Open Letter Calling on Research Institutions to Support Safe, Ethical, and Confidential Research on Child Abuse and Neglect

We, the undersigned, write in support of safe, ethical, and confidential research on child abuse and neglect, including child sexual abuse. We concur with the CDC, the IOM, and the WHO that “all violence against children and youth is preventable, and reliable information is needed to develop and implement effective prevention strategies” (Nguyen et al., 2018, p. 321).

We are motivated to write this letter to address concerns raised at premier research institutions by administrators who expressed the beliefs that questions about child sexual abuse (including both victimization experiences and perpetration behaviors) are harmful to research participants, upsetting to the parents of child participants, and should trigger mandatory reports to child protective services or law enforcement.

These beliefs contravene well-established findings of high tolerance among participants and their parents for abuse-focused research and recommendations for the conduct of good practices in such research.

I. Questions about Abuse Pose Minimal Risk to Most Research Participants

Ethical analysis of research weighs both the costs and benefits of proposed studies. One potential cost of abuse-focused research is that questions about abuse are distressing to participants. Ample evidence demonstrates that children and adults are not harmed by responding to confidential, clearly worded and behaviorally objective questions that assess child sexual abuse and other forms of abuse and neglect. For example:

- With respect to children, Finkelhor and colleagues (2014) interviewed a national sample of 4,503 U.S. children ages 10-17 and asked whether completing a survey about abuse had upset them. More than 95% of participants reported no distress. Among the few who indicated any distress, the most common cause had to do with survey duration and not item content. Notably, parents of these 4,503 children were interviewed briefly and consented to their child’s participation, suggesting that parents have a high tolerance for their own child’s participation in abuse-related research. Other large-scale studies also found that abuse-related questions posed minimal risk to children whose participation was consented to by thousands of parents (Zajac et al., 2011).

- With respect to adults, a meta-analysis of studies involving nearly 74,000 adults found them far more likely to endorse the benefits of participating in trauma-related research than distress over item content (Jaffe et al., 2015).

The studies referenced above assessed distress in response to questions about victimization, which are more common than questions about perpetration. However, research about perpetration using community (vs. forensic) samples is on the rise. Children and adults responding to confidential questions about perpetration behaviors, including problematic or illegal sexual behavior, are also not likely to experience distress. For example:

- Thousands of children and young adults ages 13-24 in dozens of countries have responded to victimization and perpetration-related questions included in the CDC’s Violence Against Children Survey (VACS), with no evidence of undue distress. The

1 In referring to ‘child’ or ‘children’ we include anyone under the age of 18, in alignment with the United Nations Conventions on the Rights of the Child.
CDC is currently partnering with the Baltimore City Health Department’s Office of Youth and Trauma Services to conduct the first U.S. adaptation of the VACS in Baltimore.

- Dr. Robert Blum, Professor at the Johns Hopkins Bloomberg School of Public Health is leading two large-scale studies, including the National Adolescent Mental Health Survey, a 3-country survey that includes thorough assessment of sexual violence perpetration behaviors and the Global Early Adolescent Study, a 15-country survey that includes thorough assessment of sexual assault and other victimization experiences. Data collection is well underway for the GEAS, with no more than minimal distress in response to item content. Data collection on the youth mental health survey is approved but delayed due to the pandemic.

- A survey of 8,718 German men assessed sexual interest in children, sexual behavior with children, and use of child sexual exploitative materials (Dombert et al., 2016). This survey is the first to establish valid perpetration prevalence estimates. More than 82% of participants who started the survey completed it. While reasons for non-completion were not obtained, this completion rate suggests participant comfort with questions about stigmatized interests and illegal behaviors.

*Does it hurt to ask?* is a perennial intuitive concern that has been robustly addressed. It does not. Questions about abuse victimization and perpetration represent minimal risk to child and adult research participants and are well-tolerated by the parents of child participants.

**II. Participation in Research Benefits Children and Society**

In response to persistent (yet unfounded) concerns that questions about abuse harm children, researchers are sometimes encouraged to limit research participation to adults. Yet engaging children in research is critically important. From a methodological standpoint, children are closer in time to childhood experiences and behaviors than adults and have more accurate and complete recall. Children’s participation therefore improves both the reliability and validity of research focused on child abuse and neglect.

