

Exploring Critical Issues in the Ethical Involvement of Children with Disabilities in Evidence Generation and Use

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INTRODUCTION

This research brief details the main ethical challenges and corresponding mitigation strategies identified in the literature with regard to the ethical involvement of children with disabilities in evidence generation activities. Evidence generation activities are defined as per the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis (2015), as research, evaluation, data collection and analysis.

The United Nations Convention on the Rights of the Child (art. 12) states that children have the right to form and express views freely in all matters affecting them and that the views of the child must be given due weight in accordance with her/his age and maturity. The United Nations Convention on the Rights of Persons with Disabilities (art. 7) states that children with disabilities must enjoy human rights and freedoms on an equal basis with other children, and that they have a right to express their views freely and should be provided with assistance where necessary to realize that right. The two conventions in general, and these two articles specifically, frame this research brief, which aims to encourage practitioners to explicitly consider ethical ways to involve children with disabilities in evidence generation.

The findings detailed in this summary brief are based on a rapid review of 57 relevant papers identified through an online search using a systematic approach and consultation with experts. There was a paucity of evidence focusing specifically on the ethical challenges of involving children with disabilities in evidence generation activities. The evidence that did exist in this area was found to focus disproportionately on high-income countries, with low- and middle-income countries markedly under-represented.

More evidence generation activities involving children with disabilities in low- and middle-income countries are urgently needed. This requires recognition and commitment from research institutions and funding bodies. As set out in the Convention on the Rights of Persons with Disabilities (art. 31), States parties have a responsibility to ensure that appropriate data and information are available to enable them to formulate and implement policies to give effect to the Convention. Governments must undertake, fund, promote, facilitate and encourage more disability-inclusive research that involves children with disabilities and which is ethical. Researchers and institutes involved in evidence generation activities also have a responsibility to address this evidence gap. While pursuing this research agenda, existing (conventional) research practices must be concurrently developed and evolved to be disability-inclusive.

GETTING IT RIGHT: THE IMPORTANCE AND VALUE OF ENGAGING CHILDREN WITH DISABILITIES IN EVIDENCE GENERATION

The ethical involvement of children with disabilities in evidence generation activities is a moral imperative that recognizes both children's rights and their competencies. It is also vital for policy development and can lead to enhanced outcomes for children with disabilities and their families.

Children and young people with disabilities are frequently homogenized as a group, with insufficient recognition given to the multiple and intersecting aspects of their identities (Loveridge & Meyer, 2010). Children with different types and severities of impairment experience exclusion from evidence generation processes to differing degrees. Other intersecting factors, such as gender, ethnicity and geographical location, also have an impact on exclusion, depending on the context.

With regard to evidence generation involving children with disabilities in low- and middle-income countries, it is necessary to unpack, understand and reflect on its colonial underpinnings. Researchers from high-income countries may unwittingly import into these contexts their own culture-bound views of childhood, disability and 'development', resulting in a failure to capture or appreciate the diversity of experiences of children with disabilities or the cultural contexts for disabilities in different settings in which evidence takes place. A critical and transformative 'decolonization' of evidence generation should be pursued to address power imbalances and misinformation/misinterpretation. This necessitates that, in order for children with disabilities to be ethically involved in evidence generation processes, they must be listened to directly and respectfully. A decolonizing approach must be underpinned by the social model with a human rights lens. Disability must be understood as a status conferred by society and their environment that may generate barriers to social participation, thereby 'disabling' individuals with impairments.

For children with disabilities to be ethically involved in evidence generation activities, it is essential that inclusive practices are understood and are both responsive and sensitive. Children with disabilities must not be manipulated nor placed at risk by evidence generation processes. The right of children with disabilities to express their views and to be *meaningfully* heard should be incorporated into evidence generation practice at all levels.

The key frameworks of the Nuremberg Code (1948), the Declaration of Helsinki (1964) and the Belmont Report (1979) have provided the guiding principles for ethical evidence generation. The debate continues as to whether they offer sufficient guidance regarding cultural awareness, responsiveness, accountability, respondent validation of findings and increased consideration of research communication and uptake practices. The International Charter for Ethical Research Involving Children was launched in 2013, suggesting a series of researcher commitments to uphold the rights of all child participants, in all circumstances, while undertaking evidence generation. Its approach presents opportunities for researchers to consider appropriate methods and means for working with children in different contexts and with different types and severities of impairment, recognizing competencies as much as challenges and needs for adaptation.

