“Speaking about Adverse Childhood Experiences (ACEs) when gathering data”

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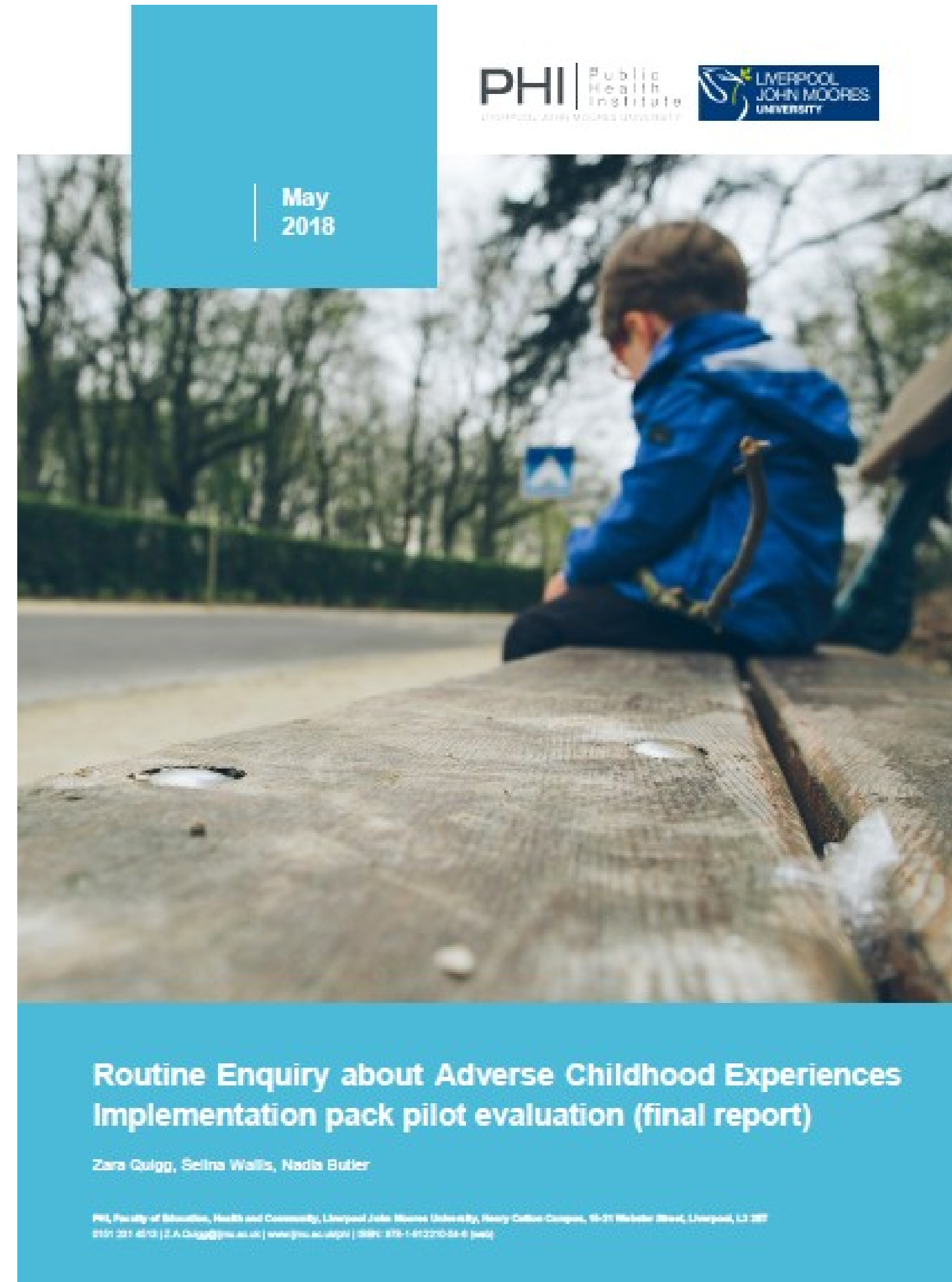


