

## Expanding the scope of ethical research with and for children and young people – six viewpoints on crisis, cross-cultural working and reciprocity

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VIEWPOINT



## Expanding the scope of ethical research with and for children and young people – six viewpoints on crisis, cross-cultural working and reciprocity

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*This Viewpoints piece is a collection of six contributions to a wider Special Issue for Children's Geographies on 'Renewed questions of ethics in research with and for children and young people.' The pieces extend the Issue in two key ways: i) by representing urgent questions of pandemic and crisis related ethics; and ii) extending the geographical and cultural scope of thinking ethically in research with children and young people.*

*This Viewpoints piece is part of a Special Issue collection for Children's Geographies on 'Renewed questions of ethics in research with and for children and young people'. In 2019, we set out to respond to Elsbeth Robson's (2018) call for continued reflection on ethical research with and for children and young people. The Special Issue develops those themes, affirming the value of evidence-based ethical reflection and practice. We see ongoing issues of funding and institutional pressures on researchers which can be in tension with the negotiated ethics of research-in-practice. Debates remain about the merits and challenges of institutional review boards.*

*However, research with and for children and young people continues to provoke new and important ethical questions, and special issues have been a key way to track and reflect on those developments (see Aitken 2001; Hopkins and Bell 2008; Sinclair 1996). As with Hopkins and Bell (2008) themes of power, competence, reciprocities and inequalities persist, but there are also renewed questions about participative working with diverse, and often disadvantaged, young people; work which crosses-cultures and engages with post- and decolonial questions of justice and reciprocity; and relational understandings with the more-than-human.*

*This Viewpoints piece emerged as a response to two key imperatives. First, since we began work on this Special Issue, the world has faced the COVID-19 pandemic, and multiple economic, social and political crises all of which raise and intensify issues for children, youth and families. We wanted to ensure we*

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represented some of the urgent questions of ethics that emerged in the context of the pandemic and these multiple, often intersecting crises. Second, we aimed to broaden the Special Issue in terms of its geographical and cultural scope and have prioritised contributions which extend and decentre euro-american experiences and in some cases enable a reflection on collaborative work with community groups.

These six contributions offer different perspectives, prompting us to challenge our assumptions, open up new ways of doing research and thinking with ethical complexities. We begin with Hayes and Dudman who reflect on research with young learning disabled and autistic participants during the COVID-19 pandemic and relational ethics-in-the moment responses to challenges around mask-wearing. Oza writes about the ethics of research with children in heavily militarised zones and the negotiation of research-participant boundaries in accepting invitations to stay in the relative safety of participant's homes in Kashmir. Lazaro, Robson and Walker then ask questions about 'ethics for whom' as they engage with the challenge of not providing compensation to child orphans or caregivers living in extreme poverty in rural Malawi. Staying with the ethics of cross-cultural research, Freeman, Ergler, Latai-Niusulu, Schaaf, Tanielu and Taua'a write about their community-based practice and the need to ensure universities recognise and enable culturally responsive modes of negotiating access, consent and reciprocity. In thinking through the personal crises which participants may face, Leon and Rosen address an ethics of discomfort. This contribution alerts us to the need for ongoing reflection in participatory research contexts – here with young asylum seekers – that may intentionally or inadvertently reproduce hierarchical relations between participants. Finally, Jarman, through an example of magnet fishing, brings to our attention the ethical complexities of methodologies which are unpredictable and experimental, especially in the context of research with children and the more-than-human. Together the contributions add to our understanding of the ethics of research with and for children in the context of intersecting intimate-geopolitical crises (Pain and Staeheli 2014), broaden the geographical and cultural scope of these issues, and set out key areas for further reflection and empirical investigation.

Our first contribution comes from researching with vulnerable young people during the COVID-19 pandemic. Hayes and Dudman use their experiences of working with learning disabled and autistic participants in a context where society, community and the institution required the wearing of masks for social protection. In this context of a global health crisis, they call for a relational ethics-in-the-moment approach to research encounters with young people.