For the involvement of children with disabilities in evidence generation activities to be ethical, the children must also find it a positive, helpful and enriching experience. A central ethical question for all evidence generation activities involving children with disabilities must be whether the potential benefits of involving them in evidence generation outweigh the risks. The exclusion of children with disabilities from such activities can lead to the perpetuation or instigation of substandard treatment, and poorer policy and programmatic outcomes for this group, as well as a poorer quality of evidence generation more generally.

KEY FINDINGS

The key ethical issues and mitigation strategies for involving children with disabilities in evidence generation, as described in the literature, are detailed below. The findings are structured around the main phases of the research cycle, in chronological order: preparation; implementation; and research communication and uptake.

Preparation phase	
Child protection	
Key challenge	Mitigation strategies
If children with disabilities participate in evidence generation activities, they must be protected and kept safe, but their right to participate in evidence generation processes must also be protected.	<p>Disability-inclusive child protection/safeguarding protocols must be developed that balance participant autonomy and protection. These must be discussed with participants and their families.</p> <p>Protection/safeguarding protocols must consider the increased risks faced by children with disabilities, as well as the barriers they may face in reporting or obtaining assistance.</p> <p>Protocols must be developed detailing how situations will be dealt with if information needs to be passed on to relevant protection bodies for the safety of a child.</p> <p>Child protection/safeguarding mechanisms can include:</p> <ul style="list-style-type: none"> ■ researchers' police/reference checks ■ clear rules about behaviour (adult child ratios and interactions – e.g., regarding solo working) ■ discussion of support options for children ■ researcher training in inclusive child protection/safeguarding policies and processes ■ supervision of researchers ■ a formal complaints procedure. <p>Children should be informed of their right to be protected from harm and about how they can make complaints or report incidents.</p> <p>Organizations should develop child safeguarding policies. These policies should directly inform individual protection /safeguarding protocols developed for evidence programmes.</p>
Researchers must recognize that although disability can result in increased vulnerabilities, inferring that all children with disabilities are automatically vulnerable can be problematic.	<p>Researchers should adopt a social model of disability for research, which frames disability as being caused by society, rather than by a child's impairment or perceived difference from a supposed 'normal'.</p> <p>Researchers should avoid imposing roles and identities on children with disabilities based on assumptions. Researchers should aim for the involvement of children with disabilities in evidence generation activities to be empowering. Researchers should not patronize children with disabilities as vulnerable and in need of help and support. Best practice is to ask the children what help and support they need.</p>
Power imbalances between the (adult) researcher and the (child) participant can increase risks of disempowerment and vulnerability for children with disabilities.	<p>Researchers may want to establish an identity as the 'least-adult' friend (i.e., not a parent or teacher) who is interested in the child and her/his ideas. Gaining children's trust and respect must be balanced with the dangers of overfamiliarity or the development of an inappropriate dependency on the adults among the children.</p> <p>Involving children with disabilities as co-researchers/peer researchers can reduce power imbalances and improve safeguarding.</p>

<p>The safeguarding of participants must continue after the study has ended.</p>	<p>Participant expectations must be managed through robust consent processes, and an exit strategy planned. The managing of expectations following the data collection phase is particularly important for children with learning impairments. Self-advocacy groups or organizations of people with disabilities may be able to provide ongoing support and appropriate follow-ups.</p>
Protection protocols	
Key challenge	Mitigation strategies
<p>The researcher has a duty not only to respect confidentiality and privacy, but also to protect the child. Information may be discovered related to current or ongoing harms or concerns that require action to be taken.</p>	<p>Protection protocols and referral pathways (both discretionary and mandatory) must be planned in advance, with input from local service providers (e.g. statutory service providers, non-government organizations and organizations of people with disabilities). Referral pathways must be inclusive and accessible for children with disabilities (including provision of barrier-free environments, accessible communication and positive attitudes).</p> <p>The terms of mandatory referrals in particular must be agreed prior to the research and consideration explicitly given to any legal requirements to report abuse.</p> <p>Where possible, participants should be free to decide whether or not to follow referral pathways. Appropriate accommodations may be required to ensure that children with communication and intellectual difficulties have the opportunity to express themselves in their preferred way (including with visual support such as signing, symbols, pictures).</p> <p>Researchers should be trained to understand:</p> <ul style="list-style-type: none"> ■ local legal issues, regulations and guidelines on abuse ■ specific risk factors (including gender, and impairment type) ■ relevant roles and responsibilities in relation to identifying and acting on worrying evidence or safety concerns ■ the referral networks that exist in the context and how to contact them.
<p>Gaps in referral pathways may result in the researcher knowing that a child needs assistance or support, but also that the child may be unable to access such help.</p>	<p>Gaps in formal services provision can be closed by partnering with local organizations of people with disabilities, community-based rehabilitation programmes or other local non-governmental organizations.</p> <p>If referral services are non-existent or inaccessible, researchers will need to carefully evaluate the risks and consider whether proceeding with the evidence generation activity is ethical.</p>
<p>Disclosing information about abuse may increase the risk of abuse.</p>	<p>The benefits and risks of undertaking the evidence generation activity must be carefully considered. It may be necessary to explain to children the requirement for the mandatory reporting of the disclosure of certain information, rather than provide blanket assurances of confidentiality.</p>
<p>Evidence generation activities may cause participants and/or parents/ caregivers distress.</p>	<p>Researchers should be trained to manage distress arising from evidence generation processes and have knowledge of sources of supports and appropriate referral pathways.</p>

