# Strengthening Families ACE's Learning Collaborative

Guidance for Pediatricians Administering the ACEs Screener









#### **EXECUTIVE SUMMARY**

It is well established that the impacts of traumatic childhood events or circumstances can be lifelong and intergenerational. These events are referred to as adverse childhood experiences (ACEs) and include abuse, neglect and household dysfunction. Research has found ACEs [or such adverse childhood experiences] to be common in Idaho. Adults who had traumatic childhoods may have poor physical, mental or behavioral health. Poor health may interfere with the person's parenting; it may reduce the parents'/caregivers' ability to provide a safe, stable and nurturing home that allows their children to be healthy and resilient. The American Academy of Pediatrics (AAP) believes multigenerational treatment is required to break the intergenerational cycle of ACEs. (Preventing Childhood Toxic Stress: Partnering with Families and Communities to Promote Relational Health, American Academy of Pediatrics Policy Statement, August 2, 2021)

According to the AAP, pediatricians are ideally placed to help parents/caregivers improve their health and break the intergenerational cycle of ACEs. Screening parents/caregivers for adverse childhood experiences is recommended to assess risk of overactive stress response and foster strong, trusted, respectful, and supportive relationships between the parent/ caregiver and providers. The screening and follow-up discussion with the pediatrician can have immediate benefits, and targeted clinical interventions can improve the health of the parent/ caregiver and child. Despite the growing recognition that ACEs screening is valuable, only a small number of pediatricians routinely screen. While the research has found that the ACEs screening is acceptable to patients, providers continue to worry that their patients don't want to talk about their childhoods.

The ACEs/Strengthening Families Learning Collaborative was conducted to provide guidance to Idaho pediatricians on how to respectfully conduct an ACEs screening and provide supportive follow-up. The Guidance Report will be used to increase Idaho

pediatricians' use of ACEs screening and improve parenting and health outcomes. Guidance was solicited from a diverse mix of Idaho parents and caregivers by holding eight focus groups. A Parent Advisory Committee (PAC) reviewed the information. They agreed on five high-priority recommendations for conducting ACEs screenings and created a list of recommended follow-up strategies.

#### High-priority Recommendations:

- 1. Parents/caregivers should be given written or verbal assurance their ACEs score and their specific ACEs won't be used to judge or test their parenting ability and that the information is confidential and won't be shared with anyone without permission.
- 2. Parents/caregiver should know there will be follow-up and the provider has helpful resources available before being asked to do the screening.
- 3. Parents/caregivers should be given information about ACEs before the screening.
- 4. The provider needs to be respectful and listen and be compassionate.
- 5. The provider needs to make it easy for the parent/ caregiver to do the screening by creating a calm, unrushed and private environment, and a flexible and respectful process.

The recommendations are supported by evidence from the focus groups and examples of ways providers can implement the recommendations are provided. Comments from the focus groups are included to bring the parents' voices into the report. Follow-up was so important to the parents that a special section examines three types of follow-up: concrete supports, referrals to professionals and creating opportunities for peer support and self-help.

#### INTRODUCTION

Intergenerational **Health Impacts** Are Caused by Childhood Trauma

Adverse childhood experiences (ACEs) are traumatic events that happen before a child turns 18. These adverse experiences can have an impact that lasts into adulthood, including an impact on parenting, according to the U.S. Department of Health and Human Services. Known as ACEs in the community health arena, these events may include abuse, neglect, and household dysfunction. Studies show that toxic stress responses caused by adverse childhood experiences can lead to detrimental health outcomes later in life. (https://www.stlukesonline.org/blogs/ st-lukes/news-and-community/2019/sep/community-healthteam-uses-stencils-to-build-resilience-in-kids).

While most ACEs research has focused on the health impacts of childhood trauma on adults, ACEs can also have a profound impact on a parent's/caregiver's ability to create a safe, stable and nurturing family environment. Adverse childhood experiences are often intergenerational, meaning the children of parents/caregivers who had adverse childhood experiences can be at greater risk for adverse experiences themselves. Parents/caregivers who had traumatic childhoods, absent of key protective factors, may have developed an overactive stress response which can increase their risk for poor physical, mental, and behavioral health. These health problems can tax a family's resources and interfere with a parent's/caregiver's ability to provide a safe, stable and nurturing family environment. In addition, parents/caregivers with an overactive stress response may have more difficulty managing stress and emotions and self-regulating in a healthy manner when engaging with their children. The lack of a positive relationship with an engaged and attuned parent/caregiver creates a higher risk of trauma and can perpetuate the intergenerational cycle.