### **'I can't see what you're saying': researching with learning disabled and autistic young people during the COVID-19 pandemic<sup>1</sup>**

'Why are you wearing a mask? Take it off', the young man demanded. Maskless, he moved closer as he spoke. What to do? Step away from him? Remove our masks? Guidance from both university and community setting was clear – precise procedures to follow. In practice, it felt different – messier.

This extract is from a collaborative community-based art project that worked with learning disabled and autistic (LDA) young people to produce artwork around themes of identity and self-advocacy. We are evaluating this using a praxis-based approach: systematically gathering, analysing and communicating qualitative data in a way that focuses on self-reflexivity, contextual knowledge, situated meanings, and practical wisdom.

Many LDA young people were severely impacted by restrictions in response to COVID-19; protecting those classed as vulnerable came at a cost. As groups and settings closed, LDA young people were compelled to stay home, reliant on family, close friends, and statutory carers. When restrictions eased, they gradually and warily emerged as settings began to reopen with mitigations to prevent infections e.g. hand sanitisers, temperature checks, lateral flow testing, increased ventilation, and – on top of all these requirements – masks.

Using a mask can compromise communication, especially with competing noise and already increased social anxiety. With mouths covered, communication relies more on eyes – problematic for some autistic young people for whom maintaining eye contact whilst listening requires huge

concentration. Communication may be more effective when a LDA person is able to listen with averted gaze or look at other parts of a face for communication cues (Disability Horizons 2022). Clear speech helps alleviate challenging communication situations, compensating for a lack of visual cues and reduced acoustic signals. It has taken months for some LDA people to overcome their fear of contact with others developed during lockdowns. Careful management of the environment is necessary to avoid a setback for the young person involved.

What seems appropriate and approvable on ethics forms is less obvious in practice. There are in-situ and in-the-moment actions to be taken, choices to be made, which cannot be fully appreciated in advance. Like Cutting and Peacock (2021) and Kraftl et al. (2021), we call for more critical reflection around the various interfaces with procedural research ethics. Researchers need the ability to weigh up risks and calculate benefits for the wellbeing of all involved, participants and researchers alike, in advance and in the moment. We argue for a shift towards more relational ethics-in-the-moment approaches, requiring research ethics training that draws on real-life examples and simulations, enabling a more balanced and inclusive approach to be taken. A responsive and responsible approach to ethics embraces the nuances of participatory research.

*In the next contribution, Oza reflects on her research in Kashmir offering important insights into the ethical complexities of doing research in heavily militarised zones. Invitations to public spaces with participants, or overnight invitations to spend time with them and their families within the relative safety of their homes raised ethical dilemmas. More research examples of ethics in times of conflict are needed, and it is crucial to ensure these children's experiences are recognised. Oza's work questions assumptions about the boundaries of researcher-participant interaction when understood in the context of militarised spaces.*

## Growing up in conflict: experiences, friendships and play for children and young people in Kashmir<sup>2</sup>

Children and young people in India-occupied-Kashmir live in one of the world's most militarised zones. This contribution focuses on children and young people's experiences of growing up in this region. Through this research I have adopted a decolonial approach (Al-Hardan 2014; Mignolo 2007; Smith 2012) to play a role in the co-production of knowledge with children that resists or even ruptures the status quo of adults as the primary holders of knowledge (Cheney 2019; Laketa 2015).

As an Indian-Hindu-Brahmin female researcher my positionality was fundamental to conceptualising and conducting the research. As the shame and guilt of this identity was carried from one interaction to next, children I interviewed insisted that 'their voice *must* be carried to Indians who *need* to listen to them'. For the children I met, India represented a colonial force in their lives. Meanwhile in India, Kashmir is portrayed as an indispensable part of the country in the ongoing project to create a Hindu *rashtra* (nation) (Kaul 2018; Zia 2020). The voice of these children has the potential to carry the lived realities of a life in conflict to the people that must *at least* bear witness to their everyday struggles. Interviews and group work were conducted in their homes and schools. Children were assertive in deciding to either give or not give their consent to be interviewed or for the interviews to be recorded. A group of girls also planned to take me on a day trip to a nearby river front. This form of participant observation, in different spaces of their public lives, especially through walking around the city gave the opportunity to explore issues of state surveillance and patriarchy. This highlights the emotional labour and the time intensiveness required, on an everyday basis, to navigate the public spaces that are both heavily militarised and male dominated.

