Screening Adolescents for ACES in SBHCs

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• No commercial disclosures

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What we will cover

• Why screen for ACES
• Trauma-Informed Approaches to Screening
• Using the PEARL screener to open up conversations with youth and families,
• Screening issues for special populations,
• Mandated reporting
• Confidential medical records.
Adverse Childhood Experiences (ACES) - child abuse, neglect, household dysfunction,

Social Determinants of Health - social and material needs essential for good health (such as stable housing and utilities, sufficient food, freedom from racism, homophobia, anti-immigrant discrimination)

Toxic stress - severe and ongoing stress, such as extreme poverty, racism, abuse or neglect, without sufficient adult support, that can harm children's developing brains and can lead to changes in how they respond to stress and damage to their immune systems

Positive Childhood Experiences - include parent-child attachment, positive parenting (e.g., parental warmth, responsiveness, and support), family health, and positive relationships with friends, in school, and in the community.
Impact of ACES

All of this evidence is epidemiological

Supported by research on the impact of toxic stress on children & adults

Long-term Impact of strategies to mitigate toxic stress still unknown
Preventing ACES could prevent...

Estimates based on 2017 Behavioral Risk Factor Surveillance System (BRFSS)

https://www.cdc.gov/vitalsigns/aces/index.html
ACEs & Overall child health at 18

Study followed children from birth to 18 years
804 adolescents w complete data
ACEs Scores similar to early childhood scores
  Total of 8 categories (vs.10)
  Maternal depression a category
Three groups analyzed
  Early childhood ACES only (7%)
  Chronic ACES (across childhood) (69%)
  Limited ACES across childhood (24%)
Overall self-evaluation of health
  overall worry about health
  Use/need for medical care
  Self-rating of health

For most children, ACES exposure diminished in older childhood, adolescence
Most common: neglect and caregiver depression
Chronic ACES group had more health worries, more medical care
Early ACES and limited ACES had similar scores
No impact of ACES on health self-report
3 Realms of ACEs

Adverse childhood and community experiences (ACEs) can occur in the household, the community, or in the environment and cause toxic stress. Left unaddressed, toxic stress from ACEs harms children and families, organizations, systems and communities, and reduces the ability of individuals and entities to respond to stressful events with resiliency. Research has shown that there are many ways to reduce and heal from toxic stress and build healthy, caring communities.

1. Household
- Sexual abuse
- Emotional neglect
- Physical neglect
- Domestic violence
- Divorce
- Incarcerated family member
- Maternal depression

2. Community
- Lack of affordable housing
- Food insecurity
- Structural racism
- Substandard schools
- Lack of jobs
- Poor water and air quality

3. Environment
- Climate crisis
- Natural disasters
- Pandemic
- Record heat & droughts
- Wildfires & smoke
- Record storms, flooding & mudslides
- Sea level rise

Thanks to Building Community Resilience Collaborative and Networks and the International Transformational Resilience Coalition for inspiration and guidance. Please visit ACESConnection.com to learn more about the science of ACEs and join the movement to prevent ACEs, heal trauma and build resilience.
Systemic Racism

Redlining in Oakland, Berkeley, Alameda, San Leandro, Piedmont, Emeryville and Albany

"Best"
"Hazardous"

Tiffany Nguyen / Staff
Source: University of Richmond’s Mapping Inequality project and Berkeley News
Hispanic and Black parents more likely than White parents to be concerned about access-related barriers to COVID-19 vaccination for their children.