This intergenerational aspect is particularly important as nurture (the environment) shapes nature (genes) via gene expression—a process called "epigenetics." This process can put children who experience trauma at higher risk for disease and other

harmful health conditions throughout life. This is because the biochemical effects of chronic stress, absent protective factors, can be toxic to a child's healthy development. (Center for Youth Wellness and ZERO TO THREE A Two-Generation Approach to ACEs, 2018. https://www.acesaware.org/wp-content/ uploads/2019/12/13-Two-Generation-Approach-to-ACEs-English.pdf) Children who experience trauma may struggle at school and are more likely to have a learning disability. They may suffer developmental delay, anxiety and ADHD. They may have behavioral problems such as bullying others. (2016-2017) National Survey of Children's Health, Department of Health and Human Services, Health Resources and Human Services Administration's Maternal and Child Health Bureau, Analysis done by Alaska Association of School Boards Staff, October 2019 for the Western School Boards Association)

**65.1%** of Idaho adults had at least one adverse childhood experience

Research has found ACEs [or such adverse childhood experiences] to be common in Idaho. 65.1% of Idaho adults had at least one adverse childhood experience, and nearly one in four had four or more ACEs. (2018 BRFSS compared to 23 states). As children, 1 in 8 Idahoans were sexually abused, 1 in 6 were physically abused, 1 in 6 witnessed intimate partner violence between their parents, 1 in 4 lived with an alcoholic and 1 in 3 experienced emotional abuse. (Adverse Childhood Experiences (ACEs) Among Idaho Adults, 2018, Idaho Behavioral Risk Factor Surveillance System (BRFSS). Idaho Department of Health and Welfare | Division of Public Health | Bureau of Vital Records and Health Statistics).

#### **ACEs Screening** Recommended

According to the American Academy of Pediatrics (AAP), multigenerational treatment is needed to prevent childhood toxic stress responses and support optimal development across the life span. The establishment of healthy relationships with engaged and attuned adults, most commonly their parents, has a profound positive influence on children. AAP concludes having safe, stable and nurturing relationships is a universal, biological imperative for children to fulfill their potential; to be healthy and resilient; to be successful academically, economically,

and socially; and, perhaps most importantly, to become the caregivers that value and build positive relationships with subsequent generations. (Preventing Childhood Toxic Stress: Partnering with Families and Communities to Promote Relational Health, American Academy of Pediatrics Policy Statement, August 2, 2021)

When parents/caregivers get the support and resources they need, they can provide safe, stable and nurturing homes and the physical, mental, and behavioral health of their children will improve. Pediatricians are ideally placed to provide such support and educate families about what a safe, stable, and nurturing family environment is. Parents/caregivers have new brain growth in the first six months after their child's birth, so this is a good time for them to learn new family-strengthening behavior. Importantly, the AAP found there will be more acceptance of prevention, intervention and treatment strategies when pediatricians have strong, trusted, respectful, and supportive relationships with patients and their families.

Talking to parents and caregivers about the experiences they had as children is a way for pediatricians to assess risk and begin a collaborative process to optimize the home environment. Leading health care and public health organizations, such as the National Academies of Science, Engineering, and Medicine, Centers for Disease Control and Prevention, and American Academy of Pediatrics, now recommend screening for adverse childhood experiences as part of a routine medical evaluation. (https://www.acesaware.org/learn-about-screening/benefitsof-ace-screening/) Screening results can be used to provide targeted clinical interventions, but screening and the immediate follow-up discussion is sometimes all that's needed to create positive outcomes. Dr. R.J. Gillespie explains, "So, for me the idea that my families can come to me with any concern or problem that they're having is the end goal, that my office is a safe place for parents to address whatever issues they're having." (https:// www.pacesconnection.com/g/california-aces-action/blog/ how-do-these-pediatricians-do-aces-screening-early-adopterstell-all).

#### **New Practices** Overcome **Barriers**

Despite growing recognition of the value of ACEs screening, only 4% of pediatricians across the U.S. actively screened for ACEs according to one study. (Kerker B.D., Storfer-Isser A., Szilagyi M. Do pediatricians ask about adverse childhood experiences in pediatric primary care? Acad Pediatr. 2016;16(2):154–160. https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC5563967/).

Pediatricians have identified things they see as barriers to conducting ACEs screening. Adding another screening to tight schedules was noted, but one study found that after starting ACE screenings, clinicians and staff found the inclusion of ACE screenings manageable without significant disruption to office flow. (https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC7498469/).

Other barriers identified include patient acceptability, clinician qualifications and training, limited reimbursement, the lack of interventions for patients exposed to ACEs, the lack of agreement regarding which ACEs tool to include, and systemlevel requirements to assure smooth processing. (Finkelhor D. Screening for adverse childhood experiences (ACEs): cautions and suggestions. Child Abuse Negl. 2018;85:174–179. And Sciolla A.F. Mary Ann Liebert, Inc; New Rochelle, NY: 2018. Screening for Childhood Adversities in Prenatal Care: What Works and Why. <a href="https://www.aap.org/en-us/professional-">https://www.aap.org/en-us/professional-</a> resources/Research/research-findings/Pages/Pediatricians-Perceived-Barriers-to-Addressing-Early-Brain-and-Child-Development-and-Inquiring.aspx).

The AAP policy statement identifies two system changes that are required for pediatricians to successfully promote safe, secure and nurturing relationships. First, pediatric providers need financial supports to expand their capacity for developing respectful, continuous, trusted, and nurturing relationships with both the patients and caregivers of their patients. Second, pediatricians and pediatric practices need the capacity to form working relationships with a wide array of community partners.

