### Chapter 4

# The Ethics of Research With Children on Violence Re-Examined

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#### **Abstract**

From an ethical point of view, the inclusion of children and young people in research is problematic due to their inability to give informed consent and meaningfully express their views. The ethical aspects of research are multiplied if the research participant might have experienced child abuse, neglect, exploitation, or other forms of violence or assisted in such acts. Talking about victimization might be difficult and generate a sense of betrayal of attachment figures. On the other hand, the usual ethical procedure of asking parents or other caretakers to give consent for their children to discuss issues of maltreatment gives them the power to act as gatekeepers to stop children from participating in research. Therefore, researchers should contemplate if parental consent should be waived and how research can be developed to mobilise children's agency and ensure their meaningful cooperation in researching different aspects of violence that affect them. This chapter presents and critically analyses different research examples and discusses their ethical dimensions from a children's rights perspective. The research questions start with discussing the utility of consulting children in research on maltreatment; the gatekeeping role of caregivers; the distress and harm eventually caused to children and young people by participation in research and the benefits of participation for children. The survey examples discussed lead to the conclusions that research on maltreatment might sometimes cause distress; caregivers' power to refuse consent for their children's participation in research on maltreatment can alter epidemiologic data and impede children's right to express their opinion on issues that are central to their lives and therefore, it should be waived; consulting children is essential for

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collecting data on and improving responses to child maltreatment; and children's contribution to research on maltreatment depends on the adopted methodologies of the research, more advanced forms of participation, and training children to express their opinions, thus enriching scientific knowledge and promoting change.

Keywords: Child participation; children's voices; parental gatekeeping; ethical dilemmas; sensitive research; empowering children

#### Introduction

Data collection on maltreatment of children in their homes; by their parents and caretakers; on school premises or in institutions; and via cyberviolence, domestic violence, community violence or peer violence are considered sensitive research topics and covered by ethics regulations. This chapter discusses key ethical considerations of research on child maltreatment, analysing examples of studies that gave children the opportunity to have their voices heard and contribute to the accumulation of knowledge with empowered voices.

Although participation of children in research becomes more and more solidly grounded ethically and methodologically, its translation in the practice and service evaluation in child protection is limited and often does not cover the most disadvantaged children (Lätsch et al., 2023; Toros et al., 2021). Children's participation in research on maltreatment is justified by the social value of their contribution to the accumulation of knowledge, which is meant to affect child protection policies, improving responses to cases of maltreatment and prevention measures. The main dilemmas for involving children and young people in research on child abuse, neglect and connected adverse experiences revolve around the importance of listening to children's views on these topics, their vulnerability and the need to protect them against the distress and trauma of investigating such topics (Bradbury-Jones et al., 2018; Gordon, 2020). From a bio-ethical-medical stance and according to the ethics regulations presented in Chapter 3, children and young people are considered less capable than adults to express their opinions and understand all implications of the research targeting them (Canadian Paediatric Society, 2008; Council for International Organizations of Medical Sciences, 2016 [CIOMS]; World Medical Association, 1964/2018). In a traditional view, children younger than the age of maturity are considered less capable than adults to understand research procedures and make decisions according to their best interest; therefore, for children, the risks of taking part in research are greater than the benefits (Mathews et al., 2022). Accordingly, children are seen as having a limited capacity to give informed consent or commit to research with the same degree of awareness as adults (Daley, 2013; Lohmeyer, 2019). On the other side, from a children's rights view, children are autonomous and agentic people (Blanchet-Cohen, 2009; Larkins et al., 2021) with the right to express their views. Therefore, in discussing ethical concerns of research involving children while pursuing their best interest, their vulnerability and agency are both relevant (though not the only) ethical concerns that need to be addressed. Further concepts discussed in this chapter are marginalisation and silencing of children's voices, empowerment and power given to children, and inclusion and influence, as discussed in a literature review on participation of vulnerable children in research by Bradbury-Jones et al. (2018).

# **Ethical Concerns in Research With Children From a Historical Perspective**

Researchers who are confronted today with the complicated ethical procedures for including minors – considered a vulnerable category compared to adults (CIOMS, 2016) – need to understand the controversial legacy of research with children of the previous century (Mudaly & Goddard, 2009). Such research took place in some well-established medical schools and education and psychology research centres before, during and after World War II. For example, in the classical experiment in 1920 with Little Albert, <sup>1</sup> a 9-month-old baby, designed by the founder of behavioural psychology, J. Watson, to prove that fright is a learnt behavioural reaction that can be conditioned, the single-case experiment involved an orphaned child.

