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'Do no harm'? Rethinking risk and harm narratives in abuse-focused research with children



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ABSTRACT

Despite increasing recognition of children's right to have a say about matters that affect them (Article 12, United Nations Convention on the Rights of the Child), this right is often denied in the context of child abuse research. This article explores the ways in which ethical decision-making can contribute to the denial of this right and the negative implications of this at both an individual and societal level.

Ethical decision-making that stymies the conduct of abuse-focused research with children is usually justified with reference to protecting participants from risk of harm. Whilst in no way suggesting that this is not a critical consideration, the authors question the simplistic and deterministic ways in which this can be understood within ethical decision-making, and the unnecessarily risk-averse decisions that can ensue.

Sharing examples from their cumulative 30 years' experience of engaging children and young people in abusefocused research, the authors stress the need for a more holistic, nuanced and dynamic approach to assessing and managing risk of harm. This would consider risks of both inclusion and exclusion. Understanding that risk and harm are neither static nor universally experienced concepts, it would recognise the implausibility of the 'do no harm' guarantees often expected of social researchers. Instead, informed by rights-respecting and traumainformed perspectives, it would focus on holistically promoting participant wellbeing in, and through, research. Key to this is permitting, and supporting, researchers to exercise contextually-informed, collaborative decision-making in the field; something the authors share their emerging practice framework for.

1. Introduction

Despite increasing recognition of children's right to have a say about matters that affect them (Article 12, United Nations Convention on the Rights of the Child (UNCRC)), this right is often stymied or denied in the context of child abuse research. We contend that this is, in part, due to the overly simplistic ways in which concepts of risk and harm can be understood and applied in this field, including within some ethical governance procedures.

While we recognise examples of ethics review processes that adopt nuanced and proportionate approaches to assessing benefit and harm in research on abuse or other 'sensitive issues', this is by no means universally the case. Researchers across diverse disciplines and geographies report attempts to engage children in such research being constrained by both the exercise, and their anticipation, of risk-averse decision-making by University ethics committees or other institutional review boards (Alves et al., 2022; Hanson et al., 2023; Stalford & Lundy, 2022). Such decisions are usually justified with reference to potential harm; the risk of which is assumed to be heightened given the perceived sensitivity of the topic and presumed vulnerability of child participants (Martins & Sani, 2020; Powell et al., 2020).

Though risk of harm is a critical ethical consideration, that must be meaningfully attended to, we question some of the ways in which this can be construed in the context of children's potential involvement in abuse-focused research. Observing the risk-averse practices that can ensue, we question the 'ethicalness' of such approaches, as others have also recently done in related fields of research with children (Shier, 2023; Stalford & Lundy, 2022). We do so not to dismiss the importance and benefit of appropriate ethical oversight, but in the hope of stimulating further debate as to what constitutes inclusive ethical practice in the field of abuse-focused research with children and how this might be better supported.

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2. What's the problem?

"Whether we like it or not, more than 30 years on from the adoption of the UNCRC, balancing institutional approaches to research ethics with children's human right to participation and protection remains a delicate dance" (Graham in Hanson et al., 2023, p. 346).

Despite most contemporary guidance on ethical research with children advocating a nuanced and balanced approach to assessing both harm and benefit (ERIC n.d; Jamieson et al., 2021, ESRC, 2022), this does not always appear to translate into ethical decision-making around children's involvement in research, particularly that which focuses on abuse or other issues deemed to be of a sensitive nature (Alves et al., 2022; Hanson et al., 2023).

2.1. 'Do no harm' narratives

We contend this is, in part, an ongoing legacy of deterministic 'do no harm' ethical mandate that understandably emerged following documented abuses in biomedical experiments during the second world war. Interestingly, despite recognition of the nuance and balance required in its interpretation in key documents such as the 1979 Belmont Report,¹ do no harm narratives have commonly been presented as an irrefutable absolute; yet at the same time with an ambiguity as to what constitutes permissible harm or how this should be determined (see Hammett et al., 2022 for more historical context).