In another instance, after I had spent days together during Eid with the family who were hosting me, two sisters in the extended family aged sixteen and eighteen, decided that they wanted to be interviewed together and invited me to spend the night at their home. Refusing invitations could have potentially undermined the relationship. The night stay would give the opportunity to spend time with the family and thus, after discussing it with the parents, I decided to accept the

invitation. This became unstructured time for sharing poetry they had written during the 2016 uprising, singing songs that are otherwise prohibited by their families, and using drawing as a tool to express how they felt living in a space of conflict. While institutional ethical approval was granted for the interview and participatory work with children, the practice of research always raises further questions that demand an ethical response in the immediacy of fieldwork, especially regarding how to be rigorous in addressing safeguarding but also respect the agency of children and young people. It is the children of Kashmir who are experts of knowledge about their lives. The ethics of childhood research in a space of conflict extends to the responsibility of writing their voice with honest reflexivity.

*The next contribution reminds us of the complexities of compensating children and young people in research, especially financially precarious – hungry – orphans or caregivers. Many researchers are now doing research with children and young people who are experiencing crisis, from the spaces of conflict outlined above, to the case which Lazaro, Robson and Walker bring to our attention, orphans living in extreme poverty in Malawi. In these contexts of personal and societal crisis, the authors are asking the research community and institutional ethics committees to re-think the question ‘ethical to whom?’ – and the changing balances of harms and benefits which might enable just compensation whilst minimising the risks of coercion for marginalised children and young people in research.*

### **Ethical research? Ethical to whom?: Emotional costs of not compensating participants when researching orphans and vulnerable children in rural sub-Saharan Africa<sup>3</sup>**

The centrality of ethics in research with and for children is ubiquitously acknowledged. Debates abound on whether participants should be compensated for their participation, with some ethics institutional review boards (IRBs) proscribing compensation. Drawing on a qualitative study with 38 orphans living in extreme poverty in rural Malawi investigating the role of grandfathers in orphan care, we interrogate the ethics of proscribing researchers from intervening in children’s situations in a rural African context.

The study included children living with poor and frail grandparents, hence experiencing extreme material deprivation. Data collection coincided with a severe drought that triggered rising costs of basic commodities. There were days when the first author visited and found the children barely surviving, having gone days without a substantial meal. For instance, he found a family with a portion of *matemba* [small dried fish] that usually would be for a single person for one meal, but during this day it was for three people for both lunch and supper, signifying their desperate situation.

These situations were numerous. Visiting the children and witnessing their suffering first-hand was emotionally challenging. The first author felt a strong urge to help, yet he could not. The two institutions in the United Kingdom and Malawi that reviewed and approved this study viewed the offering of money and/or gifts to the participants as unethical because they construed that such practices could potentially coerce participation, hence explicitly proscribed such conduct. This created ethical and moral dilemmas: on one hand, helping the participants would breach the ethical requirements set by the two IRBs. On the other hand, ignoring the children’s pertinent needs resulted in emotional impacts for the researcher due to strong feelings of helplessness, uselessness, and guilt for not intervening in the plight of the children despite having the financial capacity. This was experienced during the nine-month fieldwork period, and triggered questions such as: was it ‘ethical’ to engage the participants in such dire situations, but not attend to their pressing needs such as food? Was it morally right to turn a blind eye to their suffering? ‘Ethical’ to whom? This raises the question of whether the changing circumstances (e.g. presence of abject poverty among the participants as was the case in this study) should warrant consideration regarding compensation because such situations may change the balance of risk in terms of harm and benefit.

