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## The Adverse Childhood Experiences Study the largest, most important public health study you never heard of — began in an obesity clinic

October 3, 2012 By Jane Ellen Stevensin ACE Study, Child abuse, Child trauma, Chronic disease, Neurobiology267 Comments

Mentions of the ACE Study – the CDC's Adverse Childhood Experiences Study — have shown up in the <u>New York Times</u>, <u>This American Life</u>, and <u>Salon.com</u> recently. In the last year, it's become a buzzword in social services, public health, education, juvenile justice, mental health, pediatrics, criminal justice and even business. Many people say that just as everyone should be aware of her or his cholesterol score, so <u>should everyone know her or his ACE score</u>. But what is this study? And why is it so important to, well, almost everyone in 2012, the same way polio became important to almost everyone in the 1950s? Here's the backstory.

The ACE Study – probably the most important public health study you never heard of – had its origins in an obesity clinic on a quiet street in San Diego.

It was 1985, and Dr. Vincent Felitti was mystified. The physician, chief of Kaiser Permanente's revolutionary Department of Preventive Medicine in San Diego, CA, couldn't figure out why, each year for the last five years, more than half of the people in his obesity clinic dropped out. Although people who wanted to shed as little as 30 pounds could participate, the clinic was designed for people who were 100 to 600 pounds overweight.

Felitti cut an imposing, yet dashing, figure. Tall, straight-backed, not a silver hair out of place, penetrating eyes, he was a doctor whom patients trusted implicitly, spoke of reverentially and rarely called by his first name. The preventive medicine department he created had become an international beacon for efficient and compassionate care. Every year, more than 50,000 people were screened for diseases that tests and machines could pick up before symptoms appeared. It was the largest medical evaluation site in the world. It was reducing health care costs before reducing health care costs was cool.



Dr. Vincent Felitti

But the 50-percent dropout rate in the obesity clinic that Felitti started in 1980 was driving him crazy. A cursory review of all the dropouts' records astonished him — they'd all been losing weight when they left the program, not gaining. That made no sense whatsoever. Why would people who were 300 pounds overweight lose 100 pounds, and then drop out when they were on a roll?

The situation "was ruining my attempts to build a successful program," he recalls, and in typical Type-A fashion, he was determined to find out why.

The mystery turned into a 25-year quest involving researchers from the Centers for Disease Control and Prevention and more than 17,000 members of Kaiser Permanente's San Diego care program. It would reveal that adverse experiences in childhood were very common, even in the white middle-class, and that these experiences are linked to every major chronic illness and social problem that the United States grapples with – and spends billions of dollars on.

But in 1985, all that Felitti knew was that the obesity clinic had a serious problem. He decided to dig deep into the dropouts' medical records. This revealed a couple of surprises: All the dropouts had been born at a normal weight. They didn't gain weight slowly over several years.

"I had assumed that people who were 400, 500, 600 pounds would be getting heavier and heavier year after year. In 2,000 people, I did not see it once," says Felitti. When they gained weight, it was abrupt and then they stabilized. If they lost weight, they regained all of it or more over a very short time.

But this knowledge brought him no closer to solving the mystery. So, he decided to do face-to-face interviews with a couple hundred of the dropouts. He used a standard set of questions for everyone. For weeks, nothing unusual came of the inquiries. No revelations. No clues.

The turning point in Felitti's quest came by accident. The physician was running through yet another series of questions with yet another obesity program patient: How much did you weigh when you were born? How much did you weigh when you started first grade? How much did you weigh when you entered high school? How old were you when you became sexually active? How old were you when you married?

"I misspoke," he recalls, probably out of discomfort in asking about when she became sexually active – although physicians are given plenty of training in examining body parts without hesitation, they're given little support in talking about what patients do with some of those body parts. "Instead of asking, "How old were you when you were first sexually active," I asked, "How much did you weigh when you were first sexually active?' The patient, a woman, answered, 'Forty pounds.""