Such assertions continue to appear in contemporary ethical discourse – children should never be harmed by their participation in research, for example. The continued presence and influence of such statements – including in widely respected ethical frameworks that otherwise promote a responsible and reflexive approach to research with children – illustrates the pervasive nature of absolutist 'do no harm' narratives in relation to children's involvement in research.

Assuring no harm befall participants is not, however, a plausible reality in abuse-focused research with children, or indeed any social research. Such research is by its very nature unpredictable and dynamic, influenced by elements outside of the researcher's control. Even with comprehensive preparation, we cannot predict every potential eventuality that may occur in the field or result from dissemination, let alone assure we have eradicated all associated risks of harm (Buchanan and Warwick, 2021).

Yet, despite increasing recognition of this, some ethical decisionmaking around children's involvement in abuse-focused research appears premised on the belief that risk of harm not only can, but must, be entirely eradicated for research to be deemed to be ethical; concerns that are exacerbated by the perceived sensitivity of the topic and vulnerability of child participants. This appears particularly prevalent amongst ethics committees whose members are less familiar with this field of work and/ or with children's rights or trauma-informed practice, or those operating within stricter formal regulatory frameworks (Hanson et al., 2023; Martins & Sani, 2020).

Beyond resulting in unfavourable ethical opinions on individual studies, this can also deter other researchers from trying to involve children in their research; cognisant of their inability to ensure no harm ensues and/or in anticipation of difficulties obtaining required ethical approvals (Alves et al., 2022; Brown et al., 2020). As Hammett et al. (2022 p583) observe it can also result in researchers "*playing the game' by providing rehearsed, formulaic responses to what is seen as a bureaucratic, administrative box-ticking ritual*; providing simplistic and partial representations of risk, that bear little resemblance to the realities of ethical practice in the field.

2.2. Decontextualised assessments

Attempts to reassure ethical approval bodies that no harm will befall participants can also result in adult-centric, decontextualised assessments of risk and harm, that fail to take account of the circumstances and perspectives of those we wish to engage. This is both presumptuous and dangerous. On the one hand, as noted above, it can cause us to adopt unnecessarily risk-averse positions, for fear of the 'what if?' On the other hand, we can naively assume that we have identified and mitigated for all potential risks. This can:

- result in false assurances of safety; thus undermining participant capacity to provide informed consent, in the absence of an honest overview of the potential risks and benefits of participation;
- contribute to researcher complacency, leaving us less attentive to emergent and unexpected risks that might arise when in the field; and
- close down important opportunities to understand participants' concerns about risk and harm, and those of others supporting their involvement.

2.3. Universally understood concepts?

Such an approach also fails to account for the fact that 'risk' and 'harm' are not uncontested, objective concepts; they are differentially understood and experienced by different parties in the research process, at different points in time. This highlights important questions about who should determine what constitutes risk or harm for a participant, and whose views should hold most weight (Cody & Soares, 2023).

This is a particularly pertinent question in relation to children who have experienced abuse; often assumed to be doubly vulnerable due to their age and experiences. Evidence shows that this can mean that decisions are frequently made for them (Lefevre et al., 2018), rather than involving them and those close to them in collaborative conversations about risk, harm and safety planning. Although the relative weighting of both a child and parent/carer's contribution to such processes should be influenced by the child's developmental capacity, the right of children to be meaningfully involved in decision-making remains (Lansdown, 2005; and see Martins & Sani, 2020 for a fuller discussion on parental consent). Rather than obtaining parental consent for a child to participate in research, for example, might we obtain parental consent to invite their child to participate; thereby reinforcing the important message that parent/carer consent is not a proxy for children's consent. Furthermore, how might we meaningfully attend to the concept of consent as ongoing and dynamic, both in terms of a child's changing understanding of what participation in research means and their ability to control how and if they engage.