My doctor has helped me be a better mother and person with our conversations and by always reminding me that as much as I think otherwise, I am doing a great job. I do not want my kids to grow up in a household that has drugs and constant yelling and fighting. I can talk to my doctor about my concerns without feeling judged. He makes me feel like family. When I was feeling down and not an adequate mother, he helped me get the help I needed.

> -Parent whose provider administered the ACEs screener.

Notably, although many clinicians voiced concerns that patients would find ACEs screenings to be too invasive, the studies suggest that most patients find the ACE screening to be acceptable. In fact, the majority of patients felt the discussion of ACEs enhanced their relationship with their health care clinician. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7498469/) This aligns with the opinion of providers who routinely screen for ACEs that screening and the immediate follow-up discussion are beneficial. They have discovered that asking is a powerful form of doing.

#### Idaho **Pediatricians** Share Concerns

The Learning Collaborative held a discussion with six pediatricians selected by Tom Patterson MD, Family Medicine Residency of Idaho, to learn about their attitudes toward ACEs screening. 80% reported screening for ACEs "sometimes" and 20% reported never screening for ACEs. The providers identified reasons they didn't screen for ACEs. The providers said the parent/caregiver needs information before being asked to take the screener and the parent/caregiver needs follow-up after taking the screener. Some providers said they weren't prepared to provide either of these due to lack of time or knowledge. They said a lack of support from other staff contributed to this problem. Some providers also mentioned that parents/ caregivers wouldn't want to take the time to do the screener, that parents/caregivers wouldn't want to talk about their childhoods and that parents/caregivers might feel the results may be used against them.

## PARENT/CAREGIVER RECOMMENDATIONS FOR ACES **SCREENING**

Strengthening Families Learning Collaborative Methodology

This research was conducted by the ACEs/Strengthening Families Learning Collaborative to provide guidance to Idaho pediatricians on how to respectfully conduct an ACE screening and provide supportive follow-up. The objective is to increase use of the ACEs screener at the 4-month well-baby checkup

and break intergenerational patterns of abuse, neglect, and surmountable family challenges so that all children can thrive. The Collaborative is jointly sponsored by the Idaho Children's Trust Fund and the Idaho Resilience Project and funded by the Idaho Maternal and Child Health Department. A Steering Committee of representatives from the sponsors, funders, partners, and local experts oversaw the Collaborative. Roger Sherman, Executive Director of the Idaho Children's Trust Fund, convened the group. The members are Bill Foxcroft, Idaho Head Start Association, Tom Patterson MD, Family Medicine Residency of Idaho, Katherine Humphrey and Ashtin Glodt, Idaho Maternal and Child Health Section Idaho Department of Health and Welfare, Jackie Rivas-Barker, Bradley McKinney, and Sherry Iverson, St Luke's Health System, and Jean Fitzgerald-Mutchie, Idaho Resilience Project. Liz Paul served as the Project Coordinator.

The Learning Collaborative started with the pediatrician's focus group referenced above. This allowed the team to understand more about Idaho pediatricians' attitudes toward use of the ACE screener. The participants also shared what they wanted to learn from the parent/caregiver focus groups, and those ideas were worked into focus group questions.

Eight 90-minute focus groups were conducted via Zoom in May and June 2021 to gather information from a diverse mix of Idaho parents and caregivers. Individuals from each of the seven Idaho judicial districts were represented. Most participants were recruited through flyers (Appendix A) distributed by Idaho Head Start and Early Head Start programs. Participants were also recruited by other participants, by learning collaborative volunteers and by partner group staff. Interested individuals provided demographic information via an online application, and the Project Convenor and Coordinator selected participants to ensure diversity. Focus group participants were given a \$50 stipend and reimbursed for childcare.

One focus group was conducted in Spanish, two focus groups were held for Tribal members and one focus group was for foster care alumni. The remainder were grouped by geographic proximity. There were a total of 57 participants, 49 women and eight men. Sixteen participants were older than 45 and nine were younger than 25. Six foster parents and three people who had been in foster care participated. More participant information is available in Appendix B.

Each focus group started with an introductory presentation from a trained volunteer about adverse childhood experiences and the ACEs/Strengthening Families Learning Collaborative. The facilitator then asked a series of questions that participants answered and discussed. The questions and answers are in Appendix C.

A Parent/Caregiver Advisory Committee (PAC) reviewed the information gathered in the focus groups and developed quidance recommendations based on focus group participant ideas. PAC members were recruited from the Idaho Head Start community and were selected based on their analytical ability, reliability, and commitment to quality. The group was a purposeful mix of people from different regions and people with and without experience with statewide working committees. PAC members were Rebecca Arteaga, Burley, Sara Ball, Idaho Falls, Patrina Campbell, Plummer, Rogelio Elizondo, Wilder, Anna Fields, Hayden, Russ Ludlow, Burley, Karey Perkins, Emmett, and Miriam Staffen, Twin Falls.

The PAC attended four 2-hour meetings over three months and completed about 12 hours of homework. PAC members were given a \$250 stipend.