Percent of parents of unvaccinated children ages 12-17 who say they are very or somewhat concerned about each of the following:

<table>
<thead>
<tr>
<th>Issue</th>
<th>Total parents of unvaccinated children ages 12-17</th>
<th>Black parents</th>
<th>Hispanic parents</th>
<th>White parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not enough is known about the long-term effects of the COVID-19 vaccine in children</td>
<td>88%</td>
<td>87%</td>
<td>89%</td>
<td>89%</td>
</tr>
<tr>
<td>Their child might experience serious side effects from the COVID-19 vaccine</td>
<td>79%</td>
<td>82%</td>
<td>84%</td>
<td>75%</td>
</tr>
<tr>
<td>The COVID-19 vaccine may negatively impact their child’s fertility in the future</td>
<td>73%</td>
<td>72%</td>
<td>79%</td>
<td>71%</td>
</tr>
<tr>
<td>Their child might be required to get the COVID-19 vaccine even if they don’t want them to</td>
<td>65%</td>
<td>57%</td>
<td>73%</td>
<td>65%</td>
</tr>
<tr>
<td>They might need to take time off work to bring their child to get vaccinated or to care for them if they experience side effects</td>
<td>32%</td>
<td>34%</td>
<td>49%</td>
<td>24%</td>
</tr>
<tr>
<td>They won’t be able to get the vaccine for their child from a place they trust</td>
<td>24%</td>
<td>28%</td>
<td>49%</td>
<td>16%</td>
</tr>
<tr>
<td>They might have to pay an out-of-pocket cost to get the COVID-19 vaccine for their child</td>
<td>18%</td>
<td>30%</td>
<td>34%</td>
<td>11%</td>
</tr>
<tr>
<td>They will have difficulty travelling to a place to get their child vaccinated</td>
<td>17%</td>
<td>24%</td>
<td>40%</td>
<td>8%</td>
</tr>
</tbody>
</table>

NOTE: Among parents or guardians of children ages 12-17 who have not received a COVID-19 vaccine. See topline for full question wording.
Controversies about screening for ACES

- Concerns about “disclosure-driven services” vs. universal provision of services
  - Only available to those with disclosures of adversity?
  - Clients may feel pressure to disclose, lose control of the narrative of their own experiences

- Support of families w/ more adversity vs. Increased monitoring of BIPOC and poor families

- Impact of screening for ACES without also screening for positive childhood experiences and child/family strengths
Approaches to screening in primary care

Traditional:

Health screening to discover early signs of treatable health problems, reverse or minimize disease, prevent spread

examples: blood lead levels, tuberculosis, developmental milestones

“We screen for what we can treat”

Trauma-informed screening: opening up a conversation with children and families about adversity in order to partner with them
What is a trauma-informed approach?
What is wrong with you?

What happened to you?

What is right with you?
Framework for Screening

Critical to implement ACEs screening in the context of broader **trauma-informed care**

Screening and TIC may be more **challenging in the time of COVID** (and there may also be opportunities)

Very **little research** with adolescent populations and within school-based settings
Elmhurst United Middle School

Public middle school serving 6th-8th graders in East Oakland, CA

Enrollment data 2019-2020

- 716 students
  - 24% African American, 68% Latino, 4% Asian and 4% more than 1 ethnicity
  - 90.4% students eligible for free/reduced price meals
  - 39.5% students are English learners
    - Languages spoken: Spanish, Arabic, Amharic, Tongan

Started PEARLS screening January 2021 at SBHC for well child exams
PEARL Screener Parent Form 0-12, de-identified


PART 1:

1. Has your child ever lived with a parent/caregiver who went to jail/prison?
2. Do you think your child ever felt unsupported, unloved and/or unprotected?
3. Has your child ever lived with a parent/caregiver who had mental health issues?
   (for example, depression, schizophrenia, bipolar disorder, PTSD, or an anxiety disorder)
4. Has a parent/caregiver ever insulted, humiliated, or put down your child?
5. Has the child's biological parent or any caregiver ever had, or currently has a problem with too much alcohol, street drugs or prescription medications use?
6. Has your child ever lacked appropriate care by any caregiver?
   (for example, not being protected from unsafe situations, or not cared for when sick or injured even when the resources were available)
7. Has your child ever been separated from a parent/caregiver being screamed at, sworn at, insulted or humiliated by another adult?
   Or has your child ever been heard a parent/caregiver being slapped, kicked, punched beaten up or hurt with a weapon?
8. Has any adult in the household often or very often pushed, grabbed, slapped or thrown something at your child?
   Or has any adult in the household ever hit your child so hard that your child had marks or was injured?
   Or has any adult in the household ever threatened your child or acted in a way that made your child afraid that they might be hurt?
9. Has your child ever experienced sexual abuse?
   (for example, anyone touched your child or asked your child to touch that person in a way that was unwanted, or made your child feel uncomfortable, or anyone ever attempted or actually had oral, anal, or vaginal sex with your child)
10. Have there ever been significant changes in the relationship status of the child's caregiver(s)?
    (for example, a parent/caregiver got a divorce or separated, or a romantic partner moved in or out)