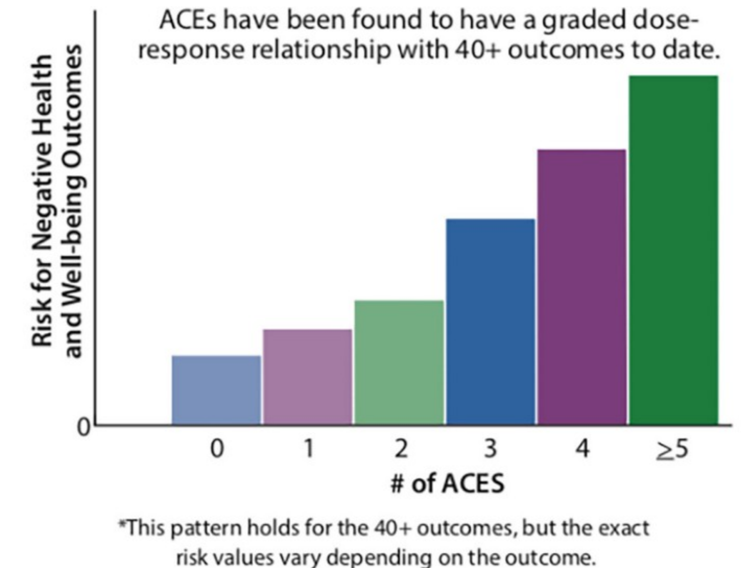
Bio

- Public Involvement Manager at the Applied Research Collaboration at the University of Liverpool
- 16 years experience in public health
- Author of several papers including a Cochrane review on breastfeeding
- Doula
- Grandmother
- Survivor of CSA

Adverse Childhood Experiences

Number of ACES reported	Prevalence
1 or more	2 out of 3
4 or more	1 out of 8

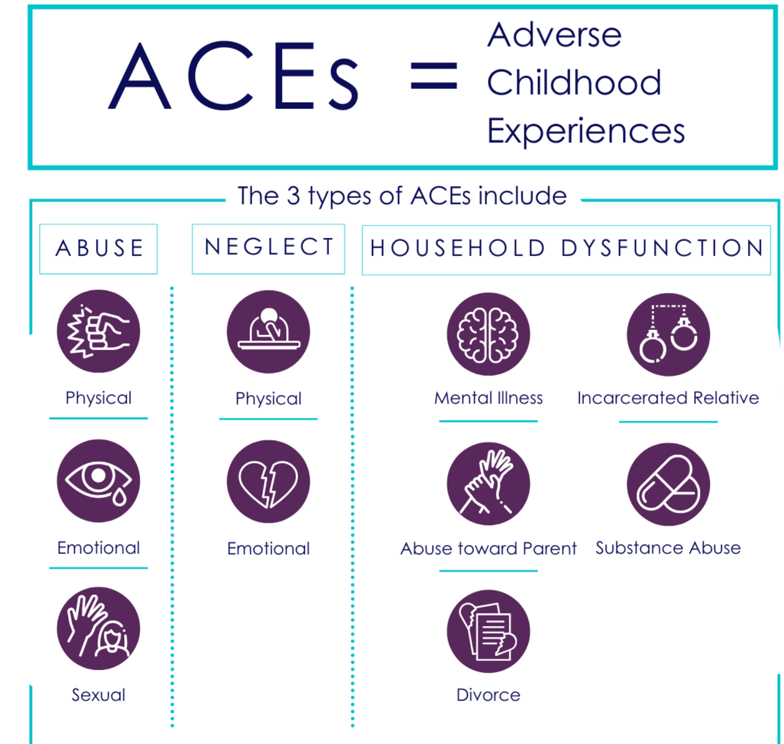
- The Adverse Childhood Experiences (ACE) study (Felliti et al, 1998) was one of the largest investigations ever to assess the association between childhood maltreatment and later health and well-being. It began in the 1980's, when Dr Vincent Felliti (from Kaiser Permanente's Health Appraisal Clinic in San Diego) noticed high drop-out rates in his obesity clinic, despite evidence of significant weight loss. He found a link between the development of obesity and childhood sexual abuse. He collaborated with Dr Robert Anda, a researcher from the Centres for Disease Control & Prevention to carry out a study to explore the association between childhood experiences and health throughout life. The study involved over 17,000 people. They were asked about their health history as well as their childhood experiences https://www.ajpmonline.org/article/S0749-3797(98)00017-8/fulltext



Two decades later, that study has been cited more than 32,000 times in more 150 different academic journals across multiple disciplines

Background

- Adverse Childhood Experiences (ACEs) are stressful events occurring in childhood including: domestic violence. parental abandonment through separation or divorce. a parent with a mental health condition. being the victim of abuse (physical, sexual and/or emotional)
- Strong associations exist between adverse childhood experiences (ACEs), including child sexual abuse and exploitation (CSAE), and poor health and social outcomes throughout the life course
- Identifying, addressing and preventing ACEs, in particular CSAE, high on the political and public agenda.
- "I have found in my own clinical practice that while the research suggested that most of my clients would have experienced some kind of childhood adversity or subsequent trauma, very few volunteered this information unless asked directly." (Warren Larkin) For me, the ACE questionnaire is a tool that facilitates this process.