He didn't understand what he was hearing. He misspoke the question again. She gave the same answer, burst into tears and added, "It was when I was four years old, with my father."

He suddenly realized what he had asked.

"I remembered thinking, 'This is only the second incest case I've had in 23 years of practice'," Felitti recalls. "I didn't know what to do with the information. About 10 days later, I ran into the same thing. It was very disturbing. Every other person was providing information about childhood sexual abuse.

I thought, 'This can't be true. People would know if that were true. Someone would have told me in medical school.'

Worried that he was injecting some unconscious bias into the questioning, he asked five of his colleagues to interview the next 100 patients in the weight program. "They turned up the same things," he says.

Of the 286 people whom Felitti and his colleagues interviewed, most had been sexually abused as children. As startling as this was, it turned out to be less significant than another piece of the puzzle that dropped into place during an interview with a woman who had been raped when she was 23 years old. In the year after the attack, she told Felitti that she'd gained 105 pounds.

"As she was thanking me for asking the question," says Felitti, "she looks down at the carpet, and mutters, 'Overweight is overlooked, and that's the way I need to be."

During that encounter, a realization struck Felitti. It's a significant detail that many physicians, psychologists, public health experts and policymakers haven't yet grasped: The obese people that Felitti was interviewing were 100, 200, 300, 400 overweight, but they didn't see their weight as a problem. To them, eating was a fix, a solution. (There's a reason an IV drug user calls a dose a "fix".)

One way it was a solution is that it made them feel better. Eating soothed their anxiety, fear, anger or depression – it worked like alcohol or tobacco or methamphetamines. Not eating increased their anxiety, depression, and fear to levels that were intolerable.

The other way it helped was that, for many people, just *being* obese solved a problem. In the case of the woman who'd been raped, she felt as if she were invisible to men. In the case of a man who'd been beaten up when he was a skinny kid, being fat kept him safe, because when he gained a lot of weight, nobody bothered him. In the case of another woman — whose father told her while he was raping her when she was 7 years old that the only reason he wasn't doing the same to her 9-year-old sister was because she was fat — being obese protected her. Losing weight increased their anxiety, depression, and fear to levels that were intolerable.

For some people, both motivations were in play.

Felitti didn't know this at the time, but this was the more important result — the mind-shift, the new meme that would begin spreading far beyond a weight clinic in San Diego. It would provide more understanding about the lives of hundreds of millions of people around the world who use biochemical coping methods — such as alcohol, marijuana, food, sex, tobacco, violence, work, methamphetamines, thrill sports — to escape intense fear, anxiety, depression, anger.

Public health experts, social service workers, educators, therapists and policy makers commonly regard addiction as a problem. Some, however, are beginning to grasp that turning to drugs is a normal response to serious childhood trauma, and that telling people who smoke or overeat or overwork that these are bad for them and that they should stop doesn't register when those approaches provide a temporary, but gratifying solution.

Ella Herman was one of the people who participated in the obesity clinic, but had dropped out because any weight she lost, she regained. Herman owned a successful childcare center in San Diego. Herman said she was sexually abused by two uncles and a school bus driver; the first time occurred when she was four years old. She married a man who abused her repeatedly and tried to kill her. With the help of her family, she fled with her children to San Diego, where she later remarried.

"I imagine I've lost 100 pounds about six times," she recalled. "And gained it back." Every time she lost weight and a man commented on her beauty, she became terrified and began eating. But she never understood the connection until she attended a meeting at which Felitti talked about what he'd learned from patients. At this time, Herman was just over five feet tall and weighed nearly 300 pounds. "He had a room full of people," she said. "The more he talked the more I cried, because he was touching every aspect of my life. Somebody in the world understands, I thought."