Meaningfully engaging with the complex, contextual and dynamic nature of risk and harm also requires us to reflect on important questions about what actually serves the best interests of the child. For example, might what we understand to be risky or harmful, be recognised as an opportunity for growth or influence by a potential participant and those who know them? Might we – or other stakeholders - deny them this opportunity, as a result of our anxiety or inability to hold that tension? Moreover, might our well-intended attempts to minimise harm inadvertently cause or compound harm in ways we might not be aware of; by further excluding those already marginalised with society, for example?

These questions hold relevance not only for decisions about who is included in research, but also for how we engage with those who are. What we perceive to be protective of a child in our engagements with

¹ The Belmont Report recognises that "such rules often are inadequate to cover complex situations; at times they come into conflict, and they are frequently difficult to interpret or apply. Broader ethical principles will provide a basis on which specific rules may be formulated, criticized and interpreted." It includes the specific example of research with children (where direct benefit to those involved cannot clearly be identified), noting "the different claims covered by the principle of beneficence [that do no harm falls under, alongside relative benefit and risk] may come into conflict and force difficult choices" (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research 1979 p2-5).

them, may in fact be experienced as harmful or disempowering. An example we often see written in ethics applications we review is the intention for a researcher to end an interview if a participant becomes visibly upset. Whilst this strategy may be informed by a protective intent, such approaches unhelpfully and unnecessarily withdraw choice and control from a participant (a core element of trauma-informed practice) and communicate the message that their trauma and distress are too much for us to handle. Such examples demonstrate the need for wider sharing of alternative participant-led and rights-based research practices (see for example, Elphick & Notté, 2023), and the importance of supporting newer researchers in the field to develop skills and confidence to implement these.

3. Why does this matter?

The risk-avoidant practices that can ensue from partial, deterministic and overly simplistic narratives can result in whole cohorts of children being excluded from research for reasons of ease rather than ethics. Such 'silencing' often disproportionately impacts those who are already marginalised within society, including those who have experienced abuse, disabled children, refugee and asylum seeking children and those from Minoritised communities (Ellis et al., 2023; Powell et al., 2020).

Children and young people, including those with lived experience, have unique and critical insights to offer to our understanding of abuse and how we might better prevent, identify and respond to it. Their understanding of the risks they face, the harms they have experienced and what they need in relation to this will inevitably differ from those of others, including from retrospective adult accounts. We need to create opportunities to safely hear these perspectives if our responses are to be better tailored to children's lived realities (Beckett et al., 2022; Cater & Øverlien, 2013). This is a particularly critical endeavour given the documented prevalence rates of abuse in childhood, and the many and significant ways in which this can impact on children's lives (Fisher et al., 2017; Harker Roa et al., 2023).

Though recognising differing opinions on this, we contend that such risk-averse approaches also deny children their right to have a say about matters that affect them, as enshrined in Article 12 of the UNCRC. This can be particularly acutely experienced by younger children and those with learning disabilities or delay, due to ongoing ambiguity around how children's 'evolving capacities' should be assessed and responded to (see Warrington & Larkins, 2019 for a fuller discussion). The mutual dependency of children's rights to protection and participation is also often overlooked through "*paternalistic approaches that sideline children's perspectives while claiming to champion their needs for protection*" (Ibid, 2019 p134; see also Hamilton et al., 2019).

Ironically, exclusionary ethical practices also replicate the very dynamics of the abuse we seek to counter. They subjugate the needs and views of children (individually and collectively) to that of those who hold power and control; silencing them, rather than enabling them to give voice to their experiences. They also deny them the opportunity to avail of the potential benefits that can ensue from research, including a sense of solidarity, self-efficacy and the opportunity to contribute towards positive change for others (Bovarnick et al., 2018; Martins & Sani, 2020).

