

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

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EXPLORING CRITICAL ISSUES IN THE ETHICAL INVOLVEMENT OF CHILDREN WITH DISABILITIES IN EVIDENCE GENERATION AND USE

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ABSTRACT

This working paper explores the main ethical challenges, and corresponding mitigation strategies, in relation to involving children with disabilities in evidence generation. Children with disabilities are defined as individuals under 18 years of age who have long-term physical, mental, intellectual or sensory impairments that, in conjunction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Evidence generation activities are defined as research, evaluation, data collection and analysis.

The purpose of this paper is to equip the reader with an understanding of some of the key ethical issues, as articulated in the literature, involved in engaging children with disabilities in evidence generation activities. A rapid review of the relevant literature was undertaken, and sources identified through an online search and consultation with experts. In total, 57 papers were deemed relevant and were included in the review. There was a paucity of evidence focusing specifically on the ethical challenges of involving children with disabilities in evidence generation. The evidence that did exist in this area was found to focus disproportionately on high-income countries (HICs), with low- and middle-income countries (LMICs) markedly under-represented.

Involving children with disabilities in evidence generation raises various issues and dilemmas over and above those usually considered for children in general. There is a tendency for children with disabilities to be deliberately or accidentally excluded from evidence generation. Processes of information giving, consent or assent, and methodologies for data collection may be insufficiently adapted to be deemed truly disability inclusive. Additionally, many negative assumptions are made about the capacity of children with disabilities to participate in generating data, and the possibility and value of including them throughout the evidence generation process is not well understood.

This paper provides an overview of the key issues drawn from the literature reviewed and suggests established and potential mitigation strategies that could improve ethical practices when involving children with disabilities in evidence generation activities (*for a summary, see Appendix 1*). More evidence generation activities with this group of children are urgently needed, and it is important that conventional and existing ethical practices used with children are further developed to embrace disability inclusion. This will encourage the realization of children's right to participate and be heard, and ensure that policy and practice are informed by the perspectives and concerns of children with disabilities. Importantly, this approach can support a wider agenda for the greater inclusion in society of children with disabilities.

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GLOSSARY OF KEY TERMS

Children: Every human being below the age of 18 years. Defined as per the United Nations Convention on the Rights of the Child (1989).

Children with disabilities: Includes those children who have long-term physical, visual, hearing and communication, learning (cognitive and intellectual) and psychosocial/behavioural impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Defined as per the United Nations Convention on the Rights of Persons with Disabilities (2006).

Evidence generation activities: Research, evaluation, data collection and analysis. Defined as per the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis (2015).

1. INTRODUCTION

This working paper explores the critical ethical issues in relation to involving children with disabilities in evidence generation. Its purpose is to equip the reader with a sound understanding of the key ethical issues involved. The information presented in this paper was informed by a rapid review of the relevant literature, which was identified through an online search and consultation with experts.

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.

This paper used these articles as the foundation for this rapid literature review, acknowledging their relevance and application to ethical evidence generation activities involving children with disabilities. The paper aims to encourage practitioners to explicitly consider ways to ethically and respectfully encourage the participation and inclusion of children with disabilities in evidence generation. It highlights ethical considerations and mitigation strategies to ensure that these children are able to participate and are respected and protected throughout the process.

Following the introduction and an overview of the methodology adopted, the paper provides an analysis of the nature and prevalence of the evidence in this area. This is followed by a section that explores the relevant background context about undertaking evidence generation involving children with disabilities and the relevant ethics frameworks.

The main section of the paper is structured around the stages of the research cycle – preparation, implementation, and research communication and uptake – with key challenges and mitigation strategies described in the literature set out for each stage. A checklist summarizes various approaches to dealing with these challenges (*see Appendix 1*). Finally, a tabulated mapping of the nature of the literature included in the report is provided (*see Appendix 2*).

1.1 Overall findings

Based on the evidence reviewed, the following key challenges and mitigation strategies were identified.

Key challenges

- Non-inclusive research methods may result in the exclusion of some or all children with disabilities from participating fully in either mainstream child-focused evidence generation or studies that specifically investigate the lives, perspectives and experiences of children with disabilities.
- The safety of children with disabilities may be compromised due to the non-adapted nature of evidence generation activities. This danger results from a failure to consider the increased risks faced by children with disabilities when they are involved in evidence generation, and the extra barriers they may face in obtaining help should they need it.

- The intersection of childhood, disability, gender and other identities or living situations may lead to disempowerment/disadvantage and may reduce opportunities for certain children's participation in evidence generation. This can be due to entrenched cultural norms, negative stereotypes and unfounded assumptions about these identities/living situations, whether considered individually or in combination.
- Children with disabilities may be excluded due to researchers' beliefs, perceptions or lack of knowledge and experience about how to use inclusive and adapted information giving, consent and assent processes, and data collection methods. Negative stereotypes or lack of skill in relating to children or about disability can lead to exclusion or unethical evidence generation.
- 'Gatekeepers' (e.g., parents or teachers) may limit access to children with disabilities or try to influence the nature of their participation in evidence generation.
- Some children's use of alternative (non-standard) communication systems may be regarded as a barrier to participation.
- Anonymity of the participants may be compromised either due to the mention of notable characteristics associated with particular children or their impairments, or due to methodological challenges.
- Confidentiality may be compromised due to the disclosure of sensitive information by children with disabilities.
- Some children with disabilities may be invited to participate despite there being little prospect of the children benefiting directly from being involved.

Key mitigation strategies

- Researchers should consider and provide mitigation strategies to address power dynamics in evidence generation – between adults and children and between individuals with and without disabilities – in an attempt to understand the implications for including children with disabilities in evidence generation.
- Child-led methodologies can be tailored to involve children with disabilities in evidence generation processes. For example, children could be involved in designing activities, collecting data, conducting analysis, interpreting results, and implementing research communication and uptake activities. Organizations representing or supporting people with disabilities should be engaged for support, not only to mobilize participation but also to offer guidance when consulted.
- Evidence generation protocols or inception reports should be inclusive and consider children's cognitive, physical, emotional management, sensory and communication competencies, and take into account other intersecting factors such as gender, ethnicity and cultural context. Researchers must ensure that all children (with or without disabilities) have the same opportunities to participate in evidence generation activities to the best of their abilities and desires. Children with disabilities may be able to participate fully if activities are sufficiently inclusive and responsive to their support needs.

- When framing evidence generation activities, practitioners should reflect on the social model of disability (i.e., that disability is socially constructed) and its implications for children with disabilities participating in evidence generation. Practically, this means that a researcher recognizes that a child's impairments only become 'disabling' when society does not respond to the child's needs. The research design should frame the evidence generation activities accordingly (including setting appropriate research questions, selecting inclusive methodologies and making provision for access needs).
- Researchers should increase gatekeepers' awareness of children's rights (including the rights of children with disabilities) and the potential for children to participate, given an inclusive approach. Greater understanding must be developed about the rights of individuals to participate in research, including through the acceptance of diverse means of participation.
- Creative methodologies (visual approaches in particular) can facilitate children's understanding of the evidence generation process and the activities involved, while also enhancing adults' understanding of what children may wish to express or communicate. Thus, the use of symbols, pictures, visual timetables or other creative methods can mitigate any communication challenges that may exist between children with disabilities and researchers.
- Researchers should clearly discuss the advantages and disadvantages of anonymity with both children with disabilities and their parents or guardians.
- A protocol must be developed explaining the process that will be followed should a child with disabilities disclose sensitive or worrying information. Within this context, a referral network must be identified, and referral pathways articulated in a clear plan.
- Organizations of people with disabilities should be consulted regarding contextual knowledge of relevance to the study area, potential support services, and research communication and uptake opportunities.
- Researchers need to be trained in child-focused methodologies, evidence generation and ethics, contextual realities, different communication methods, the diverse needs of children with different impairments, and appropriate inclusive practices and adaptations that are likely to be needed.
- Ideally, researchers with disabilities should either join or advise the evidence generation team. Organizations of people with disabilities or self-advocacy groups should be able to assist in the absence of researchers with disabilities.
- A disability-inclusive child protection/safeguarding protocol must be developed that acknowledges and addresses the rights of children with disabilities to be safe and protected from harm and which provides details of any accommodations needed for children with disabilities to be able to access their rights. The specific needs and circumstances of participating children with disabilities should be addressed at all stages of the child protection/safeguarding process.