The criminal experiments of Nazi physicians on people, including children,<sup>2</sup> are most widely known, and their condemnation was well documented during the Nuremberg medical trial. Despite the first code of ethics (Nuremberg Code of 1949) that condemned research that causes harm to people and required consent of research participants, medical experiments risking children's lives were conducted and even praised, including in the Western democracies during the second half of the last century, in the name of the greater cause served by the research. For example, from 1956 to 1970, Krugman identified the A and B forms of the hepatitis virus by experimenting with virus samples on children with mental disabilities from disadvantaged families. Children were subjected to highly risky procedures by taking advantage of the parents' hopes to place children in a special school, without having clear knowledge of the health risks for their offspring (Murphy, 2003). In the same logic of good intentions, governed by the best of anti-racist intentions and undeniably successful in demonstrating how racist ideas can manipulate children, Jane Elliott designed and replicated numerous times her 'blue eyes-brown eyes' educational classroom experiment (Bloom, 2005, 2021). Taking place in the context of the murder of Martin Luther King, Jr. in 1968, this educational research project was meant to demonstrate how arbitrary criteria can

<sup>&</sup>lt;sup>1</sup>This is a classic experiment for behavioural psychology presented on numerous websites and psychology manuals, such as https://www.simplypsychology.org/little-albert.html (see Watson & Rayner, 1920).

<sup>&</sup>lt;sup>2</sup>At the Nuremberg trial, 70 cruel medical projects were documented, and 23 Nazi physicians and scientists, who were responsible for victimising at least 70,000 individuals through their experiments, were tried. Several children (numerous twins) were victims of Mengele and his fellow physicians. See the webpage of the U.S. Holocaust Museum: https://www.ushmm.org/collections/bibliography/medical-experiments.

generate prejudices. In her capacity of being a teacher in an all-Caucasian rural Iowa elementary school, Elliott divided her class in two groups and explained that the blue-eyed students were genetically superior to the brown-eyed ones. Although she recognised the pain and suffering caused to her participants, she did not stop her experiment, counting on the debriefing session to restore children's cooperative relations and acknowledge the wrongdoing of discrimination. Although this educational experiment had strong experiential learning value, it has become an example of ethical misconduct, exposing unaware children to feeling unworthy, compared to others, and ignoring the risks to their well-being.

To avoid harm to children in research processes, international and national ethics codes and medical and social science research bodies have placed children's best interest at the forefront of the ethical assessment of the value of research, defining guidelines for the child's consent to take part in a study. As explained in Chapter 3, firm procedures and guidelines for research with children have been developed in all countries, though debates on the meaning of children's and adolescents' best interest, vulnerability, legal and developmental capacity to understand the information about the research process conveyed to them, and the consequences for their life and mental state have not yet reached a common and unique answer among different forums and countries. As a general idea, CIOMS (2016) has endorsed children and adolescents' involvement in research, unless there are strong arguments for exclusion due to risks. International and national research ethics bodies have the mandate to approve and fund research with children and adolescents, if seen as contributing to scientific progress, having practical benefits, serving the best interest of participants, and protecting them against all harm throughout the research process. According to regulations, considering children's vulnerability, parents or those acting in loco parentis need to act as gatekeepers for children's participation in research and give their consent for their children who are not of a certain age considered as developmentally appropriate for understanding the consequences of research.

For the ethical assessment of research designs regarding child maltreatment involving children, the main issues are the utility of research for the participating children and youth, their families, their communities, and the institutions and services that respond to violence against children regarding knowledge development; types of vulnerabilities (categorical, individual, group, or contextual) and the risks associated with them (Gordon, 2020; World Medical Association, 1964/2018); probability and level of harm or discomfort experienced during and after the research (CIOMS, 2016; Cohen et al., 2018; Mathews et al., 2022; Santelli et al., 2003); protection of data for privacy and confidentiality (National Bioethics Advisory Commission, 2001); level of involvement of children in research and handling of power relations between adults and children involved in research (Kyegombe et al., 2019; Larkins et al., 2021); and necessary procedures of informed consent and gatekeeping by parents or caregiving adults or the waiving of consent by legal guardian (CIOMS, 2016; Kyegombe et al., 2019; Priebe et al., 2010).

### Methodology

The objective of this study is to reveal ethical issues raised by children's participation in research on maltreatment by scrutinising examples based on different methodologies like single-case experiments, population surveys, interviews, and participatory action research. Based on the literature review by Bradbury-Jones et al. (2018), the research examples analysed in this study were selected for their relevance to the following ethical topics: (a) children seen as a vulnerable population that can be exposed to risks of harm by researchers; (b) children can have their agency barred due to gatekeeping by parents or caretakers or needing parental consent to be allowed to have their voices heard; (c) violence is considered a sensitive issue, with children facing risks when involved in research on this topic; (d) children have an opinion on topics such as violence, which they might also face in real life; and (e) children's agency and ability to act based on what they learn from research are valued.

All these ethical issues are often interrelated in studies that explore child abuse and neglect or any other form of violence, because they touch on intimate adult—child relationships or family relationships, especially the intimacy of the child involved in research. In fact, violence against minors represents a sensitive issue not only for children and young people involved in such research, but also for their families, educators or any other caretaker who needs to give consent for them and for the schools, child protection agencies and communities that are supposed to monitor children's safety. Thus, the sensitivity of the topic of such research leaves its mark on the caretaker's role in gatekeeping children's participation in research.

These issues led to the following research questions related to ethical issues:

- (1) Does consulting children in research on maltreatment contribute to the development of policies and practices in this domain?
- (2) Knowing the sensitivity of the topic for parents and other caregivers, should they be the gatekeepers for their children's participation in research on maltreatment?
- (3) Does research on maltreatment cause distress and harm to participating children?
- (4) What are the benefits of children's participation as co-researchers?