The paternalistic and simplistic discourses around vulnerability and sensitivity that often underpin risk averse approaches also unhelpfully locate risk in the individual, rather than the contexts of their experiences and how these are externally construed (Buchanan & Warwick, 2021; Luna, 2009). They unhelpfully feed problematic societal discourses that those who have experienced abuse are now singularly defined by that experience and somehow 'too vulnerable' or 'too damaged' as a result of it. Moreover, they also propagate dangerous narratives that sexual abuse is too taboo to talk about, and must remain in the shadows, further silencing and stigmatising those whose experiences have already been constituted as setting them apart (Pearce, 2017).

4. A different approach

In our cumulative 30 years' experience of involving children and young people in abuse-focused research we have found that carefully considered and well supported research offers an important opportunity to counter these damaging dynamics, at both an individual and societal level.

Though not yet widely articulated in research settings, we have found that a trauma-informed approach (SAMHSA, 2014) provides a helpful framework for navigating the ethical complexities and tensions that can arise in this work; a sentiment that is echoed when we train others on this approach. As elucidated in a forthcoming practice paper from the authors, a trauma-informed lens helpfully reminds us of both the trauma reducing and trauma (re)producing capacity of research and how our decisions and actions can contribute to this (Campbell et al., 2019; Petrone & Stanton, 2021). It reminds us to be conscious of the traumas that participants may have experienced (including those unknown to us), and how this may impact their engagements with us. Like an integrated approach to children's protective and participation rights, it encourages us to balance considerations of safety and empowerment, and to do in a collaborative and trustworthy manner with those we seek to engage (see Houghton, 2015 for an overview of a child-rights based approach to research).

Approaching our decisions and actions through the six principles of trauma informed practice – safety, trustworthiness, choice, collaboration, empowerment and cultural considerations – helps us exercise participant-centred reflexive practice across research design, conduct and dissemination. In the instance of participant distress outlined in section 2.3, for example, a trauma-informed approach encourages us to anticipate and prepare for potential for distress, to safely hold this in the moment (for as long as is needed) and to be guided by the participant as to whether it is right for them to continue, take a break or stop. It also alerts us to the need to build in appropriate wrap around support both for the participant and ourselves.

Such an approach enables us to move beyond deficit-based narratives to instead think more holistically about how participant wellbeing might be promoted in (during), and through (opportunities to participate in), research. The ability to practically do this is, we (and others) would argue, dependent upon.

- A more grounded, contextualised, nuanced and proportionate approach to understanding risk in research; and
- Better recognition of, and support for, ethics as an embodied and living practice (see also ERIC n.d; Hammett et al., 2022; Martins & Sani, 2020).

In the final two sections, we share some reflections on our experiences of trying to work in such a way, and what we have learnt from this. Whilst drawn primarily from qualitative studies on sexual abuse in the United Kingdom and other European contexts, we hope these reflections hold relevance to work in other jurisdictions and on other forms of abuse. We also hope they help usher in a more nuanced, honest and realistic conversation around what ethical research practice might look like in a field where concerns about vulnerability, harm and risk are writ particularly large.

5. Reassessing risk: strategies to support

For us, ethical and inclusive research practice is dependent upon a willingness to engage with risk, rather than deny or avoid it. Importantly, this means approaching risk considerations from the premise of supporting safe inclusion wherever possible and desired, rather than using crude understandings of risk to justify exclusionary practices.

5.1. Grounded and contextualised

Assessments of risk in research are frequently based on broad assumptions about participant cohorts (on the basis of age, or known experiences of harm, for example), with little reference to the differing realities of their individual lives or the contexts of their proposed involvement. We believe this unnecessarily excludes potential participants, whose safe involvement could be enabled if assessments of risk took an approach that is more grounded in knowledge about participants and contextualised by the resources available.

We have found that involving those with direct experience of the issues under consideration, and practice partners in the field, helps us to implement such an approach. At the research design stage this involves consultative conversations about what risks there might be in a particular study, what support participants might need around these and how this could best be provided. It also involves thinking about how we can design and resource our research to maximise inclusivity and minimise potential for participant distress (Bovarnick et al., 2018; Houghton, 2015). This might, for example, include having practice partners supporting children's involvement, exploring a topic through a third person lens, or utilising a toolkit approach that allows different participants to engage with research questions in different ways, depending on what is accessible or preferable to them.