Appendix 1 summarizes these challenges and mitigation strategies as a checklist of key questions to consider to involve children with disabilities ethically in research, evaluation or data collection processes.

1.2 Methodology

The research sought to explore critical issues in the ethical involvement of children with disabilities in evidence generation. A desk-based search for relevant literature was undertaken using a systematic approach involving combinations of the following keywords:

Term 1	Term 2	Term 3
Ethical issue*	Undertak* research	Children with disabilit*
Ethical guid*	Evidence generat*	Disabled child* ¹
Ethical challenge*	Research guid*	Youth with disabilities
	Investig*	
	Research method*	

Note: The use of * indicates a truncation command, facilitating a search for key root words with alternate endings.

These keywords were used to search databases and websites including PubMed/MEDLINE, APA PsycInfo (EBSCOhost), CINAHL (EBSCO), ERIC (Education Resources Information Center), Scopus, Ask Source, and Participatory Methods. A general search of Google Scholar was also conducted as well as a generic internet search (using Google).

In addition, a 'snowball' technique was used, whereby the reference lists and citations of relevant papers were used to identify additional papers.

All types of evidence were considered, including academic journal articles, guidance papers and grey literature. In addition to the initial literature search, seven experts working in the field of disability evidence generation, who have a research interest in children, were selected and contacted directly to provide any additional evidence and resources. Suggestions of literature to include were provided in response by four of these experts (*for further details, see the acknowledgements section*).

Where possible, information directly relevant to undertaking evidence generation activities with children with disabilities was included. Information relating to undertaking evidence generation activities with adults with disabilities was also included where necessary (i.e., due to its perceived relevance or due to a lack of child-specific information). Where such evidence is included, it is made clear that the focus was adults rather than children. Similarly, while evidence focusing on low- and middle-income countries (LMICs) was prioritized, evidence focusing on high-income countries (HICs) was included where necessary (i.e., due to its perceived relevance to the topic or due to a dearth of information on the priority contexts).

Papers identified by the search were excluded if they include only a standard mention of an ethical clearance process undertaken and do not also provide an analysis of the critical issues in the ethical

¹ In line with the United Nations Convention on the Rights of Persons with Disabilities, 'people-first' language has been used throughout this report. The search term 'disabled child' was, however, included in the desk-based search to avoid excluding literature that does not use people-first language but which is still relevant.

involvement of children with disabilities from a methodological or strategic position. Also excluded were those resources identified that focus on the medical ethics of providing clinical treatment to children with disabilities, but which do not explore ethics with regard to broader types of evidence generation.

A total of 95 pieces of evidence were identified from the initial literature search. These were assessed for relevance to the research questions. In total, 57 papers were deemed relevant and were included in the rapid review.

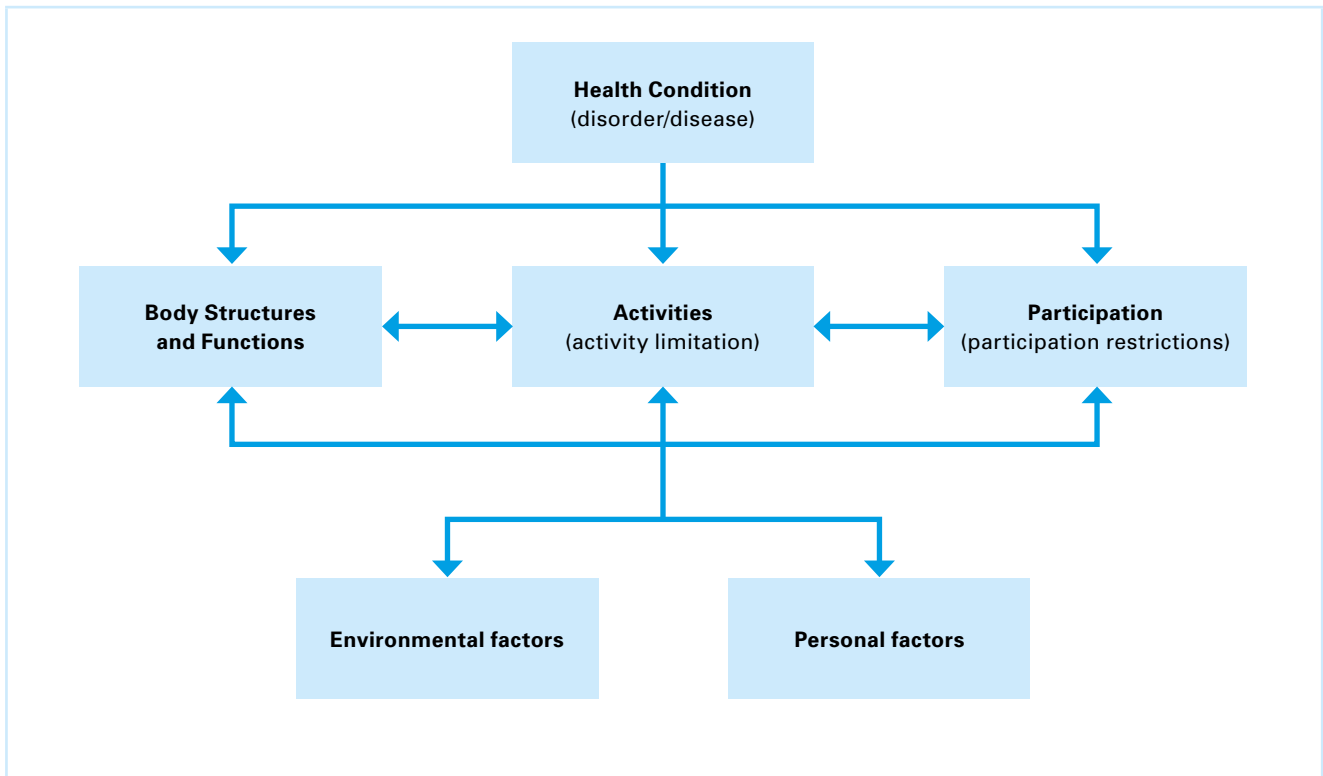
A note on terminology about disability

In this paper, the terms ‘disability’, ‘impairment’, ‘activity’ and ‘participation’ are used, following the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) model of disablement, endorsed in 2001, as represented in the figure below (*see Figure 1*). The ICF model was developed to broaden perceptions of the factors that contribute to disablement, to shift from what was previously a medical perspective to a biopsychosocial approach (henceforth referred to as the ‘social model’). As the figure shows, the conceptualization contends that a number of factors work in combination to influence whether or not an individual is seen as having a disability.

For example, a child may have cerebral palsy as a result of complications at birth. This is a *health condition*, but the effect of such a condition on the child is variable, depending on the type of condition (in this case, cerebral palsy), its severity and other factors. The cerebral palsy will affect the child’s ability to move and control her/his body. This describes the impacts on *body structure and function*, often called the *impairment*. These impacts, in turn, affect what the child can do and her/his natural range of *activities* (such as walking, eating independently, talking, holding objects). The child may be able to do more activities, however, if given equipment to help, extra support and practice and/or an adapted way to take part (e.g., wheelchair football). The way that the people around the child respond to and support her/him will affect the child’s *participation* and hence her/his inclusion in or exclusion from society.