**PAC Makes** Recommendations to Empower Parents/ **Caregivers** 

The PAC agreed on five high-priority recommendations for how pediatricians can respectfully conduct an ACE screening and provide supportive follow-up. They grouped the recommendations into four themes: commitment, education, relationship, and process. The PAC provided the reasoning behind their recommendations and provided suggestions on

specific actions providers can take. Follow-up was important to the pediatrician's focus group and the parent/caregiver focus groups, and the PAC decided to include a special section dedicated to follow-up in the report.

Personal empowerment was important to participants in every parent/caregiver focus group, and the PAC recommendations echo what they heard from the parents/caregivers. Participants were united in their desire to be empowered through knowledge about the impacts of adverse childhood experiences on themselves and their children. They want to understand the reasons their childhood experiences matter to the pediatrician and be assured the provider will help them get support and resources. They want to be empowered to make changes by working in a respectful partnership with the provider. Parent/ caregivers in all focus groups also expressed concern the ACEs screener would result in their parenting being criticized. Some parents/caregivers feared the removal of their children from their care. Participants said they would be more likely to take the ACEs screener and have an honest discussion with their pediatrician if it was a confidential and empowering process.

empowerment, not as an anchor.

-Focus group participant

#### **ONE: Commitment:**

Recommendation: Parents/caregivers should be given written or verbal assurance their ACE score and their specific ACEs won't be used to judge or test their parenting ability and that the information is confidential and won't be shared with anyone without permission.

> This is of highest priority because parents/caregivers expressed significant concern the pediatrician would judge them as a parent/caregiver based on their score. Parent/caregiver reactions to being asked to take the ACEs screener without this assurance include fear, worry, anger, confusion, and disdain. Several parents/caregivers expressed fear this information could lead to the removal of their children from their care.

Being judged is demeaning and makes a person feel bad about themselves and their ability to better themselves. Many parents/ caregivers of young children are learning how to parent and may feel insecure and be afraid they're not doing a good job. Parents/caregivers may be afraid they are being asked to take the screener because the provider thinks they are a bad person or parent. They want to know the questions are being asked to help them and their child, not criticize. Providing this assurance will show parent/caregivers respect, love, and compassion and empower them.

#### Focus group comments:

Would be a sea of red flags. I'm very careful what I say to medical professionals. It would terrify me.

When doctors ask questions, I don't always give the best answer because I feel I'm being judged.

Parents want to have the security of knowing that they won't be reported to CPS. I always think - if I tell my doctor this will they take my kids away? Sometimes I'm scared to ask my doctor things.

I would feel judged getting the screener without explanation. My mind automatically goes to fight or flight. What is the ulterior motive?

It would put parents as ease if there was a disclaimer at the top that says the answers won't be used to determine if you're a fit parent. That they won't take your child from you based on the answers.



#### Suggested **Actions:**

- Explain in writing and verbally how the information will and will not be used. An explicit explanation that the information will not be reported to Child Protective Services or to any other authority where they would get in trouble should be included in all information sharing about ACEs and the ACE screener.
- Put in writing that the provider adheres to a confidentiality policy and won't release the ACE screener information without authorization. Provide that to the parent/caregiver before the ACE screener is given. It can be months, weeks, or days ahead of the screener and it shouldn't be shared for the first time at the time of the screener.
- The provider should talk to the parent/caregiver and explain the HIPAA laws and who will have access to the information and what they'll do with the information.
- Offer the parent/caregiver an opportunity to ask questions.
- To demonstrate the information won't be used to judge or punish, the provider should tell the parent/caregiver in person they are gathering the information to help the parent/caregiver reach their full personal and parental potential. This should also be part of the written explanation.

**Recommendation:** Parents/caregiver should know there will be follow-up and should know the provider has helpful resources available before being asked to do the screening.

> This is crucial because parents/caregivers expressed significant reluctance to do the screening if they didn't know the provider would discuss it with them and if they weren't sure the provider would partner with them to improve family health. Many parents/caregivers have had frustrating and humiliating experiences carefully filling out forms that went into a medical black hole. They don't want to do things that will be ignored; they found that insulting.

Parents/caregivers want to make the best choices for their child and said they would gladly take the screener if it would have a positive effect on their child. It gave them hope to learn that it's not too late to address the impacts of their own childhood experiences. Several were happy to hear they don't have to be like their parents. It's empowering to know the provider believes they can overcome challenges and become a better parent/ caregiver.

The parents/caregivers said they would be more open and honest if they know the provider is asking out of concern. Thinking and talking about trauma can be upsetting and several parents/caregivers wanted to know support would be available immediately if it was needed. Telling the parents/caregiver there will be follow-up with resources proven to be helpful is a way the provider can demonstrate their respect and empathy for the parent/caregiver and empower them with knowledge.

comments:

Parents want to know the doctor can provide resources and tools to help overcome the impacts of ACEs.

The doctor should explain why they are asking the questions and tell you what they have for you and what they can teach you.

I've filled out surveys and then there's nothing. No one talks about it. There's no follow-up. If they're going to ask the questions, they need to do follow-up.

It's nice to know I can prevent my children from having the ACEs I've had. I don't want to pass them down.

It's important for your doctor to follow up. They are the first ones to get the information. They need to show they care and aren't just sending you off.





I'm more likely to read the screener and understand what the questions are getting at when I understand what the helpful resources are - counseling, child care, etc. The doctor should explain the types of resources right at the front.