"Did an adult or person at least 5 years older than you ever… Touch or fondle you or have you touch their body in a sexual way? or Attempt or actually have oral, anal, or vaginal intercourse with you?"

Background 2

- In 2013/14, Lancashire Care NHS Foundation Trust (LCFT) developed a training programme on Routine Enquiry about Adversity in Childhood (REACh) and implemented it across various services in England
- The rationale for REACh is to encourage disclosures of ACEs, and support practitioners to respond appropriately and plan client-centred interventions more effectively.
- In 2016 the Department of Health commissioned LCFT to implement a pathfinder project to develop a standalone Implementation Pack to support services in developing, implementing and embedding REACh, and to pilot its use across three services in North West England with clients (aged 14+ years) during routine assessments.

Changes to REACh

- The REACh pathfinder project (9 months planning with stakeholder group) originally focused on CSAE only, it was later amended to also include the other ACE questions to produce the ACE-CSE questionnaire.
- It was anticipated by LCFT that the pathfinder would follow the 'train the trainer' model used in the original REACh but due to concerns around the feasibility and affordability of this approach at national level it was decided by the project steering group that the project would involve the development and piloting of a standalone Implementation Pack that services could access and use to implement routine enquiry using the ACE-CSE questionnaire, without additional support.
- In 2017, the Implementation Pack was piloted across a Child and Adolescent Mental Health Service (CAMHS), drug and alcohol service, and sexual violence support service.
- We evaluated: the development and piloting of the Implementation Pack; practitioner views of the Implementation Pack; and practitioner (and where possible client) views on REACh.

Methods

- A range of research methods were implemented to inform this study including:

• Interviews with the Implementation Pack developers and pilot site leads;

• Surveys with practitioners and clients engaged in the pilot;

• Collation of anonymised data collected during the routine enquiries;

• Review of project documentation, including project wide and pilot site materials; and,

• Researcher observations of pilot implementation (i.e. training sessions).

Results

- Two pilot sites implemented routine enquiries, using the ACE-CSE with a subset of clients (total n=15; see Box ii). However, routine enquiry was not fully implemented or embedded across any pilot site. Reasons for this were multi-faceted, and appeared to centre around three intrinsically linked aspects:
- 1. The feasibility of implementing REACh (using the ACE-CSE questionnaire) through the use of the standalone Implementation Pack;
- 2. Staff uncertainties around the rationale, appropriateness and value of REACh (using the ACE-CSE questionnaire) across these types of services; and,
- 3. Implementation of the pilot within services that were going through an organisational restructure (resulting in changes in the pathfinder leadership team within LCFT, and implementation staff within pilot sites).

Results

- A number of specific concerns about the questions within the ACE-CSE questionnaire were also raised, particularly around the CSAE questions (e.g. appropriateness of terminology used), whether the questions were appropriate for children, and asking clients how often the childhood adversities had occurred.
- Engagement in the pathfinder raised concerns across various practitioners around the rationale and appropriateness of implementing routine enquiry using the ACE-CSE questionnaire, within these types of services.

Section 2:

We would now like to ask you to answer some more questions about other specific experiences during the first 18 years of your life. Again, you do not have to complete this section if you do not want to and you do not have to answer every question. If you would prefer not to complete section 2, please hand the questionnaire back to your worker.

Before the age of 18 years (or up until now if you are currently under 18 years)

10. a) How often did anyone at least 5 years older than you (including adults) ever **touch you sexually?**
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

b) How often did anyone less than 5 years older, the same age or younger than you ever touch you sexually when you did not want to or felt unable to say no?
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

11. a) How often did anyone at least 5 years older than you (including adults) **try to make you touch them sexually?**
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

b) How often did anyone less than 5 years older, the same age or younger than you ever try to make you touch them sexually when you did not want to or felt unable to say no?
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

12. a) How often did anyone at least 5 years older than you (including adults) **force you to have any type of sex** (oral, anal or vaginal)?
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

b) How often did anyone less than 5 years older, the same age or younger than you ever force you to have any type of sex (oral, anal or vaginal)?
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

13. Have you ever been **asked to show or send images of a sexual nature**, OR been asked to **behave in a sexual way** in person or via social media *(i.e. Facebook, Twitter, Instagram/ Snapchat, other)*
☐ 1. Yes ☐ 2. No