The ICF model highlights that the *environment* around the child (physical and structural aspects such as terrain, family factors, policies, laws, resources) is critical and that the effects of the impairment are also strongly contingent on external factors rather than on purely physical capabilities alone. A further critical consideration is *personal factors* – aspects of the individual her/himself, such as personality – which also contribute to determining the effects, opportunities and any limitations of an impairment.

All of these factors interact and combine to generate a more or less disabling situation for the individual. This model thus reduces the emphasis on the medical condition itself and the associated impairment, and instead emphasizes the role of factors around the individual, which can have a major effect on her/his well-being, identity and life chances.

Figure 1. International Classification of Functioning, Disability and Health (ICF)

Source: Adapted from WHO (2001).

There are five main categories of impairment (although the precise terminology used for each varies across languages and contexts):

- physical (mobility issues/difficulty moving)
- visual
- hearing and communication
- learning (intellectual/cognitive)
- psychosocial/behavioural (includes mental health impairments).

Of course, some individuals have several impairments, which together can affect the person in complex ways (e.g., deaf-blindness, multiple impairments), and some difficulties regarded as disabling are arguably not well accounted for by these broad categories (e.g., albinism, where stigma is a major factor).

These categories do not take into account the medical diagnosis or health condition that has caused the impairment but focus on what is easy or difficult for the individual to do and what help and support is needed. In many situations, a more functional approach is appropriate. This encourages those working with children with disabilities to think in practical ways about what the individual children can do and what they need help with.

The 'social model' of disability argues that an undue focus on the impairment of an individual can sometimes be pathologizing and generate stigma and discrimination. While medical and rehabilitation interventions are important, children with disabilities also have rights to the best possible and available services, to social supports and to opportunities that promote the realization of the full range of their rights and enhance their quality of life. Inherent to this model is an acknowledgement of the critical importance of the voices of children with disabilities to furthering these aims and securing these rights.

Limitations of the search strategy

A number of limitations to the search strategy must be acknowledged. A key limitation was that only evidence written in English was reviewed. While English is widely accepted as the international language of research, there may be many valuable resources published in French, Spanish and other languages that were overlooked solely on this basis.

The term 'impairment' was excluded from the search as it was felt that this would lead to the surfacing of a large number of 'clinical' resources detailing medical or rehabilitation studies about children with particular impairments. The focus instead was on the overarching concept of disability, as per the ICF / social model, leaning more towards the social sciences, community intervention programmes and applied practical data generation activities.

As detailed in the following section on the nature and prevalence of evidence in the area of research, 47 of the 57 papers reviewed focus on children, while 10 papers have a broader focus on people of all ages. If the search strategy had been broadened beyond its specific focus on children, it is likely that many more resources would have been identified.

Time was another major constraint. While the search strategy was thorough, what was feasible within the time available for this rapid review was limited.

As a rapid review, for the purposes of scoping only, no assessment of the quality of the evidence identified was made. While care was taken by the authors to include only resources that were judged to be of an acceptable quality, no formal assessment was undertaken. If a systematic review were to be undertaken, it would be expected that a quality and risk of bias assessment would be conducted for all resources included. It is recognized that *not* using this approach may have influenced the resources ultimately included in the present review.

1.3 The nature and prevalence of evidence in the area of research

The papers described below were included in the review and categorized using a methodology adapted from the United Kingdom of Great Britain and Northern Ireland's Department for International Development (2014) guidance on assessing evidence. Research type and research design categorization were informed by the following matrix:

Research type	Research design	Description
Primary	Observational	Particular actions, activities or phenomena are observed
	Experimental	Research manipulates an independent variable and involves treatment/control groups
	Quasi-experimental	Research either manipulates an independent variable <i>or</i> involves treatment/control groups, but does not do both
Secondary	Non-systematic literature review	Summarizes or synthesizes literature on a given topic
	Systematic review	Adopts exhaustive, systematic methods to search for literature on a given topic
Conceptual/theoretical		Idea-focused resources that do not generate empirical data/evidence. Such resources can include guidelines, theoretical discussions, and viewpoints

Papers were also categorized according to the geographical location of focus; whether they focus on a specific impairment, have a more general focus on disability, or include relevant information without being disability-focused; and whether or not they specifically focus on ethics. This latter categorization was informed by whether the term 'ethics' (or a related term) is included in the title of the resource. A further category was used to describe whether or not the paper is child-focused. Appendix 2 features a table illustrating the nature and prevalence of the literature reviewed according to these categories. Additional information that was deemed relevant to how the evidence was informed is included in the final column of the table.

1.3.1 Focus of the literature with regard to ethics

Of the 57 papers reviewed:

- 25 directly and specifically focus on ethics in evidence generation
- 32 make reference to ethics, but it is not the primary focus.

Key reflections

There is a gap in the evidence base, which should be filled with more research and guidance that focuses explicitly on the ethics of involving children with disabilities in evidence generation activities.

1.3.2 Geographical focus of the literature

Of the 57 papers identified, 27 focus on HICs (High Income Countries) (with 17 having a UK focus), while 19 have no specific geographical focus. A further 11 papers focus explicitly on Low and Middle Income Countries (LMICs).

Of these 11 LMIC papers, 5 focus on Papua New Guinea and Vanuatu (Jenkin et al., 2015; Wilson et al., 2015; Wilson et al., 2016; Jenkin et al., 2017; Jenkin et al., 2020).

The remaining 6 of these 11 papers focus on a variety of LMICs (Ellery et al., 2011; Daley et al., 2013; Wickenden & Kembhavi-Tam, 2014; Tucker & Govender, 2016; Kyegombe et al., 2019; van der Heijden et al., 2019). The range of LMICs in focus includes:

- Burundi
- India
- Madagascar
- Mozambique
- South Africa
- Sri Lanka
- Uganda
- United Republic of Tanzania (Zanzibar).

A limitation of the high representation of papers from one study group focusing on Papua New Guinea and Vanuatu is that the data for LMICs included in the rapid review may be heavily skewed towards the experiences in these countries. Therefore, generalizations about issues faced by LMICs with regard to this topic should be approached with caution.

Key reflections

LMICs are under-represented among the identified evidence focusing on ethics and children with disabilities in evidence generation activities. Vulnerability associated with disability is likely to be heightened in these contexts, where there is a well-recognized interaction between poverty and marginalization (van der Heijden et al., 2019). Evidence is needed to better understand the particular circumstances that may have an impact on the ethics of including children with disabilities in evidence generation activities in LMICs. Further research should be undertaken to address this gap.

As set out in the Convention on the Rights of Persons with Disabilities (art. 31), States parties have a responsibility to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention. As such, 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.

1.3.3 Nature of the research methods reported

Of the 57 papers reviewed, 24 are primary research papers, 11 are secondary research papers and the remaining 22 papers are conceptual or theoretical in nature.

Of the 24 primary research papers:

- 20 are observational
- 3 are quasi-experimental
- 1 is experimental – a study protocol for a pilot randomized controlled trial, as opposed to a full research paper (Bennett et al., 2016).

Of the 11 secondary research papers:

- 10 are non-systematic literature reviews
- 1 is a systematic literature review – which focuses on childhood epilepsy (Harden et al., 2016).

Seven of the primary studies – all of them observational in approach – were based in LMICs (Ellery et al., 2011; Wickenden & Kembhavi-Tam, 2014; Wilson et al., 2015; Tucker & Govender, 2016; Wilson et al., 2016; Jenkin et al., 2017; van der Heijden et al., 2019).

Just one secondary research paper with an LMIC focus presents a summary of academic literature relating to the ethics of including children with disabilities in child evidence generation (Jenkin et al., 2020). Given the paucity of primary research focusing on the ethics of involving children with disabilities in evidence generation in LMICs, it is unsurprising that secondary research on this topic is also scarce.