# **Ethical Issues Illustrated in Examples of Participatory Research With Children on Maltreatment**

The views about children as a vulnerable category of population needing protection from not only violence but also being questioned about this sensitive issue have been challenged by researchers, who saw the merits of giving children more roles in the production of scientific knowledge. The issue of participation of child victims in child protection decision-making and in research evaluating child

protection processes has generated ongoing debates (Lätsch et al., 2023; Tisdall, 2017). Recognising children as knowledgeable agents while admitting the specificities of their age-limited capabilities has contributed to increased variety of research methods. Besides using interviewing, surveying and observing to explore topics related to violence against children, multi-method 'mosaic approaches' have been developed, like the use of visual media, telephone and online enquiries, photography and photovoice, roleplaying, theatre forums and community mapping, which allowed greater flexibility in the relationship of the researcher with the children and thus, allowing children more agency (Clark & Moss, 2011; Diaconescu & László, 2016; Fargas Malet et al., 2010). The following sections explore a few such examples in search of a better understanding of children's contribution to understanding and responding to different forms of child maltreatment.

#### Does Consulting Children in Research on Maltreatment Contribute to Enhancement of the Knowledge Base in This Area and the Development of Policies and Practices?

The usefulness of including children in participatory research and the opportunities they could have in this process can be exemplified by a comprehensive worldwide United Nations study on violence (Pinheiro, 2006), which involved around 8,000 children from all continents through interviews, focus groups, online surveys, regional consultations and forums. Acknowledging that violence against children is a major threat to global development in the new millennium, the World Report on Violence collected accounts of children in their homes and families, schools, care facilities, justice institutions, work settings and neighbourhoods. The analysis of national and regional reports indicated the severity of abuses and threats faced by children due to physical punishment, sexual abuse and neglect, amplified by war, poverty, migration, injustice and discrimination with dimensions and severity that reached epidemic proportions (Lenzer, 2015). The study prioritised children's involvement in research, collecting a wealth of accounts from them and including them in presenting the reports, to make their voices heard by policymakers. This resulted in unveiling violence by child participants in discussions groups and policy forums, making 'invisible' phenomena much more visible and comprehensible for the public, professionals and policymakers. Considered an example of large participatory research on violence, the report stated that 'children have the rights to express their views, and to have these views taken into account in the implementation of policies and programs' (Pinheiro, 2006, p. 17). Following up on this recommendation, the Global Status Report on Preventing Violence Against Children (WHO, 2020) emphasised the need to consult with children, viewing them as competent partners in the protection against and prevention of violence.

#### Asking for Parental Consent and Gatekeeping by Parents

Getting clear, consistent and comparable prevalence data on different forms of violence against children with the help of population surveys, including large samples representing all segments of the population and regions, is still very challenging for the research community. Maintaining parental consent as a compulsory procedure for research and the high rates of parental refusal are often fuelled by protectionist attitudes, considering that questions related to physical, psychological and sexual abuse result in distress and aversion of children. Controversies related to children's capacity to be reliable informants for prevalence surveys on maltreatment in homes and families are unavoidable for research with children. Therefore, it is important to acknowledge that offering parents the option to decline children's participation in research - thus ignoring the conflict of interest between parents (or caretakers) being in a position of power and their children who depend on them - has the effect of silencing children with maltreatment experiences in the family. In this way, these parents become gatekeepers and deny children's right to participate in research, strengthening the taboo aspects of talking about family dynamics and eventual violence to people or professionals outside the family.

If the proportion of parents denying children's involvement in large surveys significantly increases, maltreatment prevalence rates obtained with the most statistically reliable and valid instruments might become questionable. Based on Romanian BECAN<sup>3</sup> research data (Antal et al., 2012; Roth et al., 2013), after inviting parents of 5,858 pupils to allow their children to complete a questionnaire on the topic of 'parental relationships and child rearing practices', the refusal rate by parents reached 29.1% for 11-year-olds and 26.5% for 13-year-olds (with an average of 27.8%). In some schools and areas, the refusal rate was more than one third, even reaching 40%. These high refusal rates were obtained despite adopting a passive parental consent procedure for children. For children who would disclose parental maltreatment or need support to manage distress related to questions in the survey, field researchers received many guidelines for safeguarding.<sup>4</sup> Procedures included information sheets for both parents and children about data confidentiality and anonymity and participants' rights to withdraw from the research if they did not want to continue. The detailed methodological, data protection and ethical provisions were described by Roth

<sup>&</sup>lt;sup>3</sup>The Balcan Epidemiologic Child Abuse and Neglect Research (BECAN) project was funded by European Union's 7th Framework for Research and Innovation (223478/ HEALTH/2007) and coordinated by the Institute of Child Health in Athens, Greece. Its aim was to collect data on child abuse and neglect in families in nine European countries: Albania, Bosnia, Bulgaria, Croatia, Greece, Republic of North Makedonia, Romania, Serbia and Turkey.