Add up the “yes” answers for this first section: 

Add up the “yes” answers for the second section:

Click here to continue.

This tool was created in partnership with UCSF School of Medicine.

PEARL Screener Parent Form 0-12, de-identified

**PEARL Screener Adolescent Self-Report, de-identified**

At any point in time since you were born, have you seen or been present when the following experiences happened? Please include past and present experiences.

Please note, some questions have more than one part separated by "OR." If any part of the question is answered "Yes," then the answer to the entire question is "Yes."

**PART 1:**

1. Have you ever lived with a parent/caregiver who went to jail/prison?

2. Have you ever felt unsupported, unloved and/or unprotected?

3. Have you ever lived with a parent/caregiver who had mental health issues?
   (for example, depression, schizophrenia, bipolar disorder, PTSD, or an anxiety disorder)

4. Has a parent/caregiver ever insulted, humiliated, or put you down?

5. Has your biological parent or any caregiver ever had, or currently has a problem with too much alcohol, street drugs or prescription medications use?

6. Have you ever lacked appropriate care by any caregiver?
   (for example, not being protected from unsafe situations, or not being cared for when sick or injured even when the resources were available)

7. Have you ever seen or heard a parent/caregiver being screamed at, sworn at, insulted or humiliated by another adult?
   Or have you ever seen or heard a parent/caregiver being slapped, kicked, punched beaten up or hurt with a weapon?

8. Has any adult in the household often or very often pushed, grabbed, slapped or thrown something at you?
   Or has any adult in the household ever hit you so hard that you had marks or were injured?
   Or has any adult in the household threatened you or acted in a way that made you afraid that you might be hurt?

9. Have you ever experienced sexual abuse?
   (for example, anyone touched you or asked you to touch that person in a way that was unwanted, or made you feel uncomfortable, or anyone ever attempted or actually had oral, anal, or vaginal sex with you)

10. Have there ever been significant changes in the relationship status of your caregiver(s)?
    (for example, a parent/caregiver got a divorce or separated, or a romantic partner moved in or out)

Add up the "yes" answers for this first section:

**PART 2:**

1. Have you ever seen, heard, or been a victim of violence in your neighborhood, community or school?
   (for example, targeted bullying, assault or other violent actions, war or terrorism)

2. Have you experienced discrimination?
   (for example, being harassed or made to feel inferior or excluded because of their race, ethnicity, gender identity, sexual orientation, religion, learning differences, or disabilities)

3. Have you ever had problems with housing?
   (for example, being homeless, not having a stable place to live, moved more than two times in a six-month period, faced eviction or foreclosure, or had to live with multiple families or family members)

4. Have you ever worried that you did not have enough food to eat or that food would run out before you or your parent/caregiver could buy more?

5. Have you ever been separated from your parent or caregiver due to foster care, or immigration?

6. Have you ever lived with a parent/caregiver who had a serious physical illness or disability?

7. Have you ever lived with a parent or caregiver who died?

8. Have you ever been detained, arrested or incarcerated?

9. Have you experienced verbal or physical abuse or threats from a romantic partner?
   (for example, a boyfriend or girlfriend)

Add up the “yes” answers for the second section: 

CHOOSING SUMMARY SCORE VS. IDENTIFIED ACES

**Pediatric ACES and Related Life Events Screener (PEARLS)**

**TEEN (Parent/Caregiver Report)** - To be completed by Caregiver

At any point in time since your child was born, have you seen or been present when the following experiences happened? Please include past and present experiences.