Of the conceptual or theoretical papers, eight resources are guidance notes. Three of these documents specifically focus on children with disabilities, to suggest best practice for conducting evidence generation activities on violence against children with disabilities (Kyegombe et al., 2019); how to engage children with disabilities in decisions affecting their lives (UNICEF, 2013); and inclusive practice for evidence generation with children with disabilities (Jenkin et al., 2015). The other five guidance notes do not specifically focus on children with disabilities, but rather focus on promoting ethical data management (Brus, 2015); undertaking ethical evidence generation with children in general (Graham et al., 2013); ethical guidance for evidence generation with people with disabilities in general (National Disability Authority [NDA], 2009); ethical guidelines for children's participation practice (Feinstein & O'Kane, 2008); and ethical approaches to gathering information from children and adolescents (Schenk & Williamson, 2005).

As well as varying in focus, the eight guidance notes vary in approach and detail. The guidance from Kyegombe et al. (2019) is based on the authors' experience of conducting evidence generation activities on violence against children with disabilities and is presented in the form of a published correspondence in an academic journal. UNICEF (2013) states that its guidance on the basic requirements for ethical and meaningful engagement of children with disabilities in decisions affecting their lives is based on the considerable experience gained since the adoption of the Convention on the Rights of the Child, which has led to a broad consensus on the issue. The approach undertaken in producing the UNICEF guidance is unclear, however. Jenkin et al. (2015) based their guidance note on the experience of undertaking primary research with the Voices of Pacific Children with Disability project in an LMIC.

The NDA (2009) guidance note was informed by a large-scale consultation exercise and draws on both Irish and international literature that focuses on ethically undertaking evidence generation activities involving people with disabilities. Brus (2015) has based her guidance on the field experience of Humanity and Inclusion (formerly Handicap International), an international non-governmental organization, as well as reference documents and scientific articles that focus on the ethical issues surrounding the production and analysis of evidence in humanitarian and development settings. Graham et al. (2013) urge a move beyond prescriptive approaches to ethical issues and encourage critical engagement instead by providing evidence-based information and resources to guide and improve evidence generation activities involving children. The Feinstein and O'Kane (2008) guidance is based upon Save the Children policies, practice standards and good practice guidelines for involving children in evidence generation activities. Schenk and Williamson (2005) provide practical guidance on collecting evidence from and about young people, based on a consultative process that was undertaken with various relevant stakeholders from a range of fields and backgrounds.

Key reflections

Without assessing the nature of resources focusing on ethics in general, it is difficult to comment on the representation of the different research designs and types of the papers relevant to children with disabilities included here. It is unclear whether what is needed is more primary research, more secondary research or more conceptual papers focusing on this topic. As it is generally accepted, however, that disability is an under-researched area, quality research of *any* design that focuses on or looks at disability inclusion is welcomed. A key gap in the literature is guidance focusing explicitly on the ethical inclusion of children with disabilities in evidence generation activities in LMICs.

1.3.4 Literature focusing on children

Of the 57 papers reviewed:

- 47 focus on children
- 10 have a broader focus on people of all ages.

Key reflections

It is recognized that broader bodies of literature exist that focus on relevant themes around evidence generation activities, including the ethics of involving people with disabilities of *all ages* and ethically involving *all children*, with and without disabilities. It was not possible within the scope of this rapid review to examine all of the available literature that focuses on these relevant themes.

1.3.5 Impairment focus of the literature reviewed

Of the 57 papers reviewed:

- 18 are disability-focused but do not specify a focus on a particular impairment
- 11 are not specifically disability-focused but contain sections or subsections focusing on disabilities
- 9 focus on learning impairments and 7 on intellectual impairments
- 12 were found to be diverse in focus and to use overlapping or variable terminology.

The range of focus for these last 12 papers spans: mental health impairments, neurological conditions, physical and emotional impairments, psychiatric impairments, socio-affective needs, literacy/numeracy difficulties, psychosocial impairments, behavioural problems, epilepsy, attention-deficit hyperactivity disorder (ADHD), autism spectrum disorders (ASD), communication and/or cognitive impairments, developmental disabilities and children dependent on ventilators (Alderson & Goodey, 1996; Noyes, 2000; Morris, 2003; Yan & Munir, 2004; Solyom & Moreno, 2005; Bélanger & Connelly, 2007; Koelch & Fegert, 2010; Daley et al., 2013; Nicolaidis et al., 2015; Bennett et al., 2016; Harden et al., 2016; Tucker & Govender, 2016).

Key reflections

Papers focusing specifically on visual or hearing and communication impairments were completely absent. Just one paper focusing on physical impairments was found (Alderson & Goodey, 1996), which was surprising as there is a tendency for discourse around disability to over-represent people with physical disabilities. Discussion of ethical and methodological imperatives and choices in undertaking evidence generation activities with children across the whole range of impairment categories represents another potential research gap. It is likely, however, that some of the general disability-focused papers available may cover some of these concerns relevant to research work with children with a wider range of difficulties. It is also of interest to note that none of the papers identified that explicitly concentrate on learning (intellectual/cognitive) impairments focus on LMICs. There is evidence that individuals with such impairments are particularly marginalized and excluded from mainstream activities in many countries and contexts.

2. THE IMPORTANCE AND VALUE OF ENGAGING CHILDREN WITH DISABILITIES IN EVIDENCE GENERATION

This background section introduces the critical issues around and context of involving children with disabilities ethically in evidence generation activities. It explains why ethical evidence generation involving children with disabilities is important. It also explains how children with disabilities and their families may broadly gain from participating in such evidence generation activities.

2.1 Children's rights

Children's rights to make decisions and to express their views are affirmed by human rights conventions such as the Convention on the Rights of the Child. This states that all children must be free to express their thoughts and opinions (art. 13); emphasizes the principle of non-discrimination (art. 2); and states the rights of children with disabilities to enjoy a full and decent life in conditions conducive to dignity and self-reliance (art. 23). Arguably, however, the Convention's reference to children with disabilities, and how this is worded, can now be regarded as limited and in need of updating, given the significant changes since 1989 – when the Convention was adopted – in how disability is conceptualized.

The Convention on the Rights of Persons with Disabilities, adopted in 2006, states that “children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.”

Excluding children with disabilities from participation in evidence generation activities denies them an opportunity to express their views and is discriminatory if their right to participate is removed because of their disabilities.

Including and involving children with disabilities in evidence generation activities is both a legal and moral imperative (Jenkin et al., 2020). Doing so can help to ensure that data collection is non-discriminatory, age-appropriate and inclusive, and that it recognizes both the rights and competencies of children with disabilities.

2.2 Protection and inclusion: Moving beyond vulnerability

Children may be considered to require additional safeguards to protect their welfare compared with adults. Children with disabilities may be especially vulnerable, depending on their specific circumstances, and may need additional protections. In these contexts, ethical practices and codes have the potential to be both tools for protection and, conversely, may lead to exclusion from evidence generation (van der Heijden et al., 2019). Excluding children with disabilities from evidence generation activities has often been motivated by the aims of ensuring their protection from abuse and avoiding the complexities of informed consent and adapted methodologies. But it also denies them agency and a voice. Exclusion is indefensible in terms of equity, justice and the potential benefit of research findings (Graham et al., 2013).

The consequences of an overcautious or simplistic view of protection and the prevention of gross violations is that the voices of children with disabilities continue to remain largely absent from evidence generation activities. This absence is particularly evident in LMICs (as identified in

section 1.3), though a research base with this geographical focus is slowly emerging, according to Jenkin et al. (2020).