14. Have you ever done or were you ever forced or asked to do **anything sexual** *(in person, online or via social media)* **in exchange for money, drugs/alcohol, gifts, affection, protection/safety, accommodation, employment, status (popularity), or anything else OR because you felt threatened?**
☐ 1. Yes ☐ 2. No

15. **Is any of this sexual activity still happening?**
☐ 1. Yes ☐ 2. No

If Yes, who has been involved in the sexual activity? (choose all that apply)
☐ 1.Family member ☐ 2. Non-Family member

16. **Have you ever told anyone about any of this sexual activity?**
☐ 1. Yes ☐ 2. No

If Yes, did you receive any support?
☐ 1. Yes ☐ 2. No

Resilience

17. While you were growing up, before the age of 18, was there an adult in your life who you could trust and talk to about any personal problems?
☐ 1. Never ☐ 2. Once or twice ☐ 3. Many times

Issues with the Questionnaire

- Adding to the original ACE questions invalidates the tool
- The tool had not been used with yp
- The new questions were seen as intrusive, not yp centered and potentially upsetting

"We know in our experience people feel relieved to have the ACE questions asked but we don't know what the addition of the CSA/CSE questions is."
REACh team member

Issues with services

- It was questioned as to how the information about adversities in childhood was linked to service delivery. For example, practitioners within CAMHS noted that such adversities (if historic) are risk factors for various mental and physical health problems, however, once these have occurred they are static and cannot be changed. A service such a CAMHS primarily deals with the impact of those risk factors, i.e. the presenting mental health problems. Thus exploration of how these mental health problems potentially originated (i.e. link with adversities) was noted as less helpful.
- While disclosures of ongoing abuse could lead to safeguarding procedures which address this, they felt that it was not clear how disclosures of historical abuse could positively impact outcomes.

Results

- Implementing routine enquiry during the initial assessment was viewed as not being universally appropriate, as it is vital that a good client-practitioner rapport is developed and the client displays signs of resiliency, before exploring such traumas.
- Within the sexual violence service, enquiring with a client near the end of service provision was considered potentially unethical if further support was required to deal with disclosures (that the service could not offer). Further, when a client was going through the criminal justice process or was experiencing mental health issues, routine enquiry was deemed not appropriate, or potentially risky to the client.

REACh team

- Ensuring services are ready to enquire:
- Routine enquiry with under 18s:
- Safeguarding, disclosures and referrals:
- Engagement of key stakeholders:

It was noted that routine enquiry should only be implemented if it has direct benefit to the client, minimises risks of harm, and promotes recovery and support processes.

Queries around rationale, focused on whether routine enquiry was being implemented to understand the national prevalence of CSAE, and/or to support clients more effectively, through understanding their experience of childhood adversity and how it may be linked to current health problems.

Summary

- Throughout this pathfinder further concerns were also raised around the limited availability (both within and external to the pilot site services) of specialist support for clients who may require it (following a disclosure).
- The inclusion of routine enquiry during initial (or early) client assessments was suggested as possibly detrimental to client/practitioner relationship building and services offering time limited support linked to current acute issues
- Further, concerns were raised around possible harmful effects (e.g. further traumatisation) on the client if questions are asked at the wrong time, or in an inappropriate manner.

Summary

- questions were raised around whether it was appropriate to use a questionnaire to implement REACh. Suggestions were made around gathering the information through other mediums, such as through a broader discussion with the client or through case reviews
- more evidence is needed to inform the development, implementation and embedding of REACh,

- I believe that asking about life events, good and bad, is part of our duty of care to people seeking our help, and an extension of our safeguarding responsibilities. Where there is a high likelihood of our service users experiencing childhood adversity and / or subsequent trauma, we should ask if any of these things have happened, and crucially if they are still happening.
- https://warrenlarkinassociates.co.uk/2020/04/17/ace-enquiry-what-it-is-what-it-isnt-and-why-its-important/

ACEs research since this study

- not all ACEs carry equal weight and that a simplistic ACE-aware approach or narrative based only on quantifying the problem may be less helpful than exploring and understanding the impact of specific types of trauma and adversity during the early formative years
- paying heed to the types of ACEs, as well as the number, experienced in childhood is important, especially in terms of providing a focus for policy and practice