Please note, some questions have more than one part separated by “OR.” If any part of the question is answered “Yes,” then the answer to the entire question is “Yes.”

**PART 1:**

1. Has your child ever lived with a parent/caregiver who went to jail/prison? [ ]
2. Do you think your child ever felt unsupported, abused, and/or unprotected? [ ]
3. Has your child ever lived with a parent/caregiver who had mental health issues? (for example, depression, schizophrenia, bipolar disorder, PTSD, or an anxiety disorder) [ ]
4. Has a parent/caregiver ever insulted, humiliated, or put down your child? [ ]
5. Has the child’s biological parent or any caregiver ever had, or currently has a problem with too much alcohol, street drugs, or prescription medications use? [ ]
6. Has your child ever lacked appropriate care by any caregiver? (for example, not being protected from unsafe situations, or not being cared for when sick or injured even when the resources were available) [ ]
7. Has your child ever seen or heard a parent/caregiver being screamed at, sworn at, insulted or humiliated by another adult? [ ]
8. Has your child ever seen or heard a parent/caregiver being slapped, kicked, punched, beaten up or hurt with a weapon? [ ]
9. Has any adult in the household often or very often pushed, grabbed, slapped or thrown something at your child? [ ]
10. Has any adult in the household ever hit your child so hard that your child had marks or was injured? [ ]
11. Has your child ever experienced sexual abuse? (for example, anyone touched your child or asked your child to touch that person in a way that was unwanted, or made your child feel uncomfortable, or anyone ever attempted or actually had oral, anal, or vaginal sex with your child) [ ]
12. Have there ever been significant changes in the relationship status of the child’s caregiver(s)? (for example, a parent/caregiver got a divorce or separated, or a romantic partner moved in or out) [ ]

Add up the “yes” answers for this section: [ ]

Please continue to the other side for the rest of the questions.

**PART 2:**

1. Have you ever lived with a parent/caregiver who went to jail/prison? [ ]
2. Have you ever felt unsupported, abused, and/or unprotected? [ ]
3. Have you ever lived with a parent/caregiver who had mental health issues? (for example, depression, schizophrenia, bipolar disorder, PTSD, or an anxiety disorder) [ ]
4. Has a parent/caregiver ever insulted, humiliated, or put down you? [ ]
5. Has your biological parent or any caregiver ever had, or currently has a problem with too much alcohol, street drugs, or prescription medications use? [ ]
6. Has your child ever lacked appropriate care by any caregiver? (for example, not being protected from unsafe situations, or not being cared for when sick or injured even when the resources were available) [ ]
7. Has your child ever seen or heard a parent/caregiver being screamed at, sworn at, insulted or humiliated by another adult? [ ]
8. Has any adult in the household often or very often pushed, grabbed, slapped or thrown something at your child? [ ]
9. Has any adult in the household ever hit your child so hard that your child had marks or was injured? [ ]
10. Has your child ever experienced sexual abuse? (for example, anyone touched your child or asked your child to touch that person in a way that was unwanted, or made your child feel uncomfortable, or anyone ever attempted or actually had oral, anal, or vaginal sex with you) [ ]
11. Have there ever been significant changes in the relationship status of your caregiver(s)? (for example, a parent/caregiver got a divorce or separated, or a romantic partner moved in or out) [ ]

How many “Yes” did you answer in Part 1? [ ]

Please continue to the other side for the rest of the questions.

This tool was created in partnership with UCSF School of Medicine.
Figure 1. ACEs Aware ACE Screening Pediatric Clinical Workflow

1a. Introducing the ACE Screening Purpose & Tool

Registration or clinical staff reviews patient's record to determine if PEARLS screen indicated during visit. Staff provides PEARLS tool to caregiver (0-19 years) and/or patient (12-19 years) in private setting.