After the person answers the question, the doctor should have helpful resources to give to them. Providing the resources is as important as asking the questions.

#### Suggested **Actions:**

- The provider should explain the services and support that are available to the parent/caregiver prior to the screener.
- The provider should explain that there is a new understanding of ACEs and how to prevent them and mitigate their impact. They should explain that previous generations didn't have this understanding.
- The first thing to ask after the ACEs screener is "How are you feeling?" The provider should debrief a bit after they do the screener. The screener could be triggering or traumatic. You're building rapport and gaining trust as well as helping the parent/caregiver process what they just read and maybe scored highly on.
- The provider should share an example of another person whose life was improved through ACEs awareness or maybe something from their own life to give hope and create a common connection.
- Some parents/caregivers like statistics and research results.
- The provider can say how learning about ACEs and making some life changes made a difference for others. And the provider can talk about how real people were helped by different programs, practices, and professional specialists.
- The provider should facilitate a warm handoff the provider should know the people he/she is referring the parent/caregiver to and reassure them the specialist will be able to answer questions and provide support.

#### TWO: Education

**Recommendation:** Parents/caregivers should be given information about ACEs before the screening. Information should be provided that explains the connection between the parent's/ caregiver's ACEs and their children's mental and physical health. They also want information about the purpose of the ACEs screener and how follow-up can benefit the child and parent/caregiver.

> The purpose and benefit of the ACEs screener isn't self-evident, so providing the education up front is critical to the screening process. Based on the participants in the focus groups, Idaho parents/caregivers are completely unfamiliar with ACEs and the ACEs screener. The screener questions are seen as unconnected with a well-baby visit or even worse, as prying, judgmental or hurtful. Being initially uninformed about something the parent/ caregiver then learns is very important can create feelings of quilt, inadequacy and embarrassment in the parent/caregiver. Parents/caregivers may be shocked when they learn their ACEs score.

Knowledge is power and a parent/caregiver that has a basic understanding will be less likely to feel talked down to and more likely to feel comfortable and safe taking the screener, talking about their ACEs, and taking action to improve family health. It's important to empower the parents/caregivers with the basic information – the purpose of the ACE screener and what they'll get out of it.

Focus group comments:



I would feel a little bit nervous and not understand how this pertains to my child's physical health. At a 4-month visit, your child's health is the normal topic. I would take a step back.

I'd think, 'this is not what we're here for.' I'd think I don't have time for this. It would be totally different if there was an explanation.

I enjoyed learning more about ACEs. It was eye opening and let you know as a parent that stuff that happened to you as a kid can affect your kids.



If we receive this information ahead of time, then we are well prepared. When we see it and are asked to fill it out, we wouldn't be afraid because we already understand.

I've never heard of ACEs before and that surprised

If I had known ahead of time about ACEs I wouldn't have been offended to be asked. They need to explain it to me in a way that's not condescending or gets my ire up.

I feel pressure in the doctor's office to just nod, but I'm not really getting it. Giving me time to process it would be very helpful.

#### Suggested Actions:

The provider should provide the following information ahead of the 4-month well-baby visit (or whenever they intend to offer the ACEs screener):

- Explain the acronym.
- What ACEs are and how they affect children.
- How the childhood experiences of the parent/caregiver impact the health and well-being of their children.
- People can't control what happened to them as children.
- The child and parent/caregiver will benefit from follow-up action.
- There are ways to heal from ACEs
- Explain the positive things about what the parent/caregiver can do to overcome the ACEs impact. Give hope.
- Explain the purpose of the screening.
- Assure the parent/caregiver the provider will help the parent/ caregiver strengthen family health.
- Share local statistics on prevalence of ACEs.

- Share stories of parent/caregiver success in strengthening their family.
- Include resources the parent/caregiver can use to empower themselves.
- Start the education as early as possible. Participants said it's never too soon to be educated about ACEs and prevention and mitigation strategies. There was wide and enthusiastic support for providing this information to parents/caregivers during pregnancy and at delivery. Participants said pregnant people are very curious and ready to take steps to benefit the baby and they often have more time than parents/caregivers of newborns.
- Focus group participants said they would be more comfortable taking the ACEs screener if they understood that children of parents/caregivers who experienced ACEs in their childhoods are more likely to experience ACEs and that ACEs can cause physical and mental health problems for the child that can last a lifetime. Some participants said that scientific data would be convincing. Many thought the provider should share information to help them understand ACEs were common and that many parents/caregivers face challenges created by their ACEs.

#### Suggested methods for providing the information:

- All information sent to parent/caregiver can include this language - "Screening parents/caregivers for adverse childhood experiences (ACEs) at 4-month well-baby visits is something new in our clinic. Click here to learn more about it."
- Simple flyer sent to the parent/caregiver in the email or mail – like other information the provider shares.
- Information should be provided for all educational levels and parents/caregivers should be encouraged to learn more if they desire.

