that patients with chronic health conditions often had early life adversities, which is another term for ACEs. A retrospective questionnaire about ACEs was administered to 26,000 patients, 17,000 of whom responded in two waves over 3 years. The questionnaires were then matched to the medical records and health outcomes data.

The refined questionnaire included 10 ACEs: physical abuse; sexual abuse; verbal abuse; physical neglect; emotional neglect; a family member who is depressed or diagnosed with other mental illness; a family member who is addicted to alcohol or another substance; a family member being in prison; witnessing a mother being abused; losing a parent to separation, divorce, or death. What was remarkable was that the average age of study participants was 57 years; thus, the information obtained and conclusions drawn reflected the consequences of childhood experiences on adult health half a century later.

The high prevalence of ACEs in this study of mostly middle-aged adults and the connection between ACEs and poor adult somatic, mental health, educational, occupational, and social outcomes led to the acceptance of ACEs as a major public health concern. The findings have been replicated and reported in over 75 studies by Felitti alone. The study outcomes listed earlier led to the hypothesis that ACEs lead to impaired neurodevelopment, resulting in social, emotional, and cognitive adaptations and risk factors for disease, adult-onset disability, social problems, and early death.

In 2000, the US Congress instructed the Substance Abuse and Mental Health Services Administration-funded National Child Traumatic Stress Network to address awareness and access to care for traumatized children, families, and communities. This network of frontline providers, family members, researchers, and national partners is focused on improving the lives of children through advances in research and care, including expansion of the original 10 ACEs to include accidental or violent death of a loved one, refugee and war experiences, life-threatening injury and illness, natural disasters, and terrorism. This network has been instrumental as a resource for the current COVID-19 pandemic.

**ACES IN CHILDREN WITH DEVELOPMENTAL DISABILITIES**

Approximately 1 in 6 children between the ages of 3 and 17 years in the USA have an intellectual or developmental disability. These children are at increased risk for traumatic experiences in the home, at school, and in the community. The National Child Traumatic Stress Network developed a fact sheet for professionals and families to reduce service gaps in trauma-informed care, a term that recognizes the role trauma may play in a person’s life, and promote recovery and resilience. This resource includes statistics about the incidence of trauma, with the caveat that they may actually be an underrepresentation.

**What this paper adds**

- Adverse childhood experience (ACE) research has refocused medicine from the question ‘What is wrong with you?’ to ‘What happened to you?’.
- Adopting ACE research into public policy can redirect healthcare models from providing ‘sick care’ to promoting ‘well care’.
- Not exploring the role of ACEs in children with developmental disabilities leads to further vulnerability and morbidity.
- ACEs can be mitigated by early identification and implementation of evidence-based interventions.

Maltreatment of children with disabilities is higher than for the general pediatric population. As is also the case with typically developing children, neglect is the most common form of maltreatment. Children with behavioral disorders are at the highest risk for all types of maltreatment.

Children with specific developmental disabilities are at increased risk for ACEs. This has been most widely reported in children with autism spectrum disorder. In a review of recently published studies on ACEs, children with autism spectrum disorder experienced an increased number of ACEs compared to their typically developing peers. This puts them at greater risk for mental and somatic health comorbidities. The most frequent ACEs are bullying at 3 to 4 times higher rates than typically developing peers, parental divorce, and malnutrition. This review did not find higher rates of physical and sexual abuse or neglect. Using longitudinal data from the Fragile Families and Child Wellbeing Study, a strong association was found between physical disability and ACE occurrence at age 5 years. These disorders were identified either at birth or during early childhood and included developmental disabilities such as Down syndrome and cerebral palsy. The National Survey of Child Health 2011 to 2012 added a modified ACE questionnaire called the Adverse Family Experiences questionnaire, which included five questions about the original ACEs as well as four additional questions about death of a parent, neighborhood violence, economic hardship, and discrimination based on ethnicity. An association between the number of ACEs and unmet healthcare needs was reported, including mental health, in children with autism spectrum disorder. Children with any developmental disability experienced significantly higher levels of adverse events.

Identifying ACEs in a child with autism spectrum disorder or other developmental disorders is complicated by the concept of ‘diagnostic overshadowing’. Diagnostic overshadowing, first described in 1982, is a tendency to attribute symptoms or behaviors of a person with a learning disability to an underlying cognition rather than considering other possible comorbid medical or environmental conditions. This concept has been expanded beyond learning disabilities to include mental health disorders and intellectual disability and has implications with regard to fully investigating the underlying causes of ACEs.

An analysis of the relationship between challenging behaviors, posttraumatic stress disorder symptoms, and trauma exposure during childhood in adults with mild to
moderate intellectual disability showed an association between core posttraumatic stress disorder symptoms and challenging behavior. Since individuals with intellectual disability are at higher risk of exposure to trauma, results suggest that exploring possible trauma exposure is critical. Lack of appreciation or exploration of the role of trauma may result in a lack of appropriate trauma-informed interventions, leading to further vulnerability and morbidity for the child.