2b. Receiving an Incomplete Screening Tool Back

Caregiver (0-19 years) and/or patient (12-19 years) completes PEARLS.

Provider provides education about how ACEs and buffering practices and interventions can affect health and offers patient/family opportunity to discuss and/or complete PEARLS screen.

2a. Reviewing ACE Screening Results & Treatment Plan

Screen complete

Provider or Medical Assistant transcribes ACE score (Part 1 of PEARLS tool) into EMR.

Provider reviews screen with patient/family and follows appropriate risk assessment algorithm: incomplete or at low, intermediate, or high risk for toxic stress.

Provider documents ACE score, billing code, and treatment plan, follow-up in visit note.

3. Following up on the Treatment Plan

Provider reviews ACE score, treatment plan, and follow-up prior to next visit; at next visit, updates as needed.
Dear Parent or Caregiver,

At your child's visits, we often ask you to complete a few questionnaires before meeting with your provider.

**Why do we ask these questions?**
While we’re the experts in children’s health, you are the expert on your child. Your child’s daily experiences affect their health. We want to make sure your child receives the best quality care, both physically and emotionally, and answering these questions gives your provider a clue on what is going well with your child and where you and your child may want some more support.

**We're here to help.**
We know answering these questions may be hard, so these questions are optional. Or you may choose to fill it out later and return it to our clinic. All your answers will be kept confidential. On page 2 is a list of resources that may help support your child and family. Feel free to keep this coversheet as a reference.

Your provider will review your answers to the questionnaire and may discuss available resources for support. Feel free to ask questions. We're here to help if you want us to.

Thank you,

LifeLong Medical Care – School Based Health Centers

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**COMMUNITY RESOURCES**

- **Dial 2.1.1.** for support with community resources such as access to food, shelter, legal advice
- **Food Bank 1-855-309-3663**
- **CalFresh 1-877-505-4630**
- **Trouble paying rent?** California State law protects you from eviction thru September 30, 2021 if you continue to pay at least 25% of your rent
- **Rent assistance through East Bay Housing Organizations** – call 510-899-9289, 510-860-4985 or 510-452-4541 Rent relief for low income tenants or those at risk for homelessness
- **Housing problem?** If you need help contact ECHO HOUSING 22551 Second Street # 200 Hayward, CA 94541 (510) 581-9380 or 855-ASK-ECHO
- **Family Justice Center** – 470 27th St, Oakland 94612 (510) 267-8800 - provides Family support with issues regarding domestic violence
- **Call SENECA at 1-877-441-1089** for support with accessing Behavioral Health crisis intervention
Understanding ACEs

ACEs (Adverse Childhood Experiences) are serious childhood traumas that can result in toxic stress. Prolonged exposure to ACEs can create toxic stress, which can damage the developing brain and body of children and affect overall health. Toxic stress may prevent a child from learning or playing in a healthy way with other children, and can cause long-term health problems.

- Increases problems with learning and memory.
- Increases difficulty in making friends and maintaining relationships.
- Increases stress hormones which affect the body's ability to fight infection.
- May cause lasting health problems.

Exposure to childhood ACEs can increase the risk of:
- Adolescent pregnancy
- Alcohol and drug abuse
- Asthma
- Depression
- Heart disease
- Intimate partner violence
- Liver disease
- Sexually transmitted disease
- Suicide

What is resilience?
Research shows that if caregivers provide a safe environment for children and teach them how to be resilient, that helps reduce the effects of ACEs.

What does resilience look like?
Having resilient parents and caregivers who know how to solve problems, have healthy relationships with other adults, and build healthy relationships with children.

Building attachment and nurturing relationships:
Adults who listen and respond patiently to a child in a supportive way, and pay attention to a child's physical and emotional needs.