The dilemmas encountered in this research epitomise the need to interrogate some of the ethical requirements enforced by IRBs to ascertain whether they align with the needs of specific groups, as

well as whether breaching them (e.g. compensating participants in impoverished communities for their participation) would be harmful or beneficial to the participants, while also not compromising the findings and professional conduct. Although there are no universally agreed guidelines regarding compensating research participants (Graham et al. 2013), such consideration is worth further research and policy attention. There is a need to consider both short-term and long-term benefits of research to the participants.

*Moving on from particular moments or spaces of crisis, our next contribution from Freeman, Ergler, Latai-Niusulu, Schaaf, Tanielu and Taua'a provide a broader reflection on the ongoing complexities of cross-cultural research. Here, a large team of New Zealand and Pacific Islander researchers, together reflect on moments of ethical jarring – from negotiating access to consent and reciprocity. In a broader international research environment where cross-cultural research is incentivised, the research team argue that local cultures of access and participation must be prioritised by university and funder ethical processes.*

## **Cross cultural ethics – working with Pacific Island children<sup>4</sup>**

Cross cultural working in the Pacific for our team of local and foreign researchers reveals issues common to cross-cultural research: cultural sensitivity, power relations, fieldwork ethics and diverse positionalities relating to community members and child participants. We begin by stating that the incentive for continuing our work with Pacific children are the many tangible and intangible rewards our projects have produced for the children and for us as researchers. The children are eager to let you into their life worlds whether it be through conversations, village walks, drawings, creating models, photographs, or digital interfaces. Working with Pacific children always requires considerations which lie outside official university ethics procedures.

### ***Negotiating access***

Outside researchers must work with and through the local Pacific community, what may work in Samoa may not work in Fiji or Kiribati. Only through working with local, culturally competent researchers can access for children be negotiated. Processes include conversations with elders, community members, pastors, and parents. Respect for the local cultural context is essential as in working around cultural events, festivals, exchange of gifts, or taking part in a Fijian kava ceremony. Some can be challenging for those used to western modes of working. Discomfort can occur regardless of whether researchers are foreign or local as there are always challenges given the complexities of research in communities and as part of the co-learning and decolonising process (Tuhiwai Smith 2021).

### ***Working with children***

Formal consents can be tricky in communities where 'face to face' connections are central. Consent is mutually negotiated and externally imposed bureaucratic consent forms are inappropriate. Issues of hierarchy and power dynamics can occur, in that if a community elder consents then families may feel obligated to participate. Children are invariably keen to participate and a recurrent ethical dilemma is that not all can do so. Who then gets chosen, or gets the thank you gifts? Children are generally unused to being asked their views and can try to provide the 'right', culturally appropriate answer rather than their own view.

### ***Reciprocity***

Reciprocity is key in the Pacific. It customarily involves extended family and community, and rarely fits an external time frame. Taking research back to the community is indicative of good faith, of

valuing the research and is essential in rejecting practices of ‘taking’ research away in a one-way academic process. Our last study invited a community to view the children’s ‘work’, attended by children, families and guests. Contrary to typical university ethics prohibitions on recognisable photos, all the children’s ‘selfies’ were displayed and were the children’s favourite parts of the display. Drawings retained children’s names to acknowledge their personal contributions. Should privacy and confidentiality override acknowledging the contribution of children who are proud to be part of the study? Children’s voices are seldom heard in the Pacific and need to be. Research is a conduit for enabling their voice. To do so requires patience, respect, flexibility, openness to cross cultural learning and willingness to work within a Pacific cultural framework.