- Posters on the wall of the exam room were suggested many times.
- A link to a short video clip that's shared with the check-in email. The parent/caregiver can watch it on their own time. This can be included with all the check-in emails for all the well-baby appointments. The repetition increases the chance they will watch it. Once they watch it, they will have the basic education.
- The video link could also be included in paper mailings.
- Provide written material in the waiting room. Many people read while they wait, especially first-time parents/ caregivers.
- The provider should review the material in person and ask if the parent/caregiver has questions at the 4-month checkup before they do the screener.
- A written or verbal explanation of how ACEs screening and follow-up can benefit the child and parent/caregiver.
- A verbal or written explanation of how parent/caregiver ACEs can impact the mental and physical health of the child and the mental and physical health of the parent/ caregiver.
- Provide information in a take-home packet so the parent/ caregiver can read it in private at their own speed instead of expecting them to figure it all out on the spot.
- Give the parent/caregiver time to think about the information.
- ACEs education can be provided in pre-natal classes that both parents/caregivers are encouraged to attend. ACEs education can also be provided in the WIC supplemental nutrition program because both parents/caregivers go there.

## THREE: Relationship

**Recommendation:** The provider needs to be respectful and compassionate. A trusting and wellestablished relationship needs to exist between the parent/caregiver and the pediatrician. The provider needs to be sensitive to culture.

> Building trust between the care providers and the patients is necessary due to the sensitive nature of the topic and the significant chance that the parent/caregiver would be reluctant to take the ACEs screener or answer truthfully. While some focus group participants said they trusted providers, the majority expressed concerns. Upon remembering previous provider visits, participants said they felt rushed, talked down to, scared, overwhelmed, and disrespected. Some said the provider didn't treat them as unique and special individuals. Participants mentioned the need for the provider to be sensitive to the mental health of the parent/caregiver. Participants have also experienced ethnic and racial prejudice. These negative past experiences must be overcome by providers creating safe environments for their patients. Participants said it takes time to build a trusting relationship and the relationship needs to be with the parent/caregiver and the child/children.

> The parent/caregiver wants to feel safe and valued. They want to be confident the provider cares for them and their child and wants to help. A listening and compassionate provider will create an empowering environment where discussion of ACEs will be welcome. To achieve the best results, parents/caregivers should feel the provider wants to help them reach their full parental potential. Participants advised waiting to do ACEs screening until a positive relationship was created between the provider and parent/caregiver. Parents/caregivers need to know that their culture is respected, and they are not going to be judged for something that is 'normal' with their culture. In some cultures, parents may feel a taboo about talking to outsiders about personal experiences.

#### Focus group comments:



Communication with medical professionals can be difficult and is a learned skill. The most important thing is a doctor who's willing to listen to you. The doctor has to be open and willing to listen to the patient or the patient won't want to take the action.

I'm scared to talk to doctors - they were authoritarian figures. Doctors should listen and have genuine care about their patients, have a heart, don't look at them like someone who's paying for the visit and walking out the door. If you don't have a genuine relationship, they won't want to share with you and nothing's going to change.

Why would I tell you about my trauma when you don't listen to me in the first place?

It's good when the pediatrician can connect with the child and not just relate to the parent.

#### Suggested Actions:

- Provide personal follow-up with a phone call or text.
- Provide a 24/7 platform for parents/caregivers to ask questions and be able to get answers without making an office visit – for example through MyChart.
- Bring up that everyone has experiences in their childhood that can negatively impact them.
- Share stories or experience from your own life, especially parenting experiences.
- Remember that people aren't all the same and care needs to be individualized.
- Show confidence in the parent/caregiver.
- Show patience and understanding.
- Have empathy for the childhood and current experiences of the parent/caregiver.

- Let the parent/caregiver know you are their partner in their work to create a healthy family.
- Let the parent/caregiver know they are welcome to call the provider with any questions big or small.
- Invite the parent/caregiver to opt into the ACEs screener and discussion.
- Have a basic understanding of what cultures your practice serves. Don't sound like one is better than the other. We are all equals.
- Be respectful, kind, compassionate.
- Include images of people from the cultures you are serving and use their language in educational materials.
- Do your homework and show you understand different cultures have different attitudes about privacy and different understandings of normal behavior.

#### Suggested Scripts:

I'm not here to criticize you or judge you or pry into your life. I want you to know that I'm here to help you, educate you, help you feel empowered to be able to overcome any obstacles you may have.

I understand that parenting is hard. Let's look at things that might make parenting harder for you and see if I can help you. Let's see if I can get you resources to help make this journey easier.

Moving forward with your best care, I want to share with you some important information and get some information from you to get the best health outcomes for you and your child. Would you like to learn more about that, and can I share this screener with you?

I completely understand that this is sensitive information, but I want to reassure you that I'm here to learn from you so I can understand how I can help you.

Many of these childhood experiences can influence how you are as a parent. I think it would be a good idea to go over these and it would be beneficial to you. Is it OK if we go over these questions? As a physician, this is confidential, nothing we discuss will leave this room. I want to make sure you're comfortable doing this so we can best help you and your child.

Adverse Childhood Experiences (ACEs) - is the screener I would like to offer you to complete, but before we begin, I'd like to explain what adverse means. It means unfavorable, it means acting against you. As a child we all experience good and bad experiences and both of those types of experiences help form the direction we follow, or the person we become. I would like to help you understand the challenges these good or bad experiences may bring to your children and to you, and I would like to help prevent the experiences that may deliver a negative impact to you and your children's mental and physical health in the future.