Children with disabilities are sometimes excluded from evidence generation that is designed to investigate an issue deemed relevant to the 'general' population (NDA, 2009), for example, children's experience of transport or school. Children with disabilities will have experiences and views about such matters; if their perspectives are not sought, policy and practice decisions may be made without consideration of their views. Individual data from children with disabilities that highlight their experiences can be powerful – sometimes showing how their priorities are similar to those of their peers without disabilities, at other times showing the uniqueness of their experiences. Data elicited directly from children can often differ from data drawn from proxies (such as parents or teachers) who may mistakenly presume that they can speak accurately on behalf of children with disabilities and reflect the children's personal experiences and attitudes. The overall effect of hearing children's voices directly is to humanize them, to promote understanding of children as citizens, to understand their perspectives, and to inform and ensure more equitable approaches to policies and programming that may affect them. An ethical evidence generation process ensures adequate safeguards are in place while also providing opportunities for children with disabilities to participate and contribute in suitably adapted and inclusive ways.

2.3 Intersectionality and exclusion

An inclusive approach to research planning and design demands explicit consideration of the intersectionality of different identities. For example, girls may more frequently be excluded from evidence generation or spoken for by other stakeholders because of misperceptions about their ability or willingness to participate, or due to cultural norms about gender relations (van der Heijden et al., 2019). Gatekeepers may judge that it is not possible or appropriate for children to participate.

Further, evidence has shown that the nature of the disability (impairment type) may also contribute to the exclusion from evidence generation activities of children with disabilities. Most obviously, this is true for the large group of children with learning (intellectual/cognitive) impairments, though this may also hold true for other types of impairment. Bradbury-Jones et al. (2018) undertook a qualitative systematic review of participatory evidence generation with vulnerable children and found that the issue of exclusion of this group was evident across the studies reviewed. Children who may be unable (or perceived as unable) to verbalize their experiences are at particular risk of exclusion.

Participatory approaches can allow researchers to recognize the intersectionality of different identities – such as gender, ethnicity and sexuality – that may combine with disability to generate relatively more or less marginalization. Participatory approaches explicitly set out to promote the agency and empowerment of the most excluded groups. This requires careful planning as well as reflection on the identity of participants. Inclusive and adapted methodologies such as the use of alternative and augmentative communication methods, a slower pace or single gender groups can allow children with disabilities to become involved in the construction of knowledge about themselves in safe and confidence-building spaces (Bradbury-Jones et al., 2018; Brady & Franklin, 2019). Evidence generation activities should focus on the strengths of children with disabilities, using methods of communication and data generation suited to their abilities. If children with disabilities are treated as incompetent, this may undermine or prevent positive and enabling factors that could otherwise be successful if supported by a more flexible and affirmative approach (Jenkin et al., 2020).

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). Ascribing a collective identity grounded in medical classification (or impairment type) makes unwarranted assumptions about individuals, potentially denying their differences, their individuality and their unique perspectives. It can lead to a researcher privileging some types of voices while subjugating others. A 'one-size-fits-all' plan can reinforce notions of dependency, vulnerability and incompetence, which reduces children's agency and homogenizes their diverse childhoods and lives (Richards et al., 2015).

Children with disabilities are hugely varied in their situations and experiences, and there is also considerable diversity within the categories of impairment. For example, children within a single diagnostic group may have difficulties of varying types and severity, and an individual child may have multiple impairments (e.g., physical and visual impairments) and other associated conditions (e.g., epilepsy). Researchers should not make assumptions about who particular children are and what they can or cannot do. Children with disabilities may (or may not) may not view themselves as having a disability, and if they do they may not view this as the most important or significant aspect of their identity. Children with disabilities may justifiably perceive and wish to be perceived as merely children. This then problematizes the dichotomy often used by adults of having or not having a disability. Disability is perhaps better considered as a spectrum rather than as a binary category, and with disability just one possible aspect of a child's perceived identity.

2.4 Exclusion of children with disabilities from population-based research

Children and young people with disabilities are frequently not only perceived as needing special protection and therefore excluded from evidence generation activities about their own specific situations. They are also commonly excluded from 'mainstream' evidence generation by those who control access to potential participants (Loveridge & Meyer, 2010). Generic surveys, for instance, may automatically exclude children with disabilities because of the sample design (e.g., those living in institutions may be excluded) or the use of stigmatizing tools, which rely on or narrow language or definitions, to identify disability in children. Children with disabilities are thus disadvantaged both by virtue of their potential vulnerability to the generally well-recognized risks inherent in evidence generation participation and also by their higher likelihood of exclusion from evidence generation altogether. Children with disabilities are often excluded from research due to perceived inconvenience, difficulty or cost (Yan & Munir, 2004).

Participation rates of people with disabilities in evidence generation activities among the general population are rarely reported. Low participation rates or participation biased towards certain groups viewed as 'easier' to engage with (such as those with physical or visual impairments who do not also have behavioural or communication difficulties) are seldom addressed. Individuals with severe impairments are often excluded, as are those who live in institutions, and often these two categories overlap. Other characteristics (such as belonging to an ethnic minority group) may further affect the under-representation of children with disabilities in evidence generation activities. It is still a rarity for children from the whole range of impairment types and severities to be recruited into studies. Purposive sampling, and arguably also oversampling of under-researched groups, can be appropriate and is therefore an important consideration.

2.5 Benefits to society and to the well-being of children with disabilities and their families

The rights that protect children with disabilities and which underpin their right to have a say are reinforced by evidence that where children with disabilities *have* been engaged in research that have provided significant contributions to the literature. This participation has added critical perspectives for policy development and led to enhanced outcomes for children and young people with disabilities and their families (Loveridge & Meyer, 2010). Encouraging children with disabilities to participate allows them to express their own views in their own ways, in evidence generation conducted with them rather than just about them, to provide insights into and facilitate understanding of their lived experience. Evidence suggests that this may improve the well-being of children with disabilities and ensure that the services available to them are better tailored to their needs (Schenk & Williamson, 2005; Cologon et al., 2019).

For evidence generation activities including children with disabilities to be effective and ethical, it is essential that inclusive practices are understood and are both responsive and sensitive to the characteristics and access needs of the children recruited. If not, there is a danger that children will be patronized or manipulated, placed at risk or denied opportunities to express their views, or that the evidence generation will be tokenistic. The right to be *meaningfully* heard should be incorporated into evidence generation practice at all levels. While this justly applies to evidence generation activities involving all children, it is particularly pertinent to children with disabilities, who are so often denied the right to be heard (UNICEF, 2013).

2.6 The importance of decolonizing evidence generation and reframing disabilities

Jenkin et al. (2020) describe how evidence generation involving children with disabilities in LMICs is subject to significant criticisms about its colonial underpinnings. Researchers from HICs may unwittingly import into these contexts their own culture-bound views of childhood, disability and 'development'. Such evidence generation has the potential to construct children with disabilities as 'incomplete', 'abnormal', 'inferior', 'deviant' and 'backward', particularly, for instance, if they are not attending school. Such approaches can position children with disabilities as helpless or as victims. Viewing children with disabilities in this way, omitting the human and social factors that intersect to shape their lives, fails to capture or appreciate the diversity of children's experiences. If such disabling, adult-centric and/or colonial approaches to disability are to be overcome, a critical 'decolonization' is required to achieve a transformative shift in the power relations and purpose of evidence generation in LMICs. Each local context must be appreciated and understood in relation to its social norms and beliefs about both children and disability. Traditionally marginalized knowledge should be recognized and evidence generation undertaken cautiously, flexibly and with an open mind.

Evidence generation that focuses on children with disabilities must involve listening to them directly. If evidence generation is not inclusive or participatory, it can be exploitative and unethical (Cologon et al., 2019). Local or indigenous knowledge, values and processes must be privileged, and local cultural protocols used to frame the research design. A decolonizing approach to evidence generation requires engaging in critical dialogue with all evidence generation partners to explore understandings of children with disabilities from the children's own perspectives and to embed local protocols in the evidence generation activities. Engaging local researchers or working in close collaboration with them – and, if appropriate, involving children with disabilities themselves as peer researchers – can be a way to counteract the tendencies mentioned above.