<sup>&</sup>lt;sup>4</sup>In the BECAN research report, safeguarding issues are described in detail. Any indications of being at risk of maltreatment were followed up by field researchers. Interdiction of parents to allow children to complete the survey was respected (Roth et al., 2013; Voicu et al., 2016).

et al. (2013) and Voicu et al. (2016). In contrast to parents, children's assent forms were declined by less than 1% of children in the 11–13 age range (0.21% for 11-year-olds and 0.28% for 13-year-olds). Adolescents older than 16 did not need parental consent and their consent refusal rate was 1.05%, showing their eagerness to express their views.

To understand more about parental reasons for gatekeeping, researchers analysed the phone and email messages received from parents who used the researchers' contact information from the information leaflets. The messages sent to researchers showed that receiving information leaflets and consent forms for responding to a research invitation – addressed both to them as caregivers and to their children – was new and unusual for Romanian parents because previously there had been very few social or psychological research projects that required parental consent. This has been mostly a procedure for medical experimental research. So, the procedure triggered the imagination of some parents, generating suspicions that rapidly snowballed in the school community. Despite the information offered, many parents had difficulty understanding the procedures ('I discussed with other parents, and we do not understand what is asked from our children and from us'; 'Are you taking our children somewhere for questioning?'; 'Where will the survey take place?'). A dozen parents objected to the surveys due to questions about parenting methods, abuse and especially sexual abuse, and they expressed doubts that the research had been approved by 'authorities'. From the conversations, we learnt that the information letter must feature more exact data on the procedures and timing of the survey; concrete information given to children is not enough for parents. Whenever possible, the field researchers met with groups of parents to convey the exact information and dissipate their concerns. But the sensitivity of the topic of violence against children could not be eliminated nor could such meetings change the conservative attitudes that children's participation in surveys on family relations might encourage them to rebel against parental authority.

## Distress, Risks and Harm in Research on Maltreatment (Focussing on Sexual Abuse)

Despite progress in understanding the agency and relative autonomy of children and young people and granting them space to express their opinions, there is still a reluctance of institutional ethics boards and national or professional ethics bodies to wave parental consent for such projects for children and even adolescents. The motives are often based on 'inaccurate assumptions about risks and harms to participants', 'the indiscriminate labelling of children as a vulnerable group', and 'the over-cautious position regarding trauma research in general' (Mathews et al., 2022, p. 3). Given these controversies, studies on sensitive issues such as sexuality, sexual abuse and violence are necessary because they can offer important clues on how children might be harmed or avoid distress due to research. Priebe et al. (2010) conducted such a study, measuring the negative emotions noted by research participants in Sweden or Estonia in connection with their participation

in the survey. As mentioned by the authors, the expressed feelings of distress or discomfort were situational and comparable to emotions of everyday life (Priebe et al., 2010). The results of the study showed that most adolescents did not agree with statements on emotional discomfort while answering questions related to sexual abuse. Using path model analysis, the study found that reports of penetration did not significantly explain discomfort; sexual inexperience of respondents and high ratings regarding the belief that rape is a myth had a stronger explanatory power for discomfort. For the issues of risks of harm discussed in this chapter, this means that being sexually abused was not directly related to discomfort experienced during research. According to this study, the adolescents' risks of responding to the survey were not higher than usual everyday risks.

The attitude of children towards answering surveys related to child physical, psychological and sexual abuse and neglect were examined in a qualitative, participatory way using focus groups with respondents aged 11, 13 and 16 years using the ICAST instrument, based on BECAN study in Romania (Roth et al., 2013). Assuming that asking consent from parents is less about children's competences and more about cultural reluctance to take children seriously (Alderson & Morrow, 2011; Morrow, 2009), the researchers wanted to hear from children about what it means to respond to surveys on sensitive topics. The procedure adopted for this purpose was a two-phase process: First, we asked children to complete the ICAST-C survey, then we asked them to participate in a follow-up focus-group discussion, keeping the three age groups separate. Looking into the dilemmas around children's immaturity to make decisions about participating in surveys on sensitive topics like violence, including sexual violence, children were invited to debrief after completing the survey and give their advice on how such surveys should be best carried out from their point of view. Because children often do not get credit for being competent enough to answer surveys, one question referred to whether participants felt competent to fill in the survey. Another question referred to making decisions about consent, asking if children thought parents should decide if their offspring could participate in research.

The members of the two younger age groups received parental consent before they were invited to consent to completing the survey and participating in focus groups. Children completing the surveys did not show any kind of distress during the research. The oldest participants in the focus group, 13 and 16 years old, considered that children their age should be able to participate in such surveys without their parents' consent because the questions were about topics familiar to them. Young people indicated that questions on parenting methods gave them the opportunity to reflect on their family relations, and the researchers noted that one girl (aged 16) mentioned thinking about her future parenting. These two age groups considered that for participants their age, all questions were

<sup>&</sup>lt;sup>5</sup>According to the study, many adolescents strongly disagreed with items such as: 'the questions were unpleasant to answer' (63%); 'one should not ask people such questions' (77%); 'the questions can have unfortunate impacts' (68%) and 'the questions were too private' (63%). Between 10% and 18% agreed with these statements. Country-level differences between Sweden and Estonia were noted in this study on rape myth acceptance.