Where feasible, these consultative conversations are supplemented by more individualised risk and needs conversations. These conversations, usually undertaken in partnership with a professional known to the potential participant, are designed to explore how we might manage and mitigate any identified needs or risks for that individual. This might mean adapting our approach to support children with communication needs, or avoiding particular approaches that may have negative associations for a participant (use of recording devices, for example). These conversations also helpfully allow us to explore whether engagement in research might negatively impact on other processes in a child's life that we may not have been aware of, such as a live legal case. They also enable us to implement a tailored approach to parent/carer consent, informed by the capacity of the individual child, rather than broad age-based determinations.

An important part of our approach to managing risks (of inclusion and exclusion) is recognising our own limitations and being able to resource others who can support us. For example, funding practice partners to provide wrap-around support helps mitigate risk of distress after a research interaction, and ensures children have easy access to specialist follow up support if required. Similarly, employing a specialist play therapist in one study enabled us to confidently adapt our interview processes to involve children with learning and communication disabilities and younger children, who may otherwise have been excluded (Warrington, Beckett, Ackerley, Walker, & Allnock, 2017). Relatedly, funding clinical supervision for us as researchers, given the potential for vicarious or secondary trauma, has enhanced our ability to safely and sustainably practice in the field.

We do of course recognise that resources are always finite and that this inevitably influences who can be supported to safely participate in any given research study. This is something we ourselves have experienced, and are conscious of those we have not been able to include as a result. Whilst recognising reasons for this, this is not an excuse for complacency. Considering how research budgets can be developed to help maximise safe inclusion and minimise the risk of harm is a critical part of the debate, that is often neglected when such studies are being designed, funded or reviewed.

5.2. Nuanced and proportionate

What if we were to holistically consider the potential benefits of inclusion, as well as the risks? To consider not only children's rights to have a say about matters that affect them, but also the benefits that can ensue from doing so? Or if we considered not only risks of inclusion, but the risks of exclusion? To recognise the individual and social benefits that can come from challenging traditional power hierarchies in knowledge generation, and the harms that can come from failing to do so? To try to actively counter the power-dynamics of abuse, rather than replicate them through our systems and processes?

For us, attending to such questions is a critical part of adopting a more nuanced and proportionate approach to conceptualising and assessing risk of harm; something we contend needs to be implemented more broadly in decision-making around the ethicalness and legitimacy of abuse-focused research with children. Such deliberations need to be able to hold the fact that different actors in the research process may hold different understandings of what constitutes harm and benefit, or different tolerance levels around the relative weighting of these. And to encourage reflective practice about the ways in which concern about Institutional risks, or our own anxiety around holding risk, might be driving exclusionary research practices, that we externally justify in the name of participant protection.

This was aptly illustrated in a recent project, where a practitioner shared that a young person they supported to take part in a research workshop had been 'triggered', after the research engagement stirred up difficult memories. Our initial response was guilt and questioning of the appropriateness of our approach and their involvement. However, supporting opportunities for reflective conversations between the practitioner and young person enabled us to learn that 'being triggered' was, in their words, 'a daily occurrence'. With support of the worker, the young person powerfully advocated to be supported to stay involved in the project, noting that 'having my little voice as part of a bigger collective voice' was far 'more healing' for them, than being excluded due to our anxiety or guilt about them being triggered.

While this represented a deeply personal choice – informed by this individual's needs and developmental capacity– it serves as a timely reminder of the importance of proportional responses to risk that are informed by participants' perspectives, and not just our anxieties, and the need for further discussion about the types and levels of harm that may be ethically permissible, when viewed through a more nuanced and proportionate lens.