Herman later sent a letter to Felitti. "I want to thank you for caring enough about people to read all those charts and finding out what happens to all of us who are molested, raped and abused in childhood," she wrote. "...I suffered for years. The pain became so great I was thinking of jumping off the San Diego Bay Bridge....How many people may have taken their life because they had no program to turn to? How many lives can be saved by this program?"

## What do you do when you've got something important to tell the world, but the world thinks it's stupid?

So, if you were Vincent Felitti, whom would you pick as your first audience to reveal your stunning findings? A group relatively informed about obesity that would greet the new information with extreme interest, praise and applause? Natch. So, in 1990, Felitti flew to Atlanta to give a speech to the members – many of them psychologists and psychiatrists — of the North American Association for the Study of Obesity. The audience listened quietly and politely. When he finished, one of the experts stood up and blasted him. "He told me I was naïve to believe my patients, that it was commonly understood by those more familiar with such matters that these patient statements were fabrications to provide a cover explanation for failed lives!"

At dinner, Dr. David Williamson, an epidemiologist from the U.S. Centers for Disease Control and Prevention, sat next to the perplexed Felitti. Williamson was intrigued. He leaned over and "told me that people could always find fault with a study of a couple of hundred people," says Felitti, "but not if there were thousands, and from a general population, not a subset like an obesity program. I turned to him and said, 'That's not a problem.'"



Williamson invited Felitti to meet with a small group of researchers at the Centers for Disease Control. Dr. Robert Anda, a medical epidemiologist was among them. If Felitti is the model for a TV show featuring a wise and stately chief physician who sits straight, stands straight, and keeps his personal feelings in check, Anda would be the dashing, young, brilliant researcher who wears his tie askew, slumps in chairs, laughs easily, loves to joke around, and puts his heart on his sleeve for all to see.

Anda began his career as a physician, but became intrigued with epidemiology and public health. When he met Felitti, he had been studying how depression and feelings of hopelessness affect coronary heart disease. He noticed that depression and hopelessness weren't random. "I became interested in going deeper, because I thought that there must be something beneath the behaviors that were generating them," says Anda.

Kaiser Permanente in San Diego was a perfect place to do a mega-study. More than 50,000 members came through the department each year, for a comprehensive medical evaluation. Every person who came through the Department of Preventive Medicine filled out a detailed biopsychosocial (biomedical, psychological, social) medical questionnaire prior to undergoing a complete physical examination and extensive laboratory tests. It would be easy to add another set of questions. In two waves, Felitti and Anda asked 26,000 people who came through the department "if they would be interested in helping us understand how childhood events might affect adult health," says Felitti. Of those, 17,421 agreed.

Before they added the new trauma-oriented questions, Anda spent a year pouring through the research literature to learn about childhood trauma, and focused on the eight major types that patients had mentioned so often in Felitti's original study and whose individual consequences had been studied by other researchers. These eight included three types of abuse — sexual, verbal and physical. And five types of family dysfunction — a parent who's mentally ill or alcoholic, a mother who's a domestic violence victim, a family member who's been incarcerated, a loss of a parent through divorce or abandonment. He later added emotional and physical neglect, for a total of 10 types of adverse childhood experiences, or ACEs.



The initial surveys began in 1995 and continued through 1997, with the participants followed subsequently for more than fifteen years. "Everything we've published comes from that baseline survey of 17,421 people," says Anda, as well as what was learned by following those people for so long.

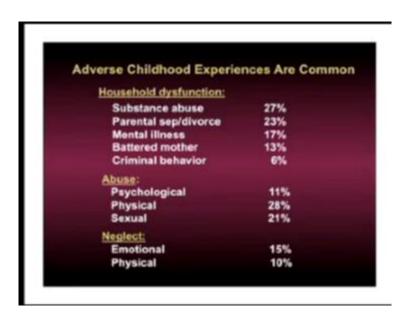
When the first results of the survey were due to come in, Anda was at home in Atlanta. Late in the evening, he logged into his computer to look at the findings. He was stunned. "I wept," he says. "I saw how much people had suffered and I wept."