*A further element of crisis to address in doing research with children and young people is the multiple personal crises that our participants may be experiencing and dealing with in their everyday life. Often seemingly banal research topics can open up conversations with young people about their personal, social and familial struggles. Of course, this is not new – children and young people have always had, and will continue to experience, multiple forms of intersecting crises but it is important in the context of this Special Issue to be reminded of the ethical implications of this, particularly when working with young co-researchers. In the following contribution, Leon and Rosen bring our attention to a disclosure of suicidal ideation by a research participant and the conversations which followed in the adult research team about power relations and how as researchers we should grapple with an ethics of discomfort.*

### **An ethics of discomfort: power relations in participatory research<sup>5</sup>**

During a post-interview check-in, Aken, a participant on the Children Caring on the Move (CCoM)<sup>6</sup> research project, spoke to Lucy in detail about his struggles with mental health, hinting at suicidal ideation. With Aken’s consent, we reached out to the third sector organisation that was providing support to him. However, as CCoM involves co-designing and undertaking collaborative research with Young Researchers (young people with migration experiences), we wondered: Should we share this information with the Young Researcher who would lead the next interview with Aken? Would this violate the confidentiality we had promised Aken, who lived in the same city as the Young Researcher and mixed in similar social circles? What would it mean for our efforts to counter hierarchies in knowledge production if we did not inform our co-researcher?

Over the past three years, CCoM has explored unaccompanied migrant young people’s experiences and understanding of care. As part of the project, we have undertaken 78 interviews with unaccompanied young people, which were led by Young Researchers. We have taken a participatory approach in an attempt to counter not only adult–child hierarchies, but also hierarchies linked to citizenship, ‘race’, and immigration status within the UK’s hostile immigration regime. We interviewed participants two or three times. To minimise time and other pressures on Young Researchers, university researchers acted as the first and consistent point of contact with participants. Doing so, university researchers and participants often built relationships during numerous calls explaining the project, seeking consent, scheduling interviews, and providing a post-interview check-in such as the one mentioned above.

In the case of Aken, we chose not to share his comments with the Young Researcher to ensure confidentiality and not breach his trust. Had the Young Researcher instead been a university researcher, perhaps we would have acted differently. Moreover, we did discuss Aken’s comments between ourselves, raising questions about our efforts to contest hierarchies through ‘co’-research. This example is emblematic of how, despite our best efforts, participatory research is always ensnared in inequitable power relations. While concurring with this well-established point in the literature (e.g. see Kindon, Pain, and Kesby 2007), we part ways with suggestions that participatory forms of research are particularly problematic and therefore to be avoided or undertaken sparingly. Instead, we maintain that whilst there is no escaping power imbalances simply by choosing the ‘right’ research methodology or applying codified ethical principles (e.g. confidentiality vs informed participation in this case), participatory approaches to knowledge production remain important politically and ethically in destabilising sedimented hierarchies.

In learning from Aken's case, we advance existing literature on participatory research to argue for an ethics of discomfort. Rather than treating ethics as a way to smooth tensions, we suggest that grappling with discomfort *is* an ethical practice. Participatory research projects, particularly within contemporary border regimes, will inevitably be uncomfortable. But by sitting with discomfort, we avoid the trap of assuming participatory research is necessarily transformative, and keep alive questions of what to do when we (inadvertently) reproduce hierarchies.

*The final contribution, from Jarman, is set in the context of the anthropocene, the ecological crisis and the layering of geological evidence and archives of human existence. Her use of experimental magnet fishing with young people (a methodology which emerged from the participants themselves) exposes a series of ethical complexities and offers a new dimension to the ethical practices of research with young people and the more-than-human.*

### Children's encounters with water as 'archive': ethical tensions within the emergent method of magnet fishing<sup>7</sup>

In this piece I discuss magnet fishing, an emergent event that took place during my research with children and digital technologies in an urban park. Magnet fishing is a relatively new phenomenon, popular in part due to YouTube video channels documenting the activity with GoPros. Essentially a leisure activity, magnet fishing involves using a powerful neodymium magnet and rope to 'fish' for ferromagnetic materials. Participants described YouTube videos with magnet fishers pulling out rusty car parts, nails, motorbikes, go-karts, and other dumped materials. In our research, we spent months walking with watery bodies, extending GoPros underwater into murky, stagnant and fast-flowing waters, full with rotting leaves, branches, crisp packets, plastics and materials that cannot dissolve. We learnt with water, following Neimanis' 'hydro-logics' (2013), recognising water as transformative, as unknowable, as destructive and, significantly, as archive. Water was not merely a 'resource to be managed' (Pacini-Ketchabaw and Clark 2014, 99) but instead held the complexities of common-world relations. Our walks became inquiries with the 'archive' of matter in the watery body; we tried magnet fishing in a shallow stream, with permission from the park ranger and the school.