You may have experienced difficult times in your past. I'm so sorry for what you experienced. My hope is to help you take action and find support to heal from those difficult times and improve the mental and physical health of you and your child. When we know better, we do better. Our experiences, good and bad, influence who we become, but you can take charge and create the happy healthy life you want for your family.

#### **FOUR: Process**

#### **Recommendation:**

The provider needs to make it easy for the parent/caregiver to do the screening by creating a calm, unrushed and private environment, and a flexible and respectful process.

> This is of high importance because it's the process that makes the experience safe and empowering not traumatic or demeaning. Getting this right is the pinnacle of patient-centered care because this is where the opinions of the participants varied widely. What's empowering and safe to one person might not

feel that way to someone else. The provider needs to be able to meet the parent/caregiver where they are and customize the process to meet their needs. A patient-centered process is the key to ultimate success because it creates the opportunity for good things to follow the ACE screener. Administering the ACEs screener is not the solution, it's the information gathering tool and conversation starter.

#### Focus group comments:

The environment plays a major role. Warmer visuals, how the room is set up, whether the atmosphere is open and inviting - doesn't necessarily look like a doctor's office. This will help, especially with young mothers who might feel like they are being judged. It will be much easier to open up.

The doctor should present the information to you at one appointment and then ask the questions at the next appointment. Then you can get prepared as to what you'll be answering. Because you might start crying in front of your kids. I wouldn't feel good answering the questions in front of my older children.

It would probably be safer to do this at the doctor's office as compared with by mail where the husband could see it. If there is an abusive relationship. And it's harder to open up in that situation too.

If we receive this information ahead of time, then we are well prepared. When we see it and are asked to fill it out, we wouldn't be afraid because we already understand.

It should be done in the doctor's office. First verbally discussed and then fill it out in private.

I'd like to have it digital. Then I'll have more time to read it thoroughly and not be rushed like I am in the office.



#### Suggested **Actions:**

- Create a relaxed and welcoming environment.
- Make everything easy to understand to alleviate fears about hidden agendas.
- Give the parent/caregiver options on how and when to do the ACEs screener and who should do it.
  - ♦ Provide an email link before the visit, so the parent/ caregiver can do it on their own time.
  - ♦ Fill out the screener during self-check-in to decrease the feeling of being judged.
  - ♦ Have the nurse explain it and give it to the parent/ caregiver while they wait for the doctor.
  - Include it in with the health history.
  - Do it on an IPAD with a short video before and after the screener.
- Have a trained person explain and answer questions before the screener and be available to stay for support if requested.
- Work with the parent/caregiver to determine if the screener should be given when their children are present.
- Expect all parent/caregivers will take the ACE screener and make it easy for them by offering a variety of ways to take the screener. Don't require the person to come to the office. Make sure everyone who's invited to take the screener gets the same education and follow-up.
- Participants had different preferences for taking the screener, some preferred in person at the provider's office, others preferred at home. There are advantages of both. Some expressed concern about taking the screener in front of their children. The PAC agreed that it would be best to offer options on when and how to take the screener. The

provider can say, "You don't need to tell me today. But I would like to know. Because I care. You can come to me at a better time."

- The PAC agreed that it's best to start with the de-identified screener which allows the respondents indicate only the total score — without identifying which ACEs they experienced.
- The overall ACEs number provides the provider enough information to determine next steps without having to know which ACEs the patient experienced.
- Some participants and PAC members were enthusiastic about offering the screener on an erasable form to ease fears of the information getting out and being used against them. The use of the de-identified screener where the only information that's saved is the ACEs score coupled with the #1 recommendation to absolutely make it clear that the information is confidential and won't be shared or used to judge their parenting made it acceptable to add the ACEs score to the medical record.

## Culture-specific Comments:

Participants in the culture-specific focus groups shared many concerns with participants in the other groups, however cultural differences were identified. These differences speak to the need to use culturally specific approaches when administering the ACEs screener.



#### **Hispanic Focus Group Comments**

Don't just offer the screener once because the timing may not be right. The Hispanic community isn't used to being open about these topics. It will be hard for the Hispanic community since we've been taught to tough it out.

There are no bilingual resources or very few. Sometimes the message gets distorted as they translate from English to Spanish. Resources need to be developed in Spanish.



#### **Tribal Focus Groups Comments**

We hold a lot of honor in my family, and we don't want to smear our own names.

Being honest and forthcoming to doctors and any kind of authority is not what's passed on to us. We've learned from a long time ago because of what's happened to our people to not tell the truth.

It feels better when it's coming from an elder or from your mom or grandma, or someone I can relate to. We need to see it everywhere but represented by our community and how we see each other.

The doctors change and it's hard to build a good relationship, but the nurses are the same.

We don't turn to outside institutions for help. Our family turns to Circle where we are around family and friends who hear you. They are a place to talk and heal.

Awful things happened to our grandparents in the boarding schools, and it's trickled down from that time.

Using our language will make a direct connection to me. And it shows the caregivers care, and they recognize the Tribe and your heritage and see you as an individual and as a nation.