Of perhaps greater relevance, the expression and participation of children in research designed to understand and benefit children have been identified as important child rights by the UNICEF Office of Research-Innocenti (Berman et al., 2018). Research facilitates these rights, in part because children have far fewer vehicles for such expression and participation relative to adults.

Most significantly, abuse-focused research informed by child participants influences public health policies and results in improved child well-being. For example, a VACS survey conducted in Swaziland indicated that nearly 40% of girls experienced sexual violence prior to age 18, most often at the hands of male neighbors and boyfriends. These data were used by Swaziland policy makers to inform the development and strategic deployment of abuse prevention and intervention strategies at the national, regional, and local levels. Following these changes, Swaziland’s ranking on an international index of African governments’ efforts to ensure child dignity and rights improved from 45th to 9th place (Mercy, 2014).

**III. Confidentiality is Essential to the Safe Conduct of Abuse-Related Research**

The collection of sensitive, personal information is essential to addressing important public health questions and researchers have ethical and legal obligations to maintain the confidentiality of these data (Wolf et al., 2015). Indeed, the assurance of confidentiality is fundamental to conducting reliable and safe human subjects research. As a result, U.S. federal grantmaking entities including the CDC, NIH, and NIJ automatically certify
the confidentiality of data collected as part of federally funded research projects. Some institutions have determined that these protections do not extend to child abuse and neglect research and insist that all affirmative responses to abuse-related questions be reported to the authorities.

If good research is to be governed by the broad ethical principles of autonomy, justice, and non-maleficence (or ‘do no harm’), then subjecting research participants to reports based solely on their responses to research questions potentially violates each of these principles. Autonomy is violated if a report is made against the respondent’s wishes or without their knowledge. Justice is violated if – as we know to be true – reports are more likely to be made and acted upon in cases involving Black, LGBTQ, poor, or otherwise disadvantaged or stigmatized respondents. Harm can occur when reports increase the risk of additional violence against respondents (e.g., by angering perpetrators or non-offending caregivers) or increase the likelihood of legal action against respondents including arrest, detention, incarceration, and sex offender registration.

The WHO (2001) developed guidelines for the safe study of gender-based violence and the CDC (2019) adapted these guidelines for the safe study of violence against children. They recommend a 3-tiered response to address the safety needs of respondents, which includes (1) providing a list of accessible and relevant resources to all respondents, (2) offering a direct referral to respondents who request such or who meet pre-specified criteria (e.g., endorsing sexual abuse victimization), and (3) linking respondents in acute need to help as quickly as possible. As the CDC notes “In general, direct service referrals are only initiated if the respondent agrees” (Nguyen et al., 2019, p. 323).

We recognize that mandated reporting laws, particularly those in the U.S., are often broad and could appear to be violated by an approach that prioritizes ethical principles and participant well-being over rigid adherence to an interpretation of broad reporting requirements. Where confidentiality protections are not already in place, we urge institutional administrators to work collaboratively with researchers to identify legitimate strategies to confidentially collect sensitive data, without which prevalence and prevention science simply cannot advance.

Developing effective public health solutions to child abuse and neglect may involve some risk to researchers and their institutions. Confronting the reality of child sexual abuse and other forms of childhood violence is emotionally fraught and disturbing. But the risks faced by researchers and institutions pale in comparison to the harms endured by child abuse victims.

As researchers seeking to understand, prevent, and address abuse, our work depends upon the support of our institutions. In particular, we call on institutional leaders and particularly the offices of research administration, risk management, and legal counsel, to work collaboratively with us to minimize avoidable risks while also advancing the strongest possible science in service of child abuse prevention. Ultimately, our shared goal is to advocate for the safety and wellbeing of all children.