6. Supporting reflexive, responsive and responsible ethical practice

Throughout our research careers, we have repeatedly learnt the impossibility of predicting or mitigating for every eventuality prior to entering the field; an observation also shared by other social researchers (Cater & Øverlien, 2013; Hammett et al., 2022). Whilst operating within jurisdictional guidelines, researchers must therefore be permitted, and supported, to make real-time decisions in the field, as to what the most ethical way forward may be in any given situation.

In our experience, the ability to exercise reflexive, responsive and responsible practice in this way has been aided by a number of different things, including.

- Careful and considered planning: addressing any risks that can be preidentified and having clarity as to what is, and is not, permissible in the field (in relation to legal duties to report harm, for example).
- Being honest with participants, and those supporting their involvement: about the research and what involvement might mean for them. Being available to discuss any questions or concerns in advance of a research engagement.
- Pre-fieldwork training and practice: practicing and scenario planning for each new project, no matter how experienced we are. This reduces potential for participant harm that might arise from our unreadiness or discomfort.
- The right researcher for the right task: considering not only research skills, but familiarity with the topic and experience of/ability to sensitively engage with the particular participant group.

- Researcher support: having an experienced member of staff on call during fieldwork to provide real-time support and to debrief at the end of fieldwork engagements. Providing access to clinical supervision wherever possible.
- Support for participants: having practice partners who are adequately resourced to provide proactive wrap-around support, and are readily available during fieldwork should any difficulties or complexities arise.
- Having a frame of reference for in-the-field decisions: for us, this is informed by legal obligations, the promotion of participant wellbeing and trauma-informed principles of practice.
- Clear and robust policies and procedures for the 'non-negotiables': managing child protection disclosures, for example.
- Accountability: documenting the reasons for our decisions and alternative responses that were considered, and being open to challenge around these.
- Embedding individual and team-based reflection: what did we learn, what worked well, what might we need to do differently next time? Wherever possible this learning loop is informed by feedback from participants and those supporting their involvement.

The ability to ethically practice in this way is, of course, also dependent upon Institutional support and accountability; something that is often reported to be absent in our field. It also requires a shift in how we currently train and support researchers, to give them the skills and confidence they need to operate in this way, and the provision of safe spaces in which to have honest learning conversations.

7. Conclusion

Within this article, we have sought to highlight some of the current shortcomings in how risk of harm in research is understood and assessed, in relation to ethical decision-making around abuse-focused research with children, and to articulate the dangers of the risk-exclusionary practices that can ensue.

We, like others working in related fields, emphasise the need for broader adoption of a more holistic, nuanced and dynamic approach to assessing and managing risk of harm. Such an approach considers risks of inclusion alongside risks of exclusion, including risks of replicating existing structural marginalisation and harm. Understanding that risk and harm are neither static nor universally experienced concepts, it recognises the implausibility of the 'do no harm' guarantees often expected of social researchers in ethics governance procedures. Informed by rights-respecting and trauma-informed perspectives it focuses on holistically promoting participant wellbeing in, and through, research; recognising this to be a variably understood concept.

Ethics, in this context, must be a reflexive, embodied and living practice, rather than a procedural barrier to be navigated. Accordingly, researchers must be permitted – and importantly, trained and supported – to determine *'the action which is likely to bring about the greatest good'* (Oliver, 2003 cited in Buchanan & Warwick, 2021) in any given situation.

We recognise that implementing such an approach in abuse-focused research with children, a field where concerns about vulnerability, risk and harm are writ large, is not without challenge. It requires a significant shift in thinking, away from paternalistic understandings of childhood and victimhood, towards an integrated understanding of the intersections of trauma, rights and ethics. It also requires an alternative means of determining the ethicalness of research, in the absence of ironglad guarantees about the specific actions to be taken in any given situation. We hope the considerations we have outlined above – researcher readiness; support for researchers and participants; alignment with trauma-informed principles; transparency, accountability and so on – may serve as a helpful basis for progressing conversations around this.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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