Use Coyote stories or other indigenous stories. And stories from elders. Bring our culture into it.



## Foster Care Focus Group Comments

I had to do a lot of questionnaires as a child. Just seeing it makes my anxiety build. It also triggers memories of those experience and increases agitation.

I get anxious about giving the 'wrong' answers and getting in trouble.

# Recommendations for Empowering Follow-up:

The PAC emphasized the importance of using ACEs screening and follow-up to empower parents/caregivers to create safe, stable and nurturing homes that allow their children to be healthy and resilient. The PAC agreed on the following general quidelines for follow-up.

- Follow-up needs to be individualized, and the provider needs to listen carefully to the parent/caregiver. Dr. Deirdre Bernard-Pearl explains, "Many people with ACEs don't want an intervention. Maybe they're not ready for something. Or maybe they don't need anything. It's been a very humbling process where we've learned to make a shift from the medical model of telling people with positive screens what to do, to being much more humble and asking them what is it that they want or need." (www.pacesconnection.com/q/california-acesaction/blog/how-do-these-pediatricians-do-acesscreening-early-adopters-tell-all).
- Follow-up should include an explanation that positive experiences counteract adverse experiences, create resilience and improve health and wellness.
- Follow-up should not create more stress.
- Follow-up that is low cost or free and, whenever possible, doesn't require a person to miss work, should be considered first.

A wide range of follow-up actions was suggested during the focus groups, and the PAC grouped them into three categories: concrete supports, professional referrals and peer support referrals/self help.

## Concrete supports:

Maslow's hierarchy of needs tells us that for anyone to focus on higher order growth and development, they must first have their basic needs met. This is apropos to how people may respond to ACEs screening and follow-up. Concrete supports, including help getting food, clothing, and shelter, are critical and will decrease household stress and increase the parents/caregiver's ability to create a safe, stable and nurturing family environment.

Resource availability varies across the state so connection to and knowledge of local resources is crucial. Medical practices should have knowledge of community resources for food, clothing, and shelter. Concrete supports also include home visiting, parenting tips and classes and free recreational programs. A digital or paper comprehensive list of resources would be good for the providers to provide after the appointment.

## Referral to professionals:

Focus group participants said it would be empowering for the provider to provide a range of professional follow-up options from which the patient could choose. The choice of intervention would be influenced by the adversities a person experienced and the mitigating positive experiences they had. Most often participants suggested referral to a mental health professional: psychologist, counselor, therapist, or social worker. Some participants reacted negatively to referral to a social worker based on previous experience with Child Protective Services. Participants recommended use of an educational resource that explained the types of mental health professionals.

Classes or group counseling to help people overcome challenges brought on by ACEs – like setting boundaries and co-dependency – were suggested as were drug and alcohol counseling and rehabilitation services.

## Peer support referrals and self help:

Peer support was a well-received option for follow-up as was self-help. People find it therapeutic to connect to others with similar experiences. Increasingly younger parents/caregivers rely on social media and want to connect through those channels

to find information and seek help. Tribal members get support from traditional community practices. Participant suggestions included:

- Create opportunities for families to provide service and other positive activities together.
- Provide learning opportunities such as learning about empathy.
- Create a closed Facebook group (and on platforms like Discord and Twitter) for people who have ACEs and want to share and ask questions.
- Develop peer support opportunities, both formal and informal to share information about ACEs.
- Develop simple videos on how to seek help that could be used by both patients and providers.
- Providers should have social media pages to share information.

Focus group

Follow-up needs to be case by case. CPS caseworkers may traumatize the parent, but not every parent will have that reaction. You must wait until the patient wants to do follow-up. The doctor should ask the patient and then give treatment options.

Doctors should listen and have genuine care about their patients, have a heart, don't look at them like someone who's paying for the visit and walking out the door. If you don't have a genuine relationship, they won't want to share with you and nothing's going to change.

Have to accommodate based on the individual. An email follow-up may be enough for one person, a phone call for another. Not just leave it at that; do follow-up in 1 month, 3 months, 6 months, 1 year.



People aren't all the same and care needs to be individualized.

The doctor should explain and reiterate that an increase in positive experience can improve health and wellness. This is a good jumping off point to talk about how the parent can provide positive experiences.

Ask the patient who they would be comfortable with, a parent recommended. There's always a power differential; you need consent.

#### Resources for Follow-up:

Many programs, services and professionals are available in Idaho to support stable, safe and nurturing families. Pediatricians can consult resource and referral networks for ACEs screening follow-up. These include the 211 Careline run by the Idaho Department of Health and Welfare (IDHW). 211 provides referrals to basic needs as well as connections to crisis services. Another electronic referral system called "Aunt Bertha" is available at www.findhelp.org. It's searchable by zip code. St Luke's Children's has a toolkit of local, state and national ACEs resources at https://projects.ihawcc.org/public/ adverse-childhood-experiences-resiliency-lc. It's also important for providers to develop collaborative relationships within their community to learn about local programs, services, and professionals that can help their patients.





This publication was made possible by B04MC33834 from the U.S. Department of Health and Human Services. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Department or HHS. October 2021.