comprehensible, including those asking about their sexual experiences. For these issues, they warned researchers against using such questions with younger children, indicating that parental consent would be necessary if questionnaires included these questions. The discussion with the 11-year-olds revealed that some of them felt the need to have parental advice before making decisions on consent to participate in such research. Overall, the youngest group favoured the idea of making the decision themselves, but preferably after having the opportunity to consult with their parents. The results indicated that children are eager to take part in surveys on the topic of family relationships and violence, although doubt about the capacity of younger children to make these decisions appeared to be internalised by the adolescents. The need of children, mostly from the younger group (11 years old), to get advice – not approval – from parents about participating in such a survey seems an expression of children's need for parental encouragement to freely express their opinions on family relations. Based on attachment theory, for some children who experienced violence, talking about parenting methods might be difficult because it involves contradictory emotions and risks or seems a betrayal of the person towards whom they feel ambivalent, both loving and being angry at them. Kilkelly and Donnelly (2011) reported similar results, also noticing that children's opinions were ambiguous: They not only want to be listened to but also need to feel supported in their opinions. Therefore, an ethical requirement in research on violence should be that field researchers understand children's ambivalence in their attitudes and offer them support in expressing their often contradictory feelings.

#### Benefits of Children's Participation as Co-Researchers

Professionals' knowledge about different forms of child maltreatment and the services dedicated to respond to victims are increasingly shaped and informed by children's views (Mathews et al., 2022; Nowland et al., 2022). Researchers need to be aware of how children conceptualise violence and how they might differ from adults in their definitions (Kosher & Ben-Arieh, 2020). Methodologies have been developed to invite children affected by adversities in their communities or by abuse or neglect to plan and evaluate programmes and services (Nowland et al., 2022). Children's opinions and programme evaluations often challenge the opinions of experts (Bradbury-Jones et al., 2018). In the Participation for Protection European project,<sup>6</sup> researchers from six countries explored children's concepts of violence, protection and support against violence, engaging 91 children (9–10 years old) and young people (15–16 years old) in 14 working groups and 1,272 school children, to answer a survey. The objective of the project was to

<sup>&</sup>lt;sup>6</sup>Participation for Protection was funded by the European Union (P4P 2018-2020 REC-CHILD-AG-2016-01); led by Queens University, Belfast; and involved Austria, Belgium, Germany, Northern Ireland, Republic of Ireland and Romania. Information about the project can be found online: https://www.qub.ac.uk/sites/participation-for-protection/.

understand children's views on forms of maltreatment and child protection issues and integrate children's voices in child protection training. The project followed the Lundy model (Lundy et al., 2011), which defines child participation by four essential components: children should have a voice, they should have a safe space to express themselves, there should be an audience to listen to what they have to say and their opinions should be taken into consideration such that they influence adults involved in children and childhood policies. To design training materials for professionals, researchers initiated working groups with children in the participating countries in the following settings: residential institutions, situations of migration, Roma children in disadvantaged Roma communities and closed residential facilities. Advisory groups of children and young people guided researchers in formulating the questions on topics commonly agreed on: how they defined different forms of violence, what kind of risks they perceived, what kind of help they expected, why children and young people might not ask for help, the best ways people their age should ask for advice and support if they are harmed, to what kind of helper they would turn etc. Based on their age differences, children and young people worked in separate groups and participated in all phases of research, designing, debating and piloting the items of the survey and voicing arguments in favour of their opinions. Teaching materials that included data and quotes from children's survey, focus groups and interview responses were much appreciated by social work trainees and teachers attending modules on children's rights and child protection. Thus, the usefulness of the research was proved by the success of the training, and the evaluation sheets showed great satisfaction (McAlister, 2020). This successful example of child participation in research was possible due to thorough planning around research ethics and handling of eventual risks of children being affected by taking part in the advisory and working groups.

All participating children and adolescents were offered training sessions to inform them about the scope, length, methods and other details of the research project. Adult facilitators explained the rights of participants in the research process, including the right to not participate or to leave the project at any time. Due to the preparatory training activities and discussions during sessions with the researchers, both the participants in the two advisory groups and those in working groups became more knowledgeable about protection against violence and the accessibility of child protection services. Leaflets were distributed to all participants with child-friendly information on violence and what services are available for them in case they experienced violence or cared for the safety of others. Information on support for victims of violence was contextualised and discussed for each country. Facilitators created a respectful and inclusive climate for discussions, giving special attention to the dynamics in the working groups with vulnerable children (centre for migration, shelter for trafficked children, residential care, LGBT children, Roma and Traveller children in disadvantaged communities, victims of domestic and political violence).

Attendance was constant for the eight children aged 9–10, but less good for the adolescents, whose enthusiasm was high at the beginning, when specific tasks were given, but fluctuated during the process. In all phases of the research, children's

and young people's feedback indicated that they felt interested in the topic and empowered by the process. Children felt valued ('what we are saying impacted the process'); they also commented on how they managed to keep the language of the research child-centred, asking questions in case they had difficulty understanding the researchers; and the schools of children responding to the surveys made signposting leaflets available for all their students.

Including children's voices in the teaching materials was much appreciated by training participants. In the evaluation forms, a trainee from Germany stated that hearing children's voices gave her more confidence in her actions; for another, it was more convincing because the knowledge came directly from children; a third expressed much appreciation about the messages coming directly from children and not statistics from the books; and a fourth one reported feeling positive because the learning process was built around children's voices.