A decolonizing approach must be underpinned by the social model of disability with human rights as an important lens. In this way impairment is accepted as a part of human diversity. This approach regards disability as a status conferred by society and its environment that generates barriers to social participation, thereby 'disabling' individuals with impairments (see *Figure 1*). Researchers from HICs, working outside their home territory, need to continually interrogate their practice and confront the ways in which research designs and methods may unwittingly cement established concepts and beliefs from their own countries, rather than serving the interests of local communities. A locally responsive approach necessitates paying attention to the diverse experiences of children with disabilities and their families. Adults involved in evidence generation should understand and appreciate the heterogeneity of children's experiences, not only between but also within countries, including the diverse constructions of childhood and disability (Jenkin et al., 2020).

2.7 Marginalized populations, disabilities and existing ethics frameworks

Ethical evidence generation guidelines and codes promote principles and frameworks that are based on historical and philosophical debates about duty, harm versus benefit, and rights. These guidelines have been regularly reviewed, updated and strengthened, drawing on learning from evidence generation practices over the last 60 years or so (Child Protection Monitoring and Evaluation Reference Group, 2012).

The main international ethical frameworks for research, which include the Nuremberg Code (1948), the Declaration of Helsinki (1964) and the Belmont Report (1979), provided the foundational guiding principles for ethical evidence generation activities involving human participants. The frameworks cover principles and issues pertaining to human rights, validity, justice, beneficence/non-maleficence and autonomy. While largely seen as having progressed research ethics, the frameworks are not without their criticism, and debate continues regarding the underlying principles of ethical evidence generation. Recent updates have encouraged a more culturally aware and responsive approach, greater accountability and respondent validation of findings, and increased consideration of research communication and uptake activities. As noted by Yan and Munir (2004), such broad frameworks may not provide adequate instructions for dealing with ethical challenges that are unique to particular populations.

The International Charter for Ethical Research Involving Children was launched in 2013. The Charter is a series of researcher commitments to uphold the rights, dignity and well-being of all child participants, in all circumstances, while embarking upon ethical and quality research. It focuses heavily on children's rights and specifically draws attention to the roles and responsibilities of research commissioners and researchers in relation to their interactions with children. It states the importance of reflective inquiry when engaging children in evidence generation endeavours. Such reflection presents researchers with opportunities 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.

3. KEY ETHICAL ISSUES AND MITIGATION STRATEGIES

The ways in which children can or should participate in evidence generation are much debated. Many of the potential challenges and mitigation strategies apply automatically to children with disabilities, although there are some additional considerations for this group (Wickenden & Kembhavi-Tam, 2014). It is ethically desirable to include children with disabilities in evidence generation activities, yet it raises many ethical dilemmas and uncertainties (Ajodhia-Andrews, 2016). In general, those collecting evidence must consider children's individual capacities at all stages of the research cycle to ensure that all children are genuinely able to participate meaningfully, understand what is happening and share their experiences in ways that work for them. Approaches to evidence generation must suit the competencies, knowledge, interests and contexts of the children, as well as encompass a variety of ways to communicate and participate, to accommodate diverse physical, and cognitive impairments (Jenkin et al., 2020).

This section describes the key ethical issues and mitigation strategies for involving children with disabilities in evidence generation. It is structured around the main phases of the research cycle, in chronological order: preparation; implementation; and research communication and uptake.

3.1 Preparation

3.1.1 Researcher positionality and adult-child relations

Ethical issues

Traditional adult-child relations in most societies dictate that adults are more powerful. Adult researchers ultimately have power over child participants in evidence generation, which may make them insensitive to children's perspectives. Contrasts and conflicts between adults' and children's interests can arise and adults' views will usually prevail (Alderson & Goodey, 1996; Clavering & McLaughlin, 2010).

Due to these differences in power and an expectation that children show obedience to adult authority, Kelly et al. (2000) argue that children may find it difficult to opt out of involvement in evidence generation (*see section 3.2.1*). While everyone has the right to *not* take part in research, a child with disabilities may feel particularly obliged to participate (especially if the child perceives the researcher to be there in an official capacity (Burke, 2005)). There is some evidence that children with disabilities tend to acquiesce and be overly compliant, placing them at risk of manipulation or coercion.

Children may be relatively passive in evidence generation processes – present, but not actively involved in the research approaches and design decisions, especially if the experience is new to them. The situation is exacerbated for children with disabilities (Ajodhia-Andrews, 2016). Children may respond to research questions with what they think the researcher wants to hear, rather than expressing their real feelings, experiences or concerns (Whyte, 2006). Many children with disabilities have limited or no experience of school, but equate the evidence generation process with a school context, where correct answers are often required.

Alderson and Goodey (1996) explain that the main challenges in ethically involving children with disabilities in evidence generation do not arise from children's inabilities or misperceptions, but from the positions ascribed to them by society. Stereotypes relating to childhood or disability can lead to

children with disabilities being treated in a particular way in evidence generation processes. For example, evidence generation focusing on children with disabilities often concentrates on their 'problems' or differences, examining perceived 'weaknesses' and needs, rather than focusing on their strengths and abilities. Problem-focused evidence generation is often framed not by the children themselves, but by others. Health professionals, parents and researchers are frequently involved in constructing the problem-related questions, reducing the child to someone who is challenging, difficult, lacking something, vulnerable and in need of help. The child with disabilities may not be regarded as having valuable opinions, goals and aspirations (Ajodhia-Andrews, 2016).

Mitigation strategies

Researchers must recognize the influence of their own values, experiences and preconceptions, as well as the structural environment in which they work, and that these shape their perceptions of children and young people with disabilities and what they, as adults, think is possible (Loveridge & Meyer, 2010). Researchers' characteristics and positionality in relation to children, childhoods and disability will influence the direction and unfolding of the project (Cologon et al., 2019).

To overcome issues of power and individual perspectives, researchers can:

- recognize their own positionality and acknowledge power and responsibility differentials (Alderson & Goodey, 1996; Clavering & McLaughlin, 2010)
- appreciate diversity in the lives of children with disabilities and recognize that their personal opinions on certain topics may relate to their own experiences as children and as citizens – rather than as children with disabilities
- treat children with disabilities as experts about their own lives, without presuming that impairments are problematic or the primary interest and focus of children with disabilities (Ajodhia-Andrews, 2016)
- acknowledge whatever truths emerge from the evidence generation process with regard to children with disabilities, and treat these as valid for those individuals (Lewis, 2002).
- To avoid manipulation or coercion and the misrepresentation of participant experience, researchers can:
 - avoid making assumptions about what specific groups of children with disabilities can or cannot do (UNICEF, 2013)
 - aim to access the views of children with disabilities in an inclusive, authentic, fair and accurate way (Lewis, 2002)
 - listen carefully to the voices of children with disabilities and use methodologies that allow them to explain and explore their experiences and concerns
 - use open or non-leading questions to minimize the risk that some children may feel unduly obliged to respond in particular ways or about difficult issues (Bélanger & Connelly, 2007)
 - remind participants that they can refuse to answer any questions they are not comfortable with or do not understand – particularly useful for children with intellectual impairments (Karellou, 2017)

- ask children to confirm whether the summary of their responses reflects what they intended and whether it is an accurate representation of their views (respondent validation). This may involve clarifying and confirming meanings, using appropriate communication techniques (verbal/non-verbal) as necessary (Whyte, 2006)
- if possible, include children in some stages of analysis – e.g., considering and negotiating which experiences and stories to include in the research, and eliciting their views on emerging themes/interpretations, and the organization and presentation of each narrative
- in preparing summaries/reports, co-construct the narratives with children with disabilities to empower and amplify their voices (Hill, 2005; Ajodhia-Andrews, 2016).