**STRESS AND BRAIN DEVELOPMENT**

The brain is the central organ involved in perceiving and adapting to adversity and stress. Research on the neurobiological effects of ACEs on brain development show that changes in brain morphology can occur in response to stress. Classification of stress responses into positive (protective), tolerable, and toxic (excessive) has led to researching the effects of ‘toxic stress’ on brain development. The impact of stress on brain structures explains how stress can have cumulative ‘wear and tear’ effects, including changes in brain architecture that may or may not be reversible.

When the brain detects a threat, multiple systems coordinate a response. These systems involve the autonomic, neuroendocrine, metabolic, and immune systems. Two neuroendocrine subsystems involved are the hypothalamic–pituitary–adrenal axis and the autonomic nervous sympathetic–adreno–medullary pathway. Cortisol, noradrenaline, adrenaline, and dehydroepiandrosterone are the primary mediators of the stress response. The three brain structures sensitive to the effects of stress are the hippocampus, amygdala, and prefrontal cortex, although widespread effects on the brain are recognized.

Allostasis is the term used to describe active adaptation to stress to maintain homeostasis. In the hypothalamic–pituitary–adrenal axis, after activation of the system and perceived subsiding of the stressor, feedback loops are triggered at various system levels (e.g. adrenal gland to pituitary, hypothalamus, and prefrontal cortex) to shut down the stress response and restore homeostasis. The term ‘allostatic load’ refers to the cumulative effect of multiple chronic stressors and how these impact on health, including brain health.

The response to stress in the brain involves genomic and nongenomic mechanisms, ranging from the cell surface to the cytoskeleton to epigenetic regulation via the cell nucleus. Glucocorticoids have direct effects on gene transcription but also have an impact via epigenetic mechanisms, including histone modification and methylation. In addition, excitatory amino acids are involved in altering the neural architecture in response to stress. A growing list of extracellular and intracellular mediators are involved in the response to stress. Examples include brain-derived neurotrophic factor and endocannabinoids.

It is important to consider the timing of stress (prenatal, postnatal, transgenerational effects), duration (acute vs chronic), and interactive gene effects from previous exposure/adversity. Stress can induce brain changes that are permanent or temporary. These initial changes in neural architecture can be thought of as adaptive; however, when persistent changes occur after the stressor has dissipated, they can be thought of as maladaptive resilience.

Resilience is an active process of adaptive plasticity to stress. Resilience is decreased and brain vulnerability is increased by ACEs. Examples of brain changes in response to early adversity involve CpG methylation of DNA as an example of the embedded influence of stress.

To our knowledge, there is currently no research on whether and how the impact of stress on brain development is different for individuals with disabilities.

**RESILIENCE**

Resilience in children can be defined as ‘the process by which the child moves through a traumatic event, utilizing various protective factors for support, and returning to “baseline” in terms of an emotional and physiologic response to the stressor’. Resilience, which is an essential component in effectively overcoming ACEs, can be considered a trait, outcome, or process. As a process, it includes both internal and external factors that can redirect a negative experience or series of stressful events into an outcome of positive personal development. Important protective factors include the social and emotional competence of the child, parental resilience, parental knowledge of child development, social connections, and specific help in times of need. Pediatricians and other childhood clinicians can provide beneficial support and recommendations.

Evaluating and promoting resilience is at the core of intervention. When gauging resilience, behavioral, emotional, and social competence and academic performance are key elements to be assessed. Internal factors including personality traits, self-efficacy, intellect, and the child’s own appraisal of stress are important protective factors.

To successfully overcome stressful or traumatic events, coping skills are important. Children have two types of coping strategies that can be examined in relation to ACEs, that is, problem-focused and avoidant emotion-focused coping. Problem-focused coping concentrates on resolving the problem. It can be evaluated using three subscales: positive reinterpretation and growth; active coping; and planning. A favorable outcome of problem-focused coping is that the problem is successfully resolved while promoting competence and self-efficacy.

In contrast, avoidant emotion-focused coping uses strategies to diminish the negative affective response to the stressor. It is associated with denial, focusing on venting of emotion and behavioral disengagement. While it might alleviate the immediate negative effects for the individual, it is temporary and the problem is unresolved. It is a type of coping that helps in the moment or for the immediate future.