Sincerely,

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Appendix: Letters of Support

Dear Elizabeth,

Dr. Elizabeth Rheingold shared with me your email describing concerns of the Johns Hopkins’ IRB and other authorities about the potential for harm associated with asking individuals under age 18 about experiences involving child maltreatment and engaging in behaviors that would be defined in most jurisdictions as delinquent or potential violations of criminal law. My colleagues and I were pioneers in conducting this type of research, having conducted the National Survey of Adolescents (NSA) in the mid-1990s and having conducted the National Survey of Adolescents-Replication (NSA-R) beginning in 2005. Both the NSA and NSA-R involved locating a national probability sample of households with 12 to 17-year-old adolescents, conducting brief interviews with a parent or guardian, and obtaining permission to interview a randomly selected adolescent within each household. After consent was obtained from the adolescent, interviews were conducted with the adolescents and included information about experiences with sexual victimization, physically abusive punishment, physical assault, witness violence, and exposure to other potentially traumatic events. Major outcomes included PTSD, depression, suicidal ideation, alcohol and drug use, substance use disorders, and delinquent behaviors including interpersonal violence directed towards peers or others. These studies were funded by the CDC, National Institute of Justice, and NICHD at NIH.

As we were designing these studies, there were three key principles that guided our work. First, we knew that it was imperative to collect as accurate data as possible about these key measures of child maltreatment and victimization as well as delinquent behaviors and mental health outcomes because such data are imperative to improve public health, mental health, and criminal justice responses to these issues. Without such data, we are flying blind, and this is totally unacceptable. Second, we knew that the only way to get accurate information about these topics was to create an environment which maximized the willingness of participants to answer behaviorally specific questions accurately which requires privacy, anonymity, and confidentiality. Third, we were strongly committed to including as many safeguards as possible to minimize distress and ensure that any participant who was distressed had access to a trained mental health counselor. This included formal questions at the end of interviews that asked if any questions had been distressing, if they were still distressed at the end of the interview, and if they would like to talk with a counselor. We also had a “child in danger” protocol that determined if the respondent appeared to be currently in danger due to a family member perpetrator having close access to the participant. In such cases, a child clinical psychologist or social worker member of the project team participated in an interview with the participant to determine whether there was a need to make a report to child protective services in order to protect the child. If so, the participant was encouraged to make a report but told that the team member would make the report if the participant did not.

Out of 7639 adolescents who completed the NSA and NSA-R, our team member never had to make a report to child protective services. In your open letter, you cited a paper by our research team describing distress among the 3614 adolescents who completed the NSA-R. Notwithstanding the extremely sensitive nature of many of the questions in the survey as described above, only 204 out of 3614 (5.7%) found some questions distressing, and only 8 adolescents out of 3614 (0.2%) indicated that there were still distressed at the end of the survey. Only 2 adolescents said that they were so distressed that they wanted to talk with a counselor, and both of these indicated that this need was not urgent and could be scheduled for the next business day. Therefore, we believe we were highly successful in being able to accomplish our study goals of collecting a substantial amount of highly sensitive, scientifically
important, information from a large national household probability sample of adolescents in a fashion that minimized distress or other harm to the adolescents. Based on these findings, we would estimate that approximately one adolescent out of every 3007 interviewed would become sufficiently distressed to request being provided a counselor. No research is entirely risk free, but I would argue that having only one adolescent out of every 3007 research participants who is sufficiently distressed that they wish to talk with a counselor is a pretty good indicator that you can do this type of sensitive research at risk levels that are far lower than most types of biomedical research if you take proper precautions.

As you know, I have been a strong advocate for victims of sexual violence and other crimes for more than four decades, and there is no one more dedicated than I am to protect their well-being. Having said that, I am also fiercely committed to the need for better science and better data to address the problem of sexual violence in our nation and communities. Our research has shown that the prevalence of sexual violence and other types of child maltreatment is substantial among those under age 18, so we desperately need information about what is happening among this age group. If we stop research inquiring about this topic among people under 18, we will be doing a great disservice to our children and adolescents because there will be no way to know how well our prevention efforts are working, whether there is a change in the scope or nature of our sexual violence problem, and we will not know the extent to which cases are being reported to law enforcement or victims are getting adequate services. It is certainly reasonable for IRBs to be concerned about research involving these topics particularly if they are unaware of the extensive information is available about the relative safety of such research. However, my understanding is that it is the responsibility of IRBs to conduct a risk-benefit analysis of the value of the information produced by the research with the risk to research participants. By focusing exclusively on potential risks and not considering the importance of the research and the benefits it can provide, IRBs run the risk of precluding the conduct of research that is vitally needed and that can produce important benefits to society as well as to the participants. By saying that we cannot even ask these important questions about sexual violence experiences, we are sending an inadvertent message that what happened to participants is not sufficiently important that we should even be allowed to ask about it. This has the inadvertent effect of harming sexual violence victims by silencing their ability to tell us what happened to them.