Building social and emotional skills:
Help children interact in a healthy way with others, manage emotions, communicate their feelings and needs, and rebound after loss and pain.

Resources:
- ACEs Too High
- ACES Connection
- Resource Center
- Parenting with ACEs

"Children with ACEs find 'resilience' because an adult provides a safe environment — in which they feel known, validated."
Donna Jackson Nakazawa
Author of Childhood Disrupted: How Your Biography Becomes Your Biology & How You Can Heal
POST-SCREENING COMPLETION FEEDBACK

1. How comfortable were you filling out this form?
   ¿Que tan cómodo estuvo llenando estas formas?
   1-Uncomfortable/Incomodo
   2
   3 – Neutral/Neutra
   4
   5-Very comfortable/Muy comodo

2. Do you understand why we are doing this screen?
   ¿Entiende usted porque estamos haciendo estas preguntas?
   Yes/ Sí
   Somewhat/Un poco
   No

3. In spite of everything going on, what is going well for you and your family right now?
   ¿A pesar de todo lo que esta pasando ahora, que hay de sueno para ti y tu familia?

4. What hobby/activity do you and your family enjoy doing together?
   ¿Que actividades o pasatiempos son los que tu y tu familia disfrutan juntos?

5. What are your dreams for your child?
   ¿Cuales son tus sueñas para tu hijo/hija?
Out of 86 feedback questionnaires received, 81% of parents/guardians reported being very comfortable with the PEARLS screener while 90% stated they understood why we were doing the screener.

“Tenemos un nuevo hogar”
“No one caught Covid”
“We both have jobs and are able to provide for our kids. Zoom school is not ideal and very difficult on our family”

“Salir al parque”
“Hacemos comidas en casa como carnes asadas”

“Que estudio y sea profesional en lo que le gusta”
This algorithm pertains to the ACE score (Part 1 of PEARLS), whose associations with health conditions are most precisely known. Social determinants of health (Part 2 of PEARLS) may also increase risk for a toxic stress response and should be addressed with appropriate services, but should NOT be added to the ACE score for this patient.
Documentation and Billing

Become certified [https://training.acesaware.org/](https://training.acesaware.org/)

Medical providers are eligible for $29 payment for ACE screenings

- Includes FQHCs, RHCs, CBRCs, and IHS

Billing coding is based on total ACE score

- G9919: ACE score 4 or more (high risk)
- G9920: ACE score 0-3 (low risk)

Documentation must include:

- Screening tool used
- Completed screen reviewed
- Results of screen
- Interpretation of results
- What was discussed with patient/family and actions taken

Screen periodically: 1 time per year, per clinician/managed care plan
Population Based Screenings

Assess mental, physical and reproductive health

• Integrated into schools
  Annual mass screenings
  Sports physicals
  Reproductive health visits

• Integrated into primary care
  Annual physical exam
  Sick visits (psychosomatic symptoms, reproductive visits, etc.)

• Increase health promotion and access to care

Shared Goal: Optimal wellbeing and success for all students
Rapid Assessment for Adolescent Preventive Services (RAAPS)

www.possibilitiesforchange.com/raaps

Standardized and validated assessment

Age specific
- RAAPS-OC 9-12 years
- RAAPS 13-17 years
- RAAPS-CA 18-24 years

Addresses social determinants for health

Recognized by leading organizations

Yearly subscription
RAAPS (13-18yrs)
Screening

'I AGREE' IN ORDER TO START THE SURVEY:
This survey asks you about things like eating habits, safety, violence, drug use, sexuality and emotions. Be sure to answer every question as honestly as possible by checking the box next to your answer.

This survey is confidential, meaning that your answers are not shared with anyone (not even your parents) unless we have reason to believe that you are hurting yourself or someone else or that someone is hurting you.
Talk to the person who asked you to complete this module if you have any questions or concerns.
If you understand and agree to continue with this survey, click on the 'I Agree' button below:

In the past 3 months, have you used any form of nicotine including *vaping* (e-cigarettes, Juul, RUBI, Suorin, Blu, hookah, vape pens), *smoking* (cigarettes, cigars, black and mild) or *chewing* tobacco (dip, chew, snus)?