In discussing this event, I wish to highlight three ethical tensions. Firstly, in this emergent method, I intended to take seriously an ethics of affirmation – a responding to what happens in the process of research, remaining open to experimentation, paying attention to relations between children, the digital and the more-than-human (following Truman 2022). Through this event we came to know the mineral magnetite, as it stuck to our magnets. We learnt about bio-magnetite, found within most living organisms, aiding navigational and migrational patterns (Kirschvink, Walker, and Diebel 2001). This extended new opportunities for learning both with watery bodies as archives and the geologic as lively (Hadfield-Hill and Zara 2019). However, an emerging tension with this is the extractivist logic of fishing, extracting, and mining geological matter. While this event extended our learning with the more-than-human through bio-magnetite, it drew attention to the dominant human-centric treatment of earth-as-resource.

This extends concerns to a second tension in the ethics of the production, use and life-cycle of neodymium magnets themselves. Drawing on Gallagher's 'geology of media', thinking beyond these and examining the 'physicality' (2019, 1) of the neodymium magnets raises other uneven relations between *other* humans and the geologic – those involved in the mining and production of these rare-earth minerals and metals; as well as the wider environmental impact in terms of their life-cycle, toxicity and recycling (Schlör et al. 2017).

A final tension concerns the institutional permissions and practicalities of proposing magnet fishing as a research method – encouraging curiosities while ensuring their safety, particularly given the potential of finding bombs, knives and guns. This meant an ethics proposal highlighting an open 'suite' of activities that may unfold through and *with* the research process, plus intentionally confining the site to a small area of a shallow, clear stream. This eliminated the risk of finding (most) metals yet generatively opened the possibility for learning with unexpected geologic matter.



Working with emerging methods within this research meant paying attention to these tensions and ethical considerations, while remaining open to new possibilities for learning with children, technologies and the more-than-human.

## Concluding reflections

*There is a strong continuity in this Viewpoints piece with the issues raised by Robson (2018) in that (i) the ethics of research in practice all too often run up against funding and institutional pressures; and (ii) our research on childhood and youth is framed by dominant cultural norms and assumptions in which institutional ethics reviews takes place. We argue that there remains strong and ongoing value to evidence-making and evidenced-based reflective ethical work. Our contribution to this prioritises renewed questions of ethics in the context of multiple, often intersecting, crises; and in a research environment which is increasingly cross-cultural and requires new sensitivities, partnerships and cultural competencies in planning, designing, reviewing and conducting research with children and young people. These viewpoints speak to us not only about ethics, but also about the changing nature of childhood and of research. It was our intention to bring these pieces together to highlight renewed ethical questions and methodologies, but also that they might serve as a prompt for further reflection and action in research with children and young people.*

*We hope that this collection will find a range of different audiences. You might be facing a particular ethical dilemma in your own research and looking to understand how others have navigated these complexities. You might be a student who is looking for inspiration on what childhood research looks and feels like in the current climate. You might be an ethics review board member who is looking to develop a praxis of review informed by diverse participant communities, and a deeper and more nuanced understanding of how researchers have been considering and approaching these issues. Whatever your reason for reading, we trust you can draw on the collective wisdom of all of the participants, communities and researchers who are reflected in the contributions here. Together, these put us in a position to better face the changing landscapes we find ourselves in, and to strive for meaningful and responsive ethics in challenging times.*

## Notes

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