3.1.2 Vulnerability and children with disabilities

Ethical issues: Assumption of vulnerability

Researchers have a responsibility to protect participants from various types of potential harm (Schenk & Williamson, 2005). Evidence generation processes must therefore be planned and implemented in ways that neither harm nor endanger those involved (Brus, 2015). There is an ethical tension between wanting to protect potential participants and protecting their right to participate in evidence generation (Loveridge & Meyer, 2010; Rumney et al., 2015). Stringent ethical frameworks are needed to protect people who may be unable to advocate for themselves without appropriate support (including children with communication and intellectual impairments, or profound and multiple disabilities). Children with psychosocial impairments are often regarded as particularly vulnerable, as are children with intellectual impairments, due to perceptions about their capacity to provide informed consent (*see section 3.2.1*) (Glantz, 1996; Yan & Munir, 2004; Iacono, 2006; Koelch & Fegert, 2010).

Inferring that all children with disabilities are automatically vulnerable can be problematic, however (Loveridge & Meyer, 2010; Flynn, 2019). Not all children with disabilities consider themselves vulnerable (Bradbury-Jones et al., 2018) – many are as able to understand situations and advocate for themselves as their peers without disabilities. Indeed, they may have greater insight into dealing with difficult situations, informed by their own life experiences.

The social model of disability frames disability as a relational concept and as a form of social oppression. Children's impairments only become disabling when they cannot participate in society on an equal basis with others because society does not meet their needs to allow them to do so.

Viewing children with disabilities as 'weak' or 'incompetent' can lead to a paternalistic need to shelter children and limit their involvement in activities and decisions that affect their lives. This protective view, fuelled by a discourse of innocence, has limited the participation of children in research to date, with adult voices often privileged as more coherent and credible (Tucker & Govender, 2016). But hearing children's own perspectives can reveal information that adults either do not know or choose not to share. This is not to suggest that children's views necessarily outweigh those of adults, but rather to highlight that their voices should be heard alongside those of adults.

Children with disabilities may be invisible to and isolated from their peers and local communities. To promote the participation in evidence generation of children with disabilities, it is first necessary to identify who they are and where they are (UNICEF, 2013). In addition, particular contextual factors

may result in children with disabilities being under-represented in or absent from evidence generation. For example, in humanitarian crises, children with disabilities may be excluded from evidence generation because data collection takes place in locations where children with disabilities simply do not go. In addition, children with disabilities may be deliberately hidden from view, due to issues associated with stigma.²

Although relevant evidence in the literature was limited, there may also be factors specifically related to undertaking research in the context of LMICs that lead to children with disabilities being absent or excluded from evidence generation. For example, children in LMICs may be more likely to be undocumented and at physical risk from armed conflict. Such settings tend to have fewer resources, and there are fewer professional services to mitigate the challenges that children face. While not focused on children with disabilities specifically, evidence indicates that the emphasis placed on concerns regarding harm to children differs across international contexts. Researchers from LMICs report that their capacity to include children's views in research was restricted by concerns related to children's safety and potential distress when undertaking the evidence generation; to the possibility that participating in research could make children vulnerable to discrimination/retaliation. In contrast, researchers from HICs reported being restricted by overly protective ethical review processes, and consent, gatekeeper or access issues (Graham et al., 2013).

By definition, nearly all impairments are permanent, although changes in their nature, severity or impact on function may occur over time. Some children may have rarer conditions, however, that can make them more identifiable or more prone to being researched.

The chronic nature of most impairments may also lead to over-enrolment of 'well-known' children with disabilities in evidence generation activities (Rumney et al., 2015). These children then become 'the usual suspects', who are over-researched and may experience research fatigue. This is a challenge as, in accordance with the ethical principle of justice, no single group should shoulder a disproportionate burden of participation in evidence generation (NDA, 2009; Rumney et al., 2015). This is particularly important if there is little prospect of the participants experiencing a direct benefit from the research. Children potentially at particular risk of over-enrolment may include those with low-incidence disabilities, including deaf children of deaf parents; those with dual impairments (e.g. deafness and blindness) (Iacono, 2006); and those who are easily accessible by virtue of their geographical location and/or access to and engagement with services and service providers.

Mitigation strategies

There are a number of ways to identify children with disabilities and reach out to them to increase their opportunities to participate in evidence generation. These include:

- using censuses and other sources of data on children with disabilities, including analyses and surveys
- engaging with local organizations of people with disabilities, which often have information about families in which there is a child with a disability

² For further information, see: Office of the United Nations High Commissioner for Human Rights. (2017). Protecting the rights of the child in humanitarian situations, Submission by UNICEF to the OHCHR report. <https://www.ohchr.org/Documents/Issues/Children/HumanitarianSituations/UNICEF.pdf>

- engaging with children’s organizations – many can provide a point of access to children with disabilities, as well as ideas on how to work effectively with the children
- undertaking community mapping, which may be most effective if led by adults or children with to overcome issues of stigma
- engaging with community-based services and institutions such as places of worship, health care facilities, child protection committees, various types of schools, and residential homes or institutions, all of which should have knowledge of children with disabilities in the local community
- using information and communication technology (ICT) and social media platforms to reach out to adolescents and young people with disabilities (UNICEF, 2013).³

Researchers need to prevent the over-enrolment of particular children with disabilities in evidence generation (Rumney et al., 2015). They should check whether certain individuals have been involved in multiple studies or projects and whether enrolling in another one is in the child’s best interests. Organizations of people with disabilities and parents’ groups can assist with building an understanding of the number and type of evidence generation projects planned or in progress and who is involved as a participant (Iacono, 2006).

While it is critical that children with disabilities are able to participate in evidence generation, researchers must aim to strike a balance between participant autonomy and protection. The risks of including children with disabilities in research that affects their lives must be balanced with the potential positive outcomes and interventions that could result from the evidence generation (Burke, 2005; Kyegombe et al., 2019). To this end, the following should be considered in the preparation stages of any project:

- Adoption of the principles of the social model of disability, which recognizes that it is the attitudes and structures of society that are disabling – i.e., having an impairment does not necessarily mean that one has a disability. The vulnerability of children with disabilities is therefore caused not by an impairment, but by society’s responses and structures (attitudinal, environmental and communication barriers) in relation to the impairment.
- Project managers should ensure that all members from the evidence generation team are cautious with and aware of the language they use to describe children (including to recruit participants). Children described by others as having disabilities may be unaware of their impairments or may not self-identify in this way. Giving children a label they did not know they had may make concrete an identity that they had not recognized about themselves.

³ For specific guidance on including children with disabilities in humanitarian action, see: United Nations Children’s Fund. (2017). *Including children with disabilities in humanitarian action: General guidance*. UNICEF, New York. http://training.unicef.org/disability/emergencies/downloads/UNICEF_General_Guidance_English.pdf

The case study below explains how children with disabilities may be excluded from certain studies due to ethical concerns about the potential impact of exploring a sensitive topic directly with them. In some instances, there may be legitimate concerns to avoid re-traumatizing children.

Case study

In 2011, Save the Children and Handicap International produced a joint report on sexual violence against children with disabilities. However, for ethical and methodological reasons it was decided that the primary source of evidence would be the memories of adult survivors of sexual violence that occurred when they were children, rather than of children themselves (Ellery, Lansdowne & Csáky 2011).

Involving children with disabilities as part of the evidence generation team can reduce power imbalances between researchers and participants. Asking intrusive questions to elicit highly sensitive and personal details of negative experiences has the potential to change the group dynamics, however, as does the need to notify parents of a disclosure of abuse, which may have to be done in the name of safeguarding. Such shifts in power may make for less equal relations between adults and children or between children with and without disabilities (Brady & Franklin, 2019).