During the past month, have you been threatened, teased, or hurt by someone (on the internet, by text, or in person) causing you to feel sad, unsafe, or afraid?
Possible Interventions

- Case Management/COST Team
  - Coordinate with team and community partners for basic/immediate needs and outside services/long term care

- Individual Counseling
  - Brief Intervention Model
    - Refer out if client is high risk/needs long term counseling

- Group Counseling

- Family Counseling/Engagement
  - Parent education groups
  - Afterschool tutoring

- Check-Ins/Check-Outs

- ETOH/Drug/Tobacco Counseling

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- SBHC provider F/U
- Behavioral Health
- Health campaigns
- Grief group
- Girls group
- CBITS trauma group
Self Care Tools

Exercise
- Walking 20 minutes a day

Nutrition
- Eat breakfast
- Increase water and decrease sugary beverages
- Increase whole grains

Sleep
- No screen 30 min before bed
- Shower/bathe before bed

Mindfulness
- Yoga
- Mindful breathing
- Apps (Calm, Headspace)

Connect to nature
Youth in Foster and Kinship Care

• Change in caregivers – deciding whom to screen
• Screening by mandated reporters may be a barrier
• Inconsistent or transient access to care – ensuring follow-up
• Navigation of services and trust building – care often based outside the SBHC
• Multiple ACEs are almost a given – does screening help?
  • Rebbe, et al (2017): mean 7.92
  • Liming, Brook, & Akin (2021: mean 8.3
• Impact of repeated disclosure of trauma
• Foster care as a source of ACEs
History of Incarceration

• Navigation of services and trust building – care often based outside the SBHC
• Multiple ACEs are almost a given – does screening help?
  • Clements-Nolle & Waddington (2019) – mean 3.7
• Incarceration as a source of ACEs
• Internal resilience and school connectedness moderate (reduce) relationship between ACE exposure and psychological distress (Clements-Nolle, 2019)
• Restorative justice models for re-integration
• Recognize school-prison pipeline – prevention strategies
Confidentiality issues:

- some parents very reluctant to have teens seen separately from caretakers
  - School-based settings can be an advantage
- Worries about gossip within small immigrant communities – may not trust interpreters
- Reluctance to disclose past traumas
- May minimize symptoms or prefer to describe using somatic terms
  - Belief in many immigrants from countries that have endured pervasive and multigenerational trauma, that talking about them makes them worse
Newcomer Youth and Youth from Immigrant Families

Advantages of using the PEARL screener with immigrant families

- Toxic stress from current difficulties navigating life in US, food, financial, housing insecurities, may be causing symptoms
- Without doing "other life events" section of the PEARL screener, may assume this stress to be from past traumas
- Youth in immigrant families may be looking for opportunities to share stories, get support

Cautions using the PEARL screener with newcomer immigrant families

- Refugees and those applying for asylum have had to tell their stories MULTIPLE times
- Screeners may not translate well via interpretation
LGBTQ+

• A survey of US & Canadian LGBTQ+ youth 14-18 found (Craig et al., 2020):
  • 43% experienced 4 or more ACES
  • Most commonly emotional abuse & neglect, living w family w mental illness
  • Highest among pansexual, transgender, gender nonconforming, Amer. Indian, LatinX, rural youth
  • Lower among youth w highly educated parents, lived with a parent, Canadian

• Support services and resilience building
  • Supportive school staff crucial (especially for those youth who are bullied at school)

• Schools with GSAs tend to have lower rates of bullying and improved school climate for all students
Children with Special Health Care Needs