Your letter has my strong support.

Best,
Dean

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Dear Elizabeth,

I have been thinking quite a bit about your recent sharing with me the concerns of some that asking child victims of sexual abuse sensitive questions is somehow harmful. Enlarging this issue to sensitive questions in youth populations (e.g., youth who consume pornography) represents a serious threat to scientific inquiry into all research with youth.

I do not understand the rationale or motivations of those who raise this question. I am sure whatever these are they are sincere and well meaning. However, except in the case of very young children this attitude furthers the silence and disempowering of youth that is at the heart of childhood sexual abuse. I have a number of concerns:

First, there seems to be a tendency to disempower youth by a priori deciding what is in their best interests. I am aware of no data that supports the idea that asking youth about sensitive questions such as “Have you ever been sexually abused?” or “How often do you watch pornography?” causes any harm. Youth in clinical practice and in research can decide if they want to answer these questions. In the case of sexual abuse, victims’ silence allows abuse to continue. An age appropriate informed consent should support research and protection of youth and let youth decide if and when they want to answer a sensitive question. It is common to remind youth that some questions may be triggering, and they do not have to answer any question they do not want to answer.

Second, while I have never seen or heard of an adverse reaction to sensitive questions it is important to remember that any negative emotions that might emerge result from the original abuse, not the questions. A sensitive question to a person who was not abused elicits no prior trauma. A sensitive question about trauma may theoretically elicit negative emotions associated not with the questions but with the trauma itself. Research and practice protocols can anticipate any adverse reactions and plan an appropriate response (including follow up at a time after the questioning). If one is really concerned about the impact of questioning, then follow up with research subjects after testing provides one means of protecting youth from adverse reactions.

Third, while the desire to protect victims is laudable, one has to balance a completely unknown and probably rare adverse reaction against the benefit of research based on the lived experience of the youth. Empowering youth to participate in research on conditions that directly impact them breaks the silence. Disallowing youth participation in research on their lives allows the conditions that negatively impact them to continue and dismisses their experience by ignoring the reality of their lives. There are a host of youth problems that can only be understood by directly involving the youth as sources of data.

Fourth, the issue of whether an investigator must report child abuse or neglect is a separate issue from that of allowing youth to describe their experiences by answering direct questions. Informed consent can certainly deal with this issue even if it may reduce the number of youth who will disclose negative experiences. More importantly most research questions are not likely to lead to information which would allow a report to CPS as it would not have the detail necessary to make a valid report. If research were required to pursue information which would support a report to CPS, then the informed consent procedure would need to detail this. It fundamentally changes the researcher – subject relationship and presents a host of practical problems including but not limited to how much non-research focused inquiry is expected when a child discloses something that could potentially be reportable; who assures that the child/youth has appropriate support after referral to CPS; who decides and who on the research team has the knowledge to decide 1) if the child’s report should go to CPS or law enforcement...
and 2) which jurisdiction should receive the report (e.g. the child resides or where the abuse took place), etc and a host of other practical issues.

As you know, I have been the Editor of the *Journal of Interpersonal Violence* for over thirty years. I have served as a therapist for youth and adults with childhood sexual abuse experiences. I have evaluated thousands of child, youth, and adult plaintiffs who allege harms from sexual abuse. I have conducted and will conduct research with youth on very sensitive subjects. I write you as one who identifies with victims of childhood sexual abuse and seeks knowledge and practices that empowers them. Your message causes me great concern for the future of research on sensitive issues that impact the population whose lives I have devoted my career to improving.

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References