Researcher positionality	
Key challenge	Mitigation strategies
Power imbalances between adult researchers and child participants can result in children not being adequately represented in the research.	<p>Researchers must recognize their own positionality (the beliefs, characteristics and biases they bring – e.g., about children and disability) and how it can shape the research.</p> <p>To overcome issues arising from power imbalances, researchers must appreciate diversity and difference, and treat children with disabilities as experts of their own lives. Perspectives emerging from the evidence generation process should be respected even if they seem counter-intuitive or contradict other data.</p> <p>Methodologies should be selected that allow children to describe their experiences and express their opinions in ways that suit them. Researchers should aim to represent their views in an authentic, fair and accurate way. Children should be asked to confirm/validate the interpretation of their data at an appropriate level of complexity.</p> <p>Involving children with disabilities in co-constructing the overarching/summary narrative can empower and amplify their voices and helps them to own and understand their data and situations. Older children and young people with disabilities can learn to be role models for younger children, and all can take on a variety of activities depending on their interests and skills.</p>
Power imbalances risk children participating without clearly assenting to the research.	<p>Children with disabilities should be repeatedly informed during the research process that they do not have to participate in the evidence generation activity. If they do participate, using open or non-leading questions can minimize the risk that children feel unduly obliged to respond in particular ways or about difficult issues.</p>
Researchers may impose stereotypes on children with disabilities, resulting in them being treated in ways that are different from how other children are treated during the evidence generation process.	<p>Assumptions about what a specific impairment/disability may entail or mean, or about what support the child may need, should be avoided. Even within categories of impairment, children may have difficulties of varying types and severity (e.g., the experience of one child who is blind will not be the same as for another child who is blind).</p> <p>Researchers should not make assumptions about how children may feel about their impairment. Children may or may not have formed views about this, depending on their individual age, skills and experience.</p> <p>Caution and sensitivity are needed in using labels such as ‘child with a disability’, as this is not necessarily an identity the child would recognize or own for her/himself. Talking about children’s strengths and what they need help with may be more useful.</p> <p>Researchers or facilitators with experience of working with and/or undertaking ethical evidence generation involving children with disabilities should be given preference when recruiting for evidence generation activities.</p> <p>If researchers or facilitators have not previously worked with children with disabilities, they should undertake extensive training before doing so (see below for details).</p>

Researcher knowledge	
Key challenge	Mitigation strategies
<p>Children with disabilities may be excluded from evidence generation activities due to evidence generation teams lacking sufficient knowledge about inclusive and ethical practices. In low- and middle-income countries, training for researchers in inclusive research methods and ethics may be limited or absent.</p>	<p>Ideally, evidence generation teams would be trained on or about:</p> <ul style="list-style-type: none"> ■ how to conduct good quality, ethical data collection with children with disabilities ■ how to adapt communication approaches to children with different impairments ■ how to communicate with participants in a way that they are comfortable with (including sign language/using visual methods) ■ local and national sociocultural, religious and political contextual realities in relation to children and disability ■ the importance of flexibility and optimism, and of adopting an inclusive, respectful and positive approach ■ how to build trust between children, families and researchers by developing an open and shared understanding of the research design and processes. <p>Organizations representing or supporting people with disabilities should be consulted to strengthen researcher knowledge by providing the perspectives of adults with disabilities. It should be noted, however, that their experiences as children may have been very different to what children with disabilities experience today.</p> <p>Where possible, the evidence generation team should involve people with disabilities and, as appropriate, children with disabilities as researchers/facilitators. These individuals will also require training in inclusive and ethical practices.</p>