The level of participation of children in research on family, peer or community violence largely depends not only on the conception of the researchers of children as autonomous beings but also on the methodology chosen to empower participating children to express themselves. 'Young people popularly symbolise a source of hope and social change' and can act 'capable and responsible, whilst also needing protection or being a risk to others' (Lohmeyer, 2019, p. 42). Adult researchers who rely on children's agency and empower them to become co-researchers can benefit from children's engagement and enthusiasm or encourage them to conduct their own research as peer researchers (Larkins et al., 2021) on topics that are important to them.

#### Discussion

Ethical issues related to children's participation in research on violence are strongly linked with the principles of children's rights as formulated in the Convention on the Rights of the Child, adopted by the United Nations (1989), and the numerous comments and other documents that followed on the best interests of children, non-discrimination, respect and confidentiality towards children, listening to them and helping them express their attitudes, protecting them, and preventing violence and providing resources to respond to violence if it occurs. Reviewing these ethical issues with practical examples of quantitative and qualitative research with children showed the utility of listening to them in a respectful way, so that children feel their opinion matters and that they are worth consulting, in the same way as any adult, without subjecting them to any forms of risks of violence or exploitation.

Acknowledging the vulnerability of children facing adults in position of power and the developmental limits of children's and young people's capacity to understand research requires that researchers do all they can to protect underage participants against any form of harm or distress and develop safeguarding procedures (Mathews et al., 2022). The recognition of children's vulnerability does not exclude recognising their capabilities to reflect on the help they need and the dangers they may face. As formulated by Lundy et al. (2011), the United

Nations Convention on the Rights of the Child has been an essential lever for creating methodologies to include children as participants or even co-researchers in studies that concern their lives. Participation in research as a right to exercise autonomy means that children are considered rights holders, capable of forming an opinion and exercising their freedom of expression, including intimate topics like their relationship with people in positions of power and attachment figures. It also means they have the right to express their views on the treatment they receive in care services and from professionals who are supposed to provide support; it means they are entitled to be included in planning prevention approaches. Many participatory research projects are not limited to the collection of data but intend to inform services or policies. Research can create a reflective, stimulating and change-oriented learning environment – and can take a critical stance (Bereményi et al., 2017; Larkins et al., 2021).

Lastly, the right to provision means children are also entitled to receive support that serves their best interests, whether they need justice or treatment for the trauma they suffered, health care interventions, or supportive actions (offline and online prevention programs, targeted community interventions, shelters, help lines, campaigns etc.) to reduce the risks of maltreatment in their families, schools and communities.

#### Conclusion

Responding to the research questions, the analysis of research examples has demonstrated the following.

Consulting children is essential for collecting data on child maltreatment. Children's contribution depends on the adopted methodologies of the research; more advanced forms of participation – following methods where children are trained to express their voices – generated more benefits for both the accumulation of knowledge and promoting changes in the response to and prevention of violence against children (Blanchet-Cohen, 2009; Larkins & Bilson, 2016; Office of the Special Representative of the Secretary-General on Violence against Children, 2020).

Examining parents' consent rates regarding their children's inclusion in large population surveys indicated that parents tend to exercise their gatekeeping role and keep children and adolescents away from expressing their views on parent—child relationships. This is likely due to reasons of protecting their offspring from being confronted with sensitive issues like different forms of abuse and neglect, including sexual abuse; fear that participation in research would encourage them to rebel against parental authority; their lack of understanding of survey procedures or simply to avoid children's disclosure of being exposed to violence in the family. High parental rates of refusing children's participation in research contrasted with children's willingness to participate, which was almost unanimous in the discussed BECAN research (Antal et al., 2012; Roth et al., 2013). Thus,

caregivers' power to decline consent for their children's participation in research on maltreatment can alter epidemiologic data and impede children's right to express their opinion on issues that are central to their lives and, therefore, should be waived as recommended by CIOMS (2016).

As mentioned in the literature and shown in the survey examples discussed in this study, research on maltreatment did sometimes – though not often – cause distress to participating children. But the feelings of research participants were situational and comparable to emotions of distress in their everyday lives (Priebe et al., 2010). Due to the sensitivity of research on maltreatment, the analysis revealed that children need a supportive attitude and clear protective procedures from the researchers (Priebe et al., 2010; Roth et al., 2013).

Despite these challenges, research can also bring benefits for children and young people. If used appropriately, participatory methods can contribute to recalibrating children's understanding of the implications of maltreatment on their lives. Thus, participatory research is beneficial for children and young people involved in research on violence by building participatory spaces where they can get the attention they need and learn skills to promote changes in their environments (Bradbury-Jones et al., 2018; Larkins & Bilson, 2016; McAlister, 2020). If their participation in research felt meaningful and contributed to change, children and young people reported more benefits for them and their peers: becoming more active and showing leadership (75.0%), followed by academic (more entrusted in school) or career benefits (55.8%), social benefits (36.5%), interpersonal skills (34.6%) and more confidence in their intellectual capacities (23.1%; Anyon et al., 2018).