This was the first time that researchers had looked at the effects of several types of trauma, rather than the consequences of just one. What the data revealed was mind-boggling.

The first shocker: There was a direct link between childhood trauma and adult onset of chronic disease, as well as mental illness, doing time in prison, and work issues, such as absenteeism.

The second shocker: About two-thirds of the adults in the study had experienced one or more *types* of adverse childhood experiences. Of those, 87 percent had experienced 2 or more types. This showed that people who had an alcoholic father, for example, were likely to have also experienced physical abuse or verbal abuse. In other words, ACEs usually didn't happen in isolation.

The third shocker: More adverse childhood experiences resulted in a higher risk of medical, mental and social problems as an adult.



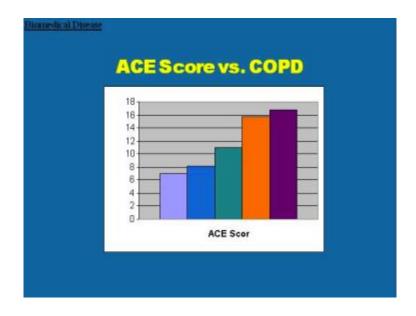
To explain this, Anda and Felitti developed <u>a scoring system for ACEs</u>. Each type of adverse childhood experience counted as one point. If a person had none of the events in her or his background, the ACE score was zero. If someone was verbally abused thousands of times during his or her childhood, but no other *types* of childhood trauma occurred, this counted as one point in the ACE score. If a person experienced verbal abuse, lived with a mentally ill mother and an alcoholic father, his ACE score was three.

Things start getting serious around an ACE score of 4. Compared with people with zero ACEs, those with four categories of ACEs had a 240 percent greater risk of hepatitis, were 390 percent more likely to have chronic obstructive pulmonary disease (emphysema or chronic bronchitis), and a 240 percent higher risk of a sexually-transmitted disease.

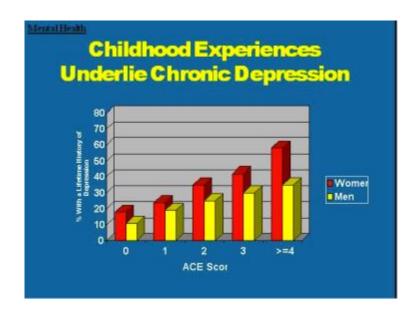


They were twice as likely to be smokers, 12 times more likely to have attempted suicide, seven times more likely to be alcoholic, and 10 times more likely to have injected street drugs.

People with high ACE scores are more likely to be violent, to have more marriages, more broken bones, more drug prescriptions, more depression, more auto-immune diseases, and more work absences.



"Some of the increases are enormous and are of a size that you rarely ever see in health studies or epidemiological studies. It changed my thinking dramatically," says Anda.



Two in nine people had an ACE score of 3 or more, and one in eight had an ACE score of 4 or more. This means that every physician probably sees several high ACE score patients every day, notes Felitti. "Typically, they are the most difficult, though the underpinnings will rarely be recognized."

The kicker was this: The ACE Study participants were average Americans. Seventy-five percent were white, 11 percent Latino, 7.5 percent Asian and Pacific Islander, and 5 percent were black. They were middle-class, middle-aged, 36 percent had attended college and 40 percent had college degrees or higher. Since they were members of Kaiser Permanente, they all had jobs and great health care. Their average age was 57.

As Anda has said: "It's not just 'them'. It's us."

## Changing the landscape of understanding human development

In the last 14 years, Anda, Felitti and other CDC researchers have published more than 60 papers in prestigious peer-reviewed journals, including the Journal of the American Medical Association and the American Journal of Preventive Medicine. Other researchers have referenced their work more than 1,500 times. Anda and Felitti have flown around the U.S., Canada and Europe to give hundreds of speeches.