Choice of methodologies for data collection and participant engagement	
Key challenge	Mitigation strategies
Negative assumptions about the ability of children with disabilities to understand and communicate can lead to their exclusion from evidence generation activities (this is a particular challenge for children with communication and intellectual impairments).	<p>Verifying the participants' level of understanding and how they express themselves best can assist with understanding individual children's ability to participate and how methods should be adapted for them.</p> <p>Inclusive evidence generation approaches tailored to the individual's needs can support children with disabilities to participate. Such approaches may include:</p> <ul style="list-style-type: none"> ■ artistic and writing activities ■ use of drawings/symbols or objects to aid the child's understanding or expression of ideas ■ use of photography and video-making ■ sign language, natural gestures and body language ■ computer-aided approaches with access adaptations. <p>Sufficient time should be given to children with disabilities to allow them to participate at a pace that suits them.</p>
Children with disabilities are under-represented in the evidence generation process.	<p>To ensure that children with disabilities are fairly represented in evidence generation activities, researchers can:</p> <ul style="list-style-type: none"> ■ use existing data sources such as censuses, analyses and surveys (remembering that numbers of children with disabilities may be underestimated) ■ engage with local organizations that represent or support people with disabilities ■ engage with children's organizations ■ undertake community mapping (which may be most effective if led by people with disabilities or children to overcome issues of stigma) ■ engage with community-based services and institutions ■ use information and communication technology (ICT) and social media to identify children and invite them to participate.
Children with disabilities with particular characteristics can be over-enrolled in evidence generation activities (leading to research fatigue).	<p>Recruitment strategies should be alert to the potential for over-enrolment and approach with caution the recruitment of children who have participated in multiple studies ('the usual suspects').</p> <p>Organizations of people with disabilities and parents' groups can provide knowledge to help avoid the over-enrolment of specific individual children with disabilities in research, sometimes to the exclusion of others.</p>
Restrictive or inflexible methodologies can be exclusionary and affect how a child with disabilities is portrayed.	<p>Researchers must adopt inclusive evidence generation processes and a flexible approach that uses a range of methods and accepts diverse responses and contributions. Child-friendly and child-led approaches can reduce the risk of methodological bias. Different types and styles of participation should be accepted and supported.</p>

Implementation phase	
Consent	
Key challenge	Mitigation strategies
<p>Children must assent to participate, and usually their parents or guardians must also consent to the child's participation.</p> <p>A perceived lack of ability to understand/communicate assent can lead to exclusion.</p> <p>Rigid definitions of competence can result in exclusion.</p>	<p>Information-giving, consent and assent processes must be disability-inclusive and accessible. Enough time must be allowed for children to make an informed decision about whether or not to join in before the actual data collection activities begin.</p> <p>Trust must be built between the researcher and the participants and their families and this may take time if the researcher is an unfamiliar person.</p> <p>Researchers must recognize that most children with disabilities have the capacity to make informed decisions if relevant information is made available and accessible to them.</p> <p>Consent, assent and dissent can be articulated verbally or non-verbally. Behaviour, facial expressions and body language can be ways to signal preferences. Researchers must decide whether a participant is having trouble articulating a refusal (which may be problematic for children with physical or communication impairments and very young children in particular).</p> <p>Children's capacity and willingness to join in evidence generation activities will depend on how these are presented and whether the children feel the activities are at the right level for them. Tasks that are too easy are patronizing, while those that are too difficult are demotivating and excluding. Researchers should be observant and sensitive to children's responses to activities.</p> <p>Adopting the social model of disability in evidence generation activities allows researchers to understand barriers to inclusion as existing outside of children with disabilities, rather than being intrinsic to the individual.</p>
<p>Using age as the sole threshold factor to determine whether consent can be independently given is problematic.</p>	<p>Researchers must establish in advance the age at which an individual can independently consent/assent to participate (which varies by national context) but should be mindful that age may not be an appropriate determinant of ability to consent/assent. Judgements made in relation to capacity are more likely to be helpful.</p>
<p>Third party gatekeepers' decisions can lead to children with disabilities being excluded from evidence generation activities.</p> <p>Gatekeepers may underestimate or misconstrue the child's abilities, leading to her/his exclusion.</p>	<p>Where parental consent is required, children should also be asked for assent.</p> <p>If needed, supported decision-making should be used, as opposed to substituted decision-making (i.e., the child is supported to make a decision with the help of someone she/he knows well).</p> <p>If a proxy is used to represent a child and generate data on the child's behalf, this should be documented during data collection and considered during analysis.</p> <p>If an adult is needed to give consent on behalf of a child, the researcher must decide whether or not the adult is deemed to be protecting the child's best interests appropriately.</p> <p>If needed, a communication partner/interpreter – ideally chosen by the child – should be able to accurately interpret the child's communication.</p> <p>Researchers may need to work to increase awareness among third parties of the individual's right to choose whether or not to participate, and their role in supporting the child.</p>