Regarding the controversies about whether children and young people are aware of the risks they might encounter and whether they can express their needs in their relationships with the adults who are supposed to protect them, the research examples consistently demonstrated that the mentioned topics are part of their lives, they are interested in and can reflect on them and they are ready to share their opinions. More scoping reviews and meta-analysis are needed to generate further evidence that could convince the international research community that children and young people, although not fully mature from a legal point of view, are autonomous enough to decide freely if they want to participate in research on violence and that gatekeeping by parents or caregivers might counter children's best interest and their right to express themselves and could even alter research results.

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#### References

- Alderson, P., & Morrow, V. (2011). The ethics of research with children and young people. Sage.
- Antal, I., Roth, M., Mezei, E., David-Kacso, A., & Voicu, C. I. (2012). The Balkan Epidemiological Study on Child Abuse and Neglect (BECAN) in Romania. *Revista de Asistență Socială* [Social Work Review], 51–63.
- Anyon, Y., Bender, K., Kennedy, H., & Dechants, J. (2018). A systematic review of youth participatory action research (YPAR) in the United States: Methodologies, youth outcomes, and future directions. *Health Education & Behavior*, 45(6), 865–878. https://doi.org/10.1177/1090198118769357
- Bereményi, B. Á., Larkins, C., Percy-Smith, B., & Roth, M. (2017). Key learnings from the PEER project: A combined research paper. https://ddd.uab.cat/pub/llibres/2017/174652/Focus\_Beremenyi\_a2017n3.pdf
- Blanchet-Cohen, N. (2009). Children, agency and violence: In and beyond the United Nations Study on Violence against Children. (Innocenti Working Paper No. IDP 2009-10). UNICEF Innocenti Research Centre. https://www.researchgate.net/publication/46473536\_Children\_agency\_and\_violence\_in\_and\_beyond\_the\_United\_Nations\_study\_on\_violence\_against\_children
- Bloom, S. G. (2005, September). Lesson of a lifetime. *Smithsonian*. https://www.smithsonianmag.com/science-nature/lesson-of-a-lifetime-72754306/
- Bloom, S. G. (2021, December 22). Did we fail Jane Elliott's blue eyes/brown eyes experiment or did it fail us? *Milwaukee Journal Sentinel*. https://eu.jsonline.com/story/opinion/2021/12/22/did-we-fail-blue-eyes-brown-eyes-experiment-did-fail-us/8896080002/
- Bradbury-Jones, C., Isham, L., & Taylor, J. (2018). The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review. Social Science & Medicine, 215, 80–91. https://doi.org/10.1016/j.socscimed.2018.08.038
- Canadian Paediatric Society. (2008). Ethical issues in health research in children. *Paediatric Child Health*, *13*(8), 707–720. https://doi.org/10.1093/pch/13.8.707
- Clark, A., & Moss, P. (2011). *Listening to young children: The mosaic approach* (2nd ed.). National Children's Bureau.
- Cohen, L., Manion, L., & Morrison, K. (2018). Research methods in education.
- Council for International Organizations of Medical Sciences (CIOMS). (2016). *International ethical guidelines for health-related research involving humans*. https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf
- Daley, K. (2013). The wrongs of protection: Balancing protection and participation in research with marginalised young people. *Journal of Sociology*, *51*(2), 121–138.
- Diaconescu, M., & László, E. (2016). Empowering youth using forum theatre in order to prevent bullying. *Revista de Asistenta Sociala* [Social Work Review], 2, 95–106.
- Fargas Malet, M., McSherry, D., Larkin, E., & Robinson, C. (2010). Research with children: Methodological issues and innovative techniques. *Journal of Early Childhood Research*, 8(2), 175–192. https://doi.org/10.1177/1476718X09345412
- Gordon, B. G. (2020). Vulnerability in research: Basic ethical concepts and general approach to review. *The Ochsner Journal*, 20(1), 34–38. https://doi.org/10.31486/toj.19.0079