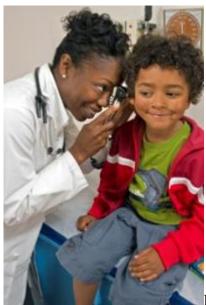
Their inquiry "changed the landscape," says Dr. Frank Putnam, director of the <u>Mayerson Center for Safe and Healthy Children</u> at Cincinnati Children's Hospital Medical Center and professor at the University of Cincinnati Department of Pediatrics. "It changed the landscape because of the pervasiveness of ACEs in the huge number of public health problems, expensive public health problems — depression, substance abuse, STDs, cancer, heart disease, chronic lung disease, diabetes."

The ACE Study became even more significant with the publication of parallel research that provided the link between why something that happened to you when you were a kid could land you in the hospital at age 50. The stress of severe and chronic childhood trauma – such as being regularly hit, constantly belittled and berated, watching your father often hit your mother – releases hormones that physically damage a child's developing brain.

Flight, fight or freeze hormones work really well to help us accelerate when we're being chased by a vicious dog with big teeth, fight when we're cornered, or turn to stone and stop breathing to escape detection by a predator. But they become toxic when they're turned on for too long.

This was determined by a group of neuroscientists and pediatricians, including neuroscientist <u>Martin Teicher</u> and pediatrician <u>Jack Shonkoff</u>, both at Harvard University, neuroscientist <u>Bruce McEwen</u> at Rockefeller University, and child psychiatrist Bruce Perry at the <u>Child Trauma Academy</u>.

As San Francisco <u>pediatrician Nadine Burke Harris recently explained to host Ira Glass on the radio program, "This American Life"</u>, if you're in a forest and see a bear, a very efficient fight or flight system instantly floods your body with adrenaline and cortisol and shuts off the thinking portion of your brain that would stop to consider other options. This is very helpful if you're in a forest and you need to run from a bear. "The problem is when that bear comes home from the bar every night," she said.



Dr. Nadine Burke Harris and faux patient (for the photo)

If a bear threatens a child every single day, his emergency response system is activated over and over and over again. He's always ready to fight or flee from the bear, but the part of his brain – the prefrontal cortex – that's called upon to diagram a sentence or do math becomes stunted, because, in our brains, emergencies – such as fleeing bears – take precedence over doing math.

For Harris' patients who had four or more categories of adverse childhood experiences "their odds of having learning or behavior problems in school were 32 times as high as kids who had no adverse childhood experiences," she told Glass.

Together, the two discoveries – the ACE epidemiology and the brain research — reveal a story too compelling to ignore:

Children with toxic stress live much of their lives in fight, flight or fright (freeze) mode. They respond to the world as a place of constant danger. With their brains overloaded with stress hormones and

unable to function appropriately, they can't focus on learning. They fall behind in school or fail to develop healthy relationships with peers or create problems with teachers and principals because they are unable to trust adults. Some kids do all three. With despair, guilt and frustration pecking away at their psyches, they often find solace in food, alcohol, tobacco, methamphetamines, inappropriate sex, high-risk sports, and/or work and over-achievement. They don't regard these coping methods as problems. Consciously or unconsciously, they use them as solutions to escape from depression, anxiety, anger, fear and shame.

What all this means, says Anda is that we need to prevent adverse childhood experiences and, at the same time, change our systems – educational, criminal justice, healthcare, mental health, public health, workplace – so that we don't further traumatize someone who's already traumatized. You can't do one or the other and hope to make any progress.

"Dr. Putnam is right — ACEs changed the landscape," Anda says. "Or perhaps the many publications from the ACE Study opened our eyes to *see the truth of the landscape*. ACEs create a "chronic public health disaster" that until recently has been hidden by our limited vision. Now we see that the biologic impacts of ACEs transcend the traditional boundaries of our siloed health and human service systems. Children affected by ACEs appear in all human service systems throughout the lifespan — childhood, adolescence, and adulthood — as clients with behavioral, learning, social, criminal, and chronic health problems."