- Children with Special Health Care Needs (CSHCN) are
  - More likely to have been abused/neglected
  - More likely to be suspended, expelled from school, even when behaviors a direct result of their chronic conditions
- Secondary analyses of the National Survey of Children’s Health 2011-2012 found that
  - children with 4 or more ACES 3x more likely to be CSHCN than children with no ACES (Kan et al., 2020)
    - Association strongest for emotional, behavioral, developmental conditions
  - Children with ASD and 3+ ACES more likely to have unmet health care needs (Berg et al., 2018)
    - More severe ASD associated with higher ACES score
Children with Special Health Care Needs

- Implications for SBHCs --
  - Youth with SHCNs may not be coming to SBHC formally but may be frequent drop-ins
  - How are we doing at serving youth with SHCNs in general?
- Screening/services in cognitive/developmental delay
  - We have limited knowledge about using the PEARLs screener in youth/young adults with cognitive/developmental differences?
<table>
<thead>
<tr>
<th>Suggestions: Brief conversations w/clients after ACES screening</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Talking with parents (Gillespie, 2019):</strong></td>
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<tr>
<td>1. Do any of these experiences still bother you now?</td>
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<tr>
<td>2. Of those experiences that no longer bother you, how did you get to the point that they don’t bother you?</td>
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<tr>
<td>3. How do you think these experiences affect your parenting now?</td>
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<td><strong>Adapted for talking with teens:</strong></td>
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</table>
Confidentiality and Cures Act

- As of April 5, 2021, the Final Rule of the 21st Century Cures Act went into effect
  - Purpose of Cures Act primarily to support research and patient access to records
  - Nothing in the Act specifically addresses clinical adolescent confidentiality
  - "Open Notes" - give caregivers access to records
  - Specialists and PCPs and parents can see all problem lists and meds, including for mental health issues, contraception and STI treatment, possibly problems/diagnoses related to ACES/child maltreatment
    - Specific therapy notes can be hidden
    - Some protections for Drug & Alcohol treatment
Confidentiality and Cures Act

- Institutions can be fined (up to $1 million) for "information blocking"
- No incentives for EMR developers to help clinics with work-arounds: increased inequities between "rich" institutions with robust EMR platforms and public/safety net clinics with bare bones EMR systems.
- There ARE exceptions to the prohibition of "information blocking" including:
  - Potential harm to the patient (or provider)
  - Disclosure would harm legal proceedings
  - **Infeasibility:** it is not feasible for the EMR to allow the provider to "segment" out the sensitive information, so the entire note MAY be blocked without triggering fines or sanctions
  - Protecting privacy guaranteed by State or Federal laws
ACEs on the Problem List?

- Strategies for managing the Cures Act/open notes and protecting adolescent confidentiality
  - Most safety net clinics are managing Cures Act by blocking all notes for teens 12-17 from release to My Chart
  - Check with your institution to see what goes on the after visit note
    - Some institutions don’t give the after visit note to teens
    - Usually possible to block confidential info from after visit note – but must be done at the time of entering it (check with your institution)
    - Consider how/if ACES score appears on the problem list
  - HIPAA vs. FERPA
Suggestions from Providers

• Involve teens in the rollout of ACES Screening:
  • Scripts for explaining the PEARL screener to other teens
• Train whole staff in trauma-informed care
• Systematic plan
• Provide resources to all families, regardless of score
• Ask about strengths & resilience
• Open the conversation
  • “Knowing and validating a patient's experience has utility as well. There's a certain proportion of providers that accept that, that sometimes a patient doesn't expect you to solve all of their problems, but just being someone who can validate that they're going through this challenge and know that that affects their health is important by itself.”
Suggestions from Teens

- Recommend de-identified screening
- Explore and strengthen peer supports
- For providers: Show genuine interest, develop comfort with asking questions & receiving any answer
- Going beyond the questionnaire to make a personal connection with youth:
  - “As well as letting them know that these resources are available at any moment for you and to not just jump on the call with CPS, because there's more to what's on the paper, and what is on the paper can be taken out of context almost immediately, and just reiterating the fact that asking the patient what they want for that specific day.”