<p>A number of factors should be considered in relation to ensuring the privacy of a child with a disability during data collection.</p>	<p>When considering the privacy of a child with a disability during data collection, a researcher should consider the:</p> <ul style="list-style-type: none"> ■ child's age and capacities ■ child's comfort with talking to and doing activities with unfamiliar adults ■ child's safety ■ child's ability to communicate with or without the support of a family member ■ nature of the information being sought. <p>The right to privacy should be discussed with the parents and the child, using appropriate language.</p>
<p>Some aspects of consent and assent may change during the evidence generation process, and children may change their minds about participation as different activities and expectations arise.</p>	<p>Consent, assent and dissent processes should be treated as an ongoing conversation with both children with disabilities and their families/caregivers. Accessible information must be provided to children, in formats suited to different impairments. This information should include information in relation to the right to not participate, to withdraw from the evidence generation activity at any time or to skip questions.</p>
Anonymity	
Key challenge	Mitigation strategies
<p>Anonymity can be compromised due to an impairment, geographical location or another factor being recognizable because it is very specific, rare or well known. In some situations, children may ask to be identified.</p>	<p>The evidence generation protocol should be designed to ensure that no child is put at risk through identification. If necessary, some characteristics of participants can be changed to obscure their identity, as long as this does not distort the interpretation of the data.</p> <p>Children with disabilities can be involved in creating pseudonyms for themselves.</p> <p>The risks and benefits of identification must be explained to the child and the parents/guardians. In some situations, real names may be used, with appropriate caution.</p>
Confidentiality, privacy and security	
Key challenge	Mitigation strategies
<p>Confidentiality must be maintained as far as possible, but it must never replace the need to protect children.</p>	<p>Where appropriate, children should be given the option to participate privately on their own or with a family member, rather than with other children or with an unfamiliar person.</p> <p>There may be occasions when confidentiality must be broken if this is judged to be in the interests of the child's safety. This will need to be carefully explained to and discussed with the child, including why and how this will happen.</p>
<p>Confidentiality/privacy may be understood differently in some families or contexts.</p>	<p>The concept of confidentiality must be discussed with family members who support children with disabilities. Boundaries and rules about privacy vary across cultures. The reasons why protecting privacy may be important, even if the concept is unfamiliar, will require sensitive explanation.</p>

Research communication and uptake	
Key challenge	Mitigation strategies
Evidence generation teams must consider from the outset how to communicate their research in ethical and inclusive ways, and identify what impact they hope it will achieve.	<p>Research communication and uptake must be treated as an integral part of the evidence generation process. Accordingly, an inclusive and accessible research communication or uptake plan must be developed from the outset.</p> <p>Ideally, this will be devised in consultation with the participants, who may have their own ideas about where the evidence should be shared, in what formats and with whom.</p> <p>Participants should have an opportunity to validate the interpretation of their data.</p> <p>Evidence should be communicated in a number of formats and at various levels of complexity suited to different audiences, including children with disabilities and their families.</p> <p>Organizations of people with disabilities should assist with research communication and uptake.</p>
Visual methods have a strong emphasis on communication, which can lead to challenges in relation to anonymity.	For methodologies where visual communication forms an important part of the evidence generation process (such as the generation of drawings, photos or videos), masking techniques can be used to anonymize subjects (e.g., turning photographs into cartoons).