Protective factors at the family level, including stable caregiving and supportive relationships, are an integral
component in developing resilience. Specific factors include family cohesion, extended family support, parental involvement, and positive parenting practices. Parental resilience, parental knowledge of child development, and exhibiting social and emotional competence are all important protective factors for children.32

Safe, stable, and nurturing relationships during childhood are important protective factors, which can diminish long-term physical and mental health problems in adulthood.33 The external support of having an adult who helps to make the child feel safe is an effective protective factor that may build resilience and ultimately help mitigate the impact of ACEs. Family protective factors can help the child build and demonstrate resilience post-ACEs, the greatest impact being when the parent and child communicate about topics of importance. Having the parent or caregiver understand the impact of trauma, attune to the child’s needs, and provide a safe environment contribute to building resilience within the child. At the community level, social connections, peer relationships, and religious connections are all potential protective factors that can contribute to resilience. Several evidenced-based treatment models or approaches have been shown to mitigate the impact of trauma effectively. There is evidence for mind-body methods toward promoting trauma healing, resilience, and one’s ability to regulate stress, emotions, and behaviors.34 Some of these mindfulness-based mind-body practices include biofeedback, hypnosis, tai chi, meditation, guided imagery, progressive muscle relaxation, and deep breathing exercises.

With regard to evidence-based practice with a structured approach to help people who have experienced a traumatic event or complex trauma, trauma-focused cognitive behavioral therapy includes a component specific to relaxation and mindfulness. Trauma-focused cognitive behavioral therapy is an evidence-based treatment model designed for children and adolescents who have emotional or behavioral difficulties due to a traumatic experience or ongoing complex trauma.35 This treatment model incorporates a safe parent or caregiver in the treatment. Children with developmental disabilities are just as susceptible, if not more, to ACEs than their typically developing peers.

The literature on resilience and children/adolescents with developmental disabilities is limited. In a meta-analysis reviewing 26 studies looking at which factors may contribute to resilience in familiar caregivers of children with developmental disabilities, the strongest connection was between social support and resilience.27 This brings the attention to community-level protective factors, resources, and policies to best support the families of children with developmental disabilities and specifically those who have experienced ACEs during childhood.

**POLICY**

ACEs are a problem with international scope. One billion children worldwide experienced violence in 2014, necessitating common approaches to policy development, which can be further refined at the local level.36

An important component of ACE prevention is at the societal level, with effective policies developed to promote
child well-being (Fig. 1). These include the formal recognition of children’s rights, legal protection to prevent and combat violence, norms to promote children’s rights, and policies to combat economic vulnerability and discrimination.37 Another important consideration is policy directed toward interventions aimed at improving parenting skills, fostering strong relationships between parents and children, and promoting resilience in children.

The World Health Organization’s International Classification of Functioning, Disability and Health is a classification system that serves as a framework to describe and organize information on functioning and disability.38 Activity and participation are measured in the context of environmental and personal factors. This classification is applied from the individual to the policy level. Juxtaposing the ecobiodevelopmental model (Fig. 1) to the International Classification of Functioning, Disability and Health framework allows us to examine adversity and resilience with these two approaches combined.

A key component in policy development is the concept of inclusion health, which addresses the extreme health and social inequities of vulnerable and excluded populations. Inclusion health highlights and addresses the underlying risk factors and barriers to promoting physical and mental health, including homelessness, addiction, and imprisonment.39 In this regard, a recognized need is the inclusion of ‘experts by experience’, that is, those who have directly experienced adversity. Other important upstream policy measures include addressing poverty and deprivation and establishing appropriate housing and treatment protocols.

Financial considerations require the establishment of effective policy for those with and without developmental disabilities. Total annual costs attributable to ACEs are estimated to be US$581 billion in Europe and US$748 billion in North America.40 Rebalancing expenditures away from acute care and toward developing safe and nurturing childhood environments is required both from an overall health perspective and to reduce personpower and financial pressures on healthcare systems.

CONCLUSIONS

Since the original studies, there has been mounting evidence highlighting the detrimental long-term effects of ACEs on physical, behavioral, and mental health. In a dose-dependent fashion, ACEs contribute to long-term morbidity across many organ systems and early mortality. These effects are seen across a broad range of epidemiological variables, from socioeconomic status and development disability to ethnicity.

It is important to recognize that individuals with disabilities may experience higher levels of adversity. As such, this requires vigilance on the part of the healthcare providers supplying management for this vulnerable group of people. Further research should address the neurobiological implications of toxic stress on brain development in this population.

Improving long-term outcomes will require utilizing an understanding of the underlying neurobiology of ACEs to establish effective prevention and mitigation strategies.41 Pediatric and allied health professionals can play an important role in medical care. A developmental approach to health, combined with the recognition that prevention is better than remediation, should drive advocacy efforts in determining policy.42

In summary, building child resilience, supporting family and community protective factors, identifying ACEs during early childhood, and implementing evidence-based interventions are powerful strategies to mitigate the long-term effects of ACEs, especially in children with developmental disabilities.

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