- Kilkelly, U., & Donnelly, M. (2011). Participation in healthcare: The views and experiences of children and young people. *The International Journal of Children's Rights*, 19, 107–125.
- Kosher, H., & Ben-Arieh, A. (2020). Children's participation: A new role for children in the field of child maltreatment. *Child Abuse & Neglect*, 110(Pt. 1), 104429. https://doi.org/10.1016/j.chiabu.2020.104429
- Kyegombe, N., Banks, L. M., Kelly, S., Kuper, H., & Devries, K. M. (2019). How to conduct good quality research on violence against children with disabilities: Key ethical, measurement, and research principles. *BMC Public Health*, *19*, 1133. https://doi.org/10.1186/s12889-019-7456-z
- Larkins, C., & Bilson, A. (2016). The magic 6: Participatory action and learning experiences with Roma Youth Training Manual. Cluj University Press.
- Larkins, C., Nowland, R., Robertson, L., Farrelly, N., Sharpe, D., Roy, A., Morocza, N., & de Lemos, J. B. (2021). Peer research by children and young people and their allies. The Centre for Children's and Young People's Participation. http://clok.uclan.ac.uk/39353/
- Lätsch, D., Quehenberger, J., Portmann, R., & Jud, A. (2023). Children's participation in the child protection system: Are young people from poor families less likely to be heard? Children and Youth Services Review, 145. https://doi.org/10.1016/j.childyouth.2022.106762
- Lenzer, G. (2015). Violence against children. In W. Vandenholle, E. Desmet, D. Reynaert, & S. Lembrechts (Eds.), *Routledge international handbook of children's rights studies*. Routledge International Handbook.
- Lohmeyer, B. A. (2019). 'Keen as fuck': Youth participation in qualitative research as 'parallel projects'. *Qualitative Research*, 20, 39–55.
- Lundy, L., McEvoy, L., & Byrne, B. (2011). Working with young children as co-researchers: An approach informed by the United Nations Convention on the Rights of the Child. *Early Education & Development*, 22(5), 714–736. https://doi.org/10.1080/10409289.2011.596463
- Mathews, B., MacMillan, H. L., Meinck, F., Finkelhor, D., Haslam, D., Tonmyr, L., Gonzalez, A., Afifi, T. O., Scott, J. G., Pacella, R. E., Higgins, D. J., Thomas, H., Collin-Vézina, D., & Walsh, K. (2022). The ethics of child maltreatment surveys in relation to participant distress: Implications of social science evidence, ethical guidelines, and law. *Child Abuse & Neglect*, 123, 105424. https://doi.org/10.1016/j.chiabu.2021.105424
- McAlister, S. (2020). An outcomes-focused evaluation of the Participation for Protection Project. Centre for Children's Rights, Queen's University Belfast. https://www.qub.ac.uk/sites/participation-for-protection/FileStore/Filetoupload,935700,en.pdf
- Morrow, V. (2009, August). The ethics of social research with children and families in young lives: Practical experiences. Young Lives. Working Paper No. 53. Department of International Development, University of Oxford, Oxford, UK.
- Mudaly, N., & Goddard, C. (2009). The ethics of involving children who have been abused in child abuse research. *The International Journal of Children's Rights*, 17, 261–281.
- Murphy, T. (2003). The ethics of research with children. *AMA Journal of Ethics*, 5(8), 333–335.

- National Bioethics Advisory Commission. (2001). Ethical and policy issues in research involving human participants, Bethesda, Maryland.
- Nowland, R., Laura, Robertson, A. R., Sharpe, D., Harris, C., Morocza, N., Farrelly, N., & Larkins, C. (2022). Collaborative research methods and best practice with children and young people: Protocol for a mixed-method review of the health and social sciences literature. *BMJ Open*, *12*, e061659. https://doi.org/10.1136/bmjopen-2022-061659
- Office of the Special Representative of the Secretary-General on Violence against Children. (2020). When children take the lead: 10 child participation approaches to tackle violence. United Nations.
- Pinheiro, P. S. (2006). World report on violence against children. United Nations.
- Priebe, G., Bäckström, M., & Ainsaar, M. (2010). Vulnerable adolescent participants' experience in surveys on sexuality and sexual abuse: Ethical aspects. *Child Abuse & Neglect*, *34*(6), 438–447.
- Roth, M., Voicu, C., David-Kacso, A., Antal, I., Muntean, A., Bumbulut, S., & Baciu, C. (2013). Asking for parental consent in research on exposure of children to violence. Revista de Cercetare şi Intervenție Socială [Review of Social Research and Intervention], 42, 85–100. https://www.rcis.ro/images/documente/rcis42\_05.pdf
- Santelli, J. S., Smith Rogers, A., Rosenfeld, W. D., DuRant, R. H., Dubler, N.,
  Morreale, M., English, A., Lyss, S., Wimberly, Y., & Schissel, A. (2003).
  Guidelines for adolescent Health Research: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33(5), 396–409.
- Tisdall, E. K. M. (2017). Conceptualising children and young people's participation: Examining vulnerability, social accountability and co-production. *The International Journal of Human Rights*, 21(1), 59–75. https://doi.org/10.1080/13642987. 2016.1248125
- Toros, K., Falch-Eriksen, A., & Wu, J. (2021). Listening to Children's Voices in Child Protection Practices. In R. Baikady, S. Sajid, J. Przeperski, V. Nadesan, I. Rezaul, & J. Gao (Eds.), *The Palgrave handbook of global social problems*. Palgrave Macmillan. https://doi.org/10.1007/978-3-030-68127-2\_31-1
- United Nations. (1989). Convention on the Rights of the Child General Assembly Resolution 44/25. United Nations General Assembly.
- Voicu, C., Antal, I., & Roth, M. (2016). Involvement of children in the preparation and development of the BECAN research (Balkan Epidemiological Study on Child Abuse and Neglect). *Revista de Asistență Socială* [Social Work Review], 2, 123–132.
- Watson, J. B., & Rayner, R. (1920). Conditioned emotional reactions. *Journal of Experimental Psychology*, 3(1), 1–14. https://doi.org/10.1037/h0069608
- World Health Organization. (2020). Global status report on preventing violence against children 2020. World Health Organization. https://apps.who.int/iris/handle/10665/332394
- World Medical Association. (1964/2018). Declaration of Helsinki Ethical principles for medical research involving human subjects. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/