But our society has tended to treat the abuse, maltreatment, violence and chaotic experiences of our children as an oddity instead of commonplace, as the ACE Study revealed, notes Anda. And our society believes that these experiences are adequately dealt with by *emergency* response systems such as child protective services, criminal justice, foster care, and alternative schools. "These services are needed and are worthy of support — but they are a dressing on a greater wound," he says.

"A hard look at the public health disaster calls for the both the prevention and treatment ACEs," he continues. "This will require integration of educational, criminal justice, healthcare, mental health, public health, and corporate systems that involves sharing of knowledge and resources that will replace traditional fragmented approaches to burden of adverse childhood experiences in our society."

As Williamson, the epidemiologist who introduced Felitti and Anda, and also worked on the ACE Study, says: "It's not just a social worker's problem. It's not just a psychologist's problem. It's not just a pediatrician's problem. It's not just a juvenile court judge's problem." In other words, this is everybody's problem.

According to a <u>CDC study released earlier this year</u>, just *one* year of confirmed cases of child maltreatment costs \$124 billion over the lifetime of the traumatized children. The researchers based their calculations on only confirmed cases of physical, sexual and verbal abuse and neglect, which child maltreatment experts say is a small percentage of what actually occurs.

## The breakdown per child is:

- \$32,648 in childhood health care costs
- \$10,530 in adult medical costs
- \$144,360 in productivity losses
- \$7,728 in child welfare costs
- \$6,747 in criminal justice costs
- \$7,999 in special education costs

You'd think the overwhelming amount of money spent on the fallout of adverse childhood experiences would have inspired the medical community, the public health community and federal, state and local governments to integrate this knowledge and fund programs that have been proven to prevent ACEs. But adoption of concepts from the ACE Study and the brain research has been remarkably slow and uneven.

On the federal level, the <u>Substance Abuse and Mental Health Services Administration</u> (SAMHSA) – probably the largest federal agency you never heard of – launched the <u>National Child Traumatic Stress Network</u> in 2001, and the <u>National Center for Trauma-Informed Care</u> (NCTIC) in 2005. Much of the work focused on stress from *individual* traumatic events, or individual types of child abuse; only recently has there been a focus on dysfunctional families or changing systems that engage those families to become trauma-informed, i.e., not further traumatizing already traumatized people, as so many of our systems do.

Until the last 10 months, the medical community practically ignored the ACE Study. Just last December, the <u>American Academy of Pediatrics issued a policy statement</u> recommended that its members look for toxic stress in their patients. Except with local exceptions, the public health community has not embraced it. In fact, the CDC — the one agency you might think would use its own research to reorganize how it approaches prevention of alcohol, obesity, sexually transmitted diseases and smoking — has whittled down funding for the ACE Study to practically nothing, and nobody's working on it full time.

However, on a local and state level, there's been considerably more action. Washington was the first state to embrace the ACE Study and the research on children's developing brains, when its <u>Family Policy Council</u> distributed the information through a statewide network of 42 communities. Over the last three years, 18 states have done their own ACE surveys, with results similar to the CDC study.

Some cities have set up ACE task forces. Trauma-informed practices are popping up around the U.S., Canada, and countries in Europe, Asia, and Central and South America in schools, prisons, mental clinics and hospitals, a few pediatric practices, crisis nurseries, local public health departments, homeless shelters, at least one hospital emergency room, substance-abuse clinics, child welfare services, youth services, domestic violence shelters, rehab centers for seniors, residential treatment centers for girls and boys, and courtrooms.

In these dozens of organizations, the results of the new approach are nothing less than astounding: the most hopeless of lives turned around, parents speaking "ACEs" and determined not to pass on their high ACEs to their children, and a significant reduction in costs of health care, social services and criminal justice.