Research with children and young people not on them. What can we learn from non-clinical research?

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In their 2016 article, Sammons at al summarise the recommendations of the Nuffield Council on Bioethics report *Children and Clinical Research: the ethical Issues*.[1] We welcome the article's important message that researchers look beyond age when considering ethical and participatory issues and respond as critical friends (more friend rather than critical) to the six issues they identify. We provide additional material on the history and wider context, including child public health, education and social care research, bearing in mind that the service context for children has tended to be more multi-professional than for adults. Social science and social care have a sustained history to offer on participation and how to research *with* and not *on* children and young people.

1. **Clinical research and its context**; The Nuffield report considered clinical research to include '*any encounter with children and young people that holds out the prospect of improving healthcare including preventative healthcare.*' The National Cancer Institute defines clinical research as an endeavour '*in which people, or data or samples of tissue from people, are studied to understand health and disease,*' whilst the ever useful Wikipedia describes clinical research as '*a branch of healthcare science that determines the safety and effectiveness of medications, devices, diagnostic products and treatment regimens.*'

The wider context: Are research encounters with children and young people *clinical* when they include education, social care and research with mothers, who after all provide the lionesses' share of health care in its widest sense? Probably not, though we acknowledge that extending the medicalisation of everyday life has positive as well as problematic effects. On the plus side, clinical studies bring the benefit of an authority rare in other disciplines. Less positively, the lack of attention to the much longer tradition of exploring the ethics of inclusive research with children in the social sciences risks reinventing the wheel. Jenny Morris's work[2] on including profoundly disabled children in research and the work by Ash et al[3] demonstrating the benefits of training youngsters with disabilities to act as interviewers on inclusive education are among the building blocks and continue to have salient messages including that:

a) young people can improve research when they are included as equal partners in a context that emphasises their competency and skills

b) since a 'medical model' is by no means always well-aligned with peoples' experiences clinical and lay expertise are both needed.

Parity of esteem is needed at both a disciplinary and an individual 'lay' level.

2. **What is ethically different about children?** The authors make important points on developmental issues and individual difference in decisions about consent, communication and design.

The wider context: Research in the social sciences highlights additional issues, including power, gender, disability, social class and time.[4-6] It is easier to recruit paupers than princes, and easy to forget that one of the few resources children might hope to have at their own disposal (at least sometimes) is time. The power differential between children and adults can render decision-making in relation to research a-symmetrical, particularly in spaces where adult authority is strong, such as schools and hospitals. Health researchers often appreciate working in schools, with access to a large number of children in a single location, but this can add to the pressures on children and their teachers facing an increasingly tight school timetable. It can be difficult for children in a cluster randomised controlled trial or even a straightforward survey in school to withhold consent, even where there is provision for opt out.

3. **The vulnerability of children:** The authors' descriptions of mitigating vulnerability through good research practice and sensitive methods are needed, as is working with children, young people and parents as partners in research planning to minimise the risks to study participants.

The wider context: There are barriers to these mitigations which go well beyond the research context. Just as disability campaigners have aptly reminded us that disabilities often reside in environments rather than bodies, it would be a mistake to see children, young people, or people with learning disabilities as inherently vulnerable. Their vulnerability often resides in the adults around them and the contexts in which they find themselves. Despite the sometimes substantial survival benefit from clinical trials research

including children and the general altruism of children and parents, the authors correctly identify vulnerability as being a sticking point for some clinicians and ethics committees. Work with unaccompanied children leaving the care system and earlier work on learning disabled young people [7-9] suggests that excluding those considered the most vulnerable may inadvertently increase their vulnerability. This applies to clinical as much as social research, and in both cases limits generalisability.

4. **Research priorities for children and young people:** The prioritisation exercises described by the authors can make a significant and positive difference to the research problems addressed.

The wider context: That said, developing and maintaining the 'inclusive' partnerships described is not straightforward in a world where expertise, social class, and high status occupations confer a degree of power. The James Lind Alliance, whilst providing an inspirational platform for patient-led research ideas with strategic links to research funding did not, as the authors suggest, 'lead the way'. Participatory work in Europe,[10 11] global health[12] and work over several decades in the 3rd sector[13] have been doing much the same thing, often showing that even for those with significant health problems, it is frequently the *determinants* of health such as food, housing, education and work that are their priorities.

5. **Partnership and review of research:** As the authors make clear, recruiting children to studies can meet barriers from both professionals and families. However, it is difficult to square the authors' gentle criticism of clinicians worried about burdening children and families with their suggestion that families are well-placed to 'minimise the burdens of research' and undertake to 'explain any risks clearly and concisely.' Just as it has taken time for the unpaid work of women in home and emotional work in the labour force to be recognised, there may be insufficient recognition here of the considerable altruism of the unpaid work and time involved in children and parents' contribution to research.

The wider context: Clinical research has lagged behind the third sector and social science research in terms of partnership with citizens and users. There is high demand for involving children and the frail elderly as partners in research but if this is to be a shared enterprise, rather than a box to be ticked, it needs to be recognised that it demands resources on both sides. A degree of reciprocity[14] and an awareness of the imbalance of power[15] are required

to work on these issues, as well as a degree of willingness by research funders to fully recognise the time costs for both lay people and researchers in doing this well. Finding ways to model this is a challenge, but raising the availability and awareness of modest funding pots to develop strong research proposals may be one way forward.

6. **Consent and assent:** A crucial of this discussion by the authors is their emphasis that children should feel they have had a stake in the decision and been treated as individuals who matter.

The wider context: Research time is expensive, and for researchers and their funders, much of the research effort in clinical research has tended to be directed towards getting to 'yes' to recruitment, rather than understanding refusal or reluctance. We are aware that participants as well as researchers sometimes feel that conditions imposed by research ethics committees are unreasonable and limit their own agency.[16]

Consent to research is rather different from consenting to an intervention where time is of the essence, such as emergency surgery. Consent should be a process rather than an event, with all of the complexities that this brings, such as full or partial withdrawal of consent. Children may need to be trained to say 'no' or 'wait' in this kind of situation and a body of practice examples collected to assist researchers and ethics committees.

Conclusion

Whilst some areas of clinical research with (or on) children, have transformed children's lives, so have the social sciences. Cohort studies have enabled us to see the links between early events and later outcomes, in particular the positive effect of education (and not just health education) on health. These in turn have had a clear influence on policy direction in the early years in the UK and elsewhere. The attention to, and development of, research methods in qualitative research, ethnographies, and participatory work over several decades have enabled us to learn how better to engage and understand the priorities of children and young people. Priscilla Alderson's[17] much reprinted report commissioned by Barnardo's *Listening to Children: Ethics and Social Research* was ground-breaking, and has influenced research and ethics committees over more than two decades.

Research needs to build in a stepwise way on what has gone before, and this is certainly an area where clinical studies have the edge over much social science. Despite funding calls for cross-disciplinary work and collaboration, social science studies such as those referred to above are often under-represented in searches, particularly if the work is in books, reports or the grey literature. The tendency to cite only recent texts exacerbates a failure to build on what has gone before.

We have highlighted six points that need both debate and practice improvement to enable children's active participation in research. Greater co-production in intervention and study design has the potential to enable children's agency and participation in research, including their capacity to consent.

 The direction of travel is a positive one, but recognising children as citizens with their own rights to time, and autonomy, and being aware that not everything that counts can be counted remain a work in progress.

Acknowledgements

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