Criticisms of ACES

- Criticisms levelled at the ACEs framework include its choice of, and restriction to, the ten ACEs and its failure to acknowledge the existence and impact of a wide range of other sources of adversity, as well as structural and social inequalities
- Screening for ACEs has been controversial, with some noted concerns regarding costs and potential negative effects of screening (e.g., lack of training for proper screening and lack of resources when adversity is identified)
- Using ACES (population data) to predict individual risk- one of the strongest areas for criticism is reserved for the 'ACE score' (the counting of number of ACEs experienced) to predict outcomes

Criticisms of ACES

- ACEs have garnered a lot of attention and it’s about time we ask ourselves why the ACEs framework has risen so quickly. What purpose does it serve? What narrative on the evidence does it foreground?
- potential for pathologising and seeking to apply clinical solutions to social issues and placing the responsibility for solving them on parents- the underlying logic and practices of ACE frameworks and scores can be seen to contribute to a continuation of social narratives that tell students there is something wrong with them because something happened to them
- It doesn’t distinguish between adversities that occurred in the past and those that are ongoing, which would necessitate different responses and interventions.
- Fail to take into account the existence of any protective and mitigating factors, including sources of resilience and the importance of self-determination

ACES and CSA

- The 5-year modifier is now widely used to CSA most often when the ACE Study Questionnaire is used but it has also diffused through the literature to appear on additional CSA assessments https://dc.etsu.edu/cgi/viewcontent.cgi?article=5052&context=etd
- In a sample of college students who experienced CSA that were divided into groups by perpetrator age- child, teen, or adult, there were no significant differences for anxiety, depression, or sexual functioning, nor any significant differences for PTSD symptoms between perpetrator age groupings, even after controlling for psychological abuse (Allen et al., 2014).

Discussion questions

- Have you ever been asked about ACES?
- If not would you have liked to have been asked?
- Do you think it is helpful to ask people? Should we screen children?
- Is it more important to ask about CSA than ACE's? Does asking about the other ACEs obscure CSA?
- Do you think the ACES questionnaire is a good way to ask?
- McLennan and colleagues argue that the inaccuracy of the screening tools and the absence of guaranteed services to refer onto render routine ACEs screening inappropriate- do you agree?

Research ACES and CSA

- Research studies (Nelson et al 2013, Nelson 2018) confirmed there has been considerable dissatisfaction among adult survivors of CSA, with both mental health and general health services. That is the starting point which national policy needs to address. These complaints have centred around adherence to purely medical-model diagnoses and stigmatising personality disorder diagnoses; around polypharmacy, with damaging side effects; failure to inquire into an abuse history or to follow it up; dismissal of disclosures, and unsafe or triggering behaviours and healthcare environments.
- The biggest single complaint from abuse survivors about responses from health professionals is that once their abuse history or indeed their mental ill health status is known, medical staff readily dismiss their conditions as hypochondriacal or "all in their heads" while some GPs see them as "heartsink patients". This shows that having CSA on your health records is not sufficient in itself to ensure an impartial approach to patients' health problems (Dr Sarah Nelson)

https://blogs.ed.ac.uk/CRFRresilience/2019/08/14/childhood-sexual-abuse-part2/

Research

- “The differential impact of specific types of ACE, as well as the number, is a relatively untapped area of potential academic research that could significantly enhance our understanding of these experiences and how they factor in a range of negative outcomes. An approach that identifies the risks associated with specific experiences may also yield more policy value than the overarching language and theory of ACEs. Relatedly, our results suggest there is value in exploring the range of potentially relevant experiences beyond those in the original Felitti et al. (1988) study.”
- The bottom line is that we ignore trauma at our peril – the important message from ACEs research is that is has a huge impact on people’s outcomes and then we need to be very mindful as to how we apply this knowledge (Greg Fell DPH https://gregfellpublichealth.wordpress.com/2019/06/06/the-problem-with-aces-a-critique-of-the-critique/)

Conclusion

- It was the impact of childhood sexual abuse trauma which gave Professor Vincent Felitti and colleagues the first, vital clues to persistent poor health and unhealthy behaviours in adults. It was the trigger to the range of ACE studies they then conducted, and to numerous others held internationally ever since. Attempts to reduce childhood sexual abuse in society, and to address its damaging effects in adulthood, need to form and remain one of the key components of ACES policy. And although the recent, belated emphasis on understanding the role of traumas in general in the lives of children and adults which ACES have helped to promote is valuable and welcome, attention within that to sexual abuse remains marginal, and at times nonexistent.” (Dr Sarah Nelson) https://blogs.ed.ac.uk/CRFRresilience/2019/07/05/childhood-sexual-abuse/