3.1.3 Child protection and safeguarding considerations*Ethical issues*

Child protection and safeguarding considerations are a key ethical concern when preparing to undertake evidence generation activities with children with disabilities (Wilson et al., 2015). While focusing exclusively on vulnerability can prevent the active participation of these children entirely, it must be recognized that researchers have a duty of care to these cohorts if and when they do take part. To this end, consideration should be given to potential protection and safeguarding issues that may arise and steps taken to mitigate potential harm to participants. These steps should include planning and providing for requisite protections and responses to such issues should they arise.

Mitigation strategies

During the preparation phase, researchers must establish protection protocols to ensure that child protection and safeguarding are adequately addressed in evidence generation. These protocols should consider the increased risks faced by children with disabilities during evidence generation activities and also the extra barriers they may face in obtaining help should they need it. Protocols should include:

- plans to discuss with children with disabilities and their families issues around safety and child protection, how confidentiality will be respected, and the types of circumstances in which confidentiality would be breached for children's safety
- building safeguarding principles and procedures into the evidence generation process (Jenkin et al., 2015; Jenkin et al., 2020)

- conducting police and reference checks for researchers (where possible)
- training all staff involved in the evidence generation in engaging with children and their communities on relevant child protection/safeguarding policies and processes, including specific content to address disability and additional risks for children with disabilities
- training that reflects and explores specific risk factors and mitigation strategies (including risks related to gender and to specific impairments)
- explicit recognition of the increased risks for children with disabilities, and the creation of processes for regular reflection and review of child protection/safeguarding guidelines by the team during projects and programmes
- creating clear rules about behaviour (e.g., there should always be more than one adult present during data collection with a child or children) (Wilson et al., 2015). There should be clear guidance and agreement about which adults provide personal assistance to children (e.g., helping children to move, use the toilet or communicate)
- preparation of a clear step-by-step plan outlining the team's roles and responsibilities, and detailing what support may be provided to children, and by whom, if needed
- discussion of support options for children such as linking children to other people in their community who can provide support (including formal child protection services) (Jenkin et al., 2015; Jenkin et al., 2020)
- identification of a referral network of existing state, civil society and community resources (Schenk & Williamson, 2005). If possible, it should be determined if such resources are disability-inclusive and, where this is not the case, what support the resources might need (e.g., sign language interpreter) to provide appropriate services to individual children with disabilities
- the inclusion of supervision processes to ensure that those engaging with children and communities are abiding by ethical research principles and processes, and using reflective practice to continually improve their engagement with children
- establishing a transparent and accessible formal complaints procedure to allow children to make a complaint in confidence and in their preferred communication format. Information about the complaints procedure should be provided in relevant languages and accessible formats (UNICEF, 2013). Ultimately, researchers should remain sensitive to participant concerns throughout the evidence generation (Jenkin et al., 2020).

3.1.4 Mandatory reporting of safeguarding breaches

Ethical issues

When undertaking evidence generation with children with disabilities, evidence generation team members must be prepared for the possibility that they will discover information that requires action to be taken and referral pathways to be followed (Schenk & Williamson, 2005). Gaps in referral pathways may present an ethical challenge for the researcher – knowing that a child needs assistance or support, but also that the child may be unable to access such help. In addition, while researchers

have a duty to respect confidentiality, they also have a duty to protect children (Kyegombe et al., 2019).

Discretionary referrals allow the participant to choose whether or not to go through with the proposed strategies. Children with communication difficulties may need appropriate accommodations (e.g., picture/symbol formats) to express what they want to happen next (Kyegombe et al., 2019).

Mandatory referrals may be required for certain types of disclosures (e.g., an account of sexual violence) and for disclosures concerning certain children (e.g., those under the age of consent for consensual sex) or certain professionals (e.g., doctors, nurses, teachers, social workers, researchers). Disclosing information about abuse may increase the risk of further abuse of the participant by the perpetrator(s) (Kyegombe et al., 2019). In addition, mandatory reporting requirements may conflict with the researcher's role in data collection. There is always a possibility that evidence generation procedures may cause participants and/or parents/caregivers distress, and researchers must have a protocol in place to manage this risk (Bennett et al., 2016).

Where mandatory reporting exists, explicit reflection is required on the potential impacts on participants and their families, and on whether the potential harms could possibly outweigh the benefits of proceeding with the evidence generation project.

Mitigation strategies

Researchers should be aware that referrals may become necessary as a direct or indirect consequence of research. The question of referrals is all the more crucial when the issues discussed are sensitive, or when the evidence generation activities may affect the relational, emotional or economic stability of a household or community. The benefits and risks of the activity must be considered, and the short- and long-term well-being and protection of the participants must inform any decision. Researchers should be able to rapidly inform individuals identified as potentially in need of assistance about available services and existing referral mechanisms (Brus, 2015).

In cases where reporting is mandatory for researchers, considered responses to participant disclosures are required rather than blanket reassurances of confidentiality (Lewis & Porter, 2004). If confidentiality is selected over taking action to protect a participant, further harm may come to the participant, which is unethical.

At the outset, consideration must be given to cases where a child may require support following completion of the broader study. In these contexts careful consideration given to the longevity of the referral network linkages. Partners must be chosen with care to ensure that they will address the needs of the individual children requiring assistance. Poorly handled referrals have the potential to cause harm (Kyegombe et al., 2019). Where possible, participants should be free to decide whether or not to follow the advice given and to accept the help offered (Brus, 2015).

If what is disclosed by participants requires referral to child protection services, such services must be both accessible to and inclusive of children with disabilities. Researchers must consider that children with disabilities may face physical, geographical, social, economic and institutional barriers to accessing these services (Kyegombe et al., 2019). If there are gaps in the provision of formal services, researchers should work in partnership with local organizations of people with disabilities and/or community-based rehabilitation programmes to establish referral networks. If referral services

are non-existent or inaccessible, researchers will need to carefully consider whether proceeding with the evidence generation is ethical, weighing up the risks of *not* conducting the research if it has the potential to have a positive impact on children's lives (Kyegombe et al., 2019).

The terms of mandatory referrals must be agreed prior to evidence generation activities being undertaken. Where reporting is not mandatory for researchers, consideration should be given to protecting the safety and well-being of children who disclose abuse. This should be undertaken in collaboration with local service providers (Feinstein & O'Kane, 2008). Researchers should be trained to manage distress arising as a result of the evidence generation process and to signpost participants to sources of support (such as local mental health services) if necessary (Bennett et al., 2016).

When undertaking evidence generation activities with children with disabilities, researchers should:

- explicitly reflect on the process of mandatory reporting of abuse and means to embed it into the evidence generation project such that the privacy of the child is protected to the greatest degree possible and the child's safety ensured
- plan for the inclusion in protection protocols of a clear statement of the limits of privacy, if mandatory reporting is required
- develop referral pathways and include these in protection protocols
- ensure that all staff involved in the evidence generation receive training on local legal issues, regulations and guidelines surrounding physical, emotional and sexual abuse.

3.1.5 Researcher training and experience

Ethical issues

Children with disabilities are often excluded from evidence generation due to researchers lacking knowledge, clarity and confidence about how to approach and engage with children with diverse impairments (Ajodhia-Andrews, 2016). This is in part due to the impact of stereotypes relating to childhood or disability, as mentioned above. In LMICs, training for researchers in inclusive research methods and ethics may be limited or absent (Daley et al., 2013). When children with disabilities are included in evidence generation with insufficient preparation and expertise on the part of researchers, ethical standards may inadvertently be compromised (Wilson et al., 2015).

Mitigation strategies

To mitigate this challenge, evidence generation teams must be trained on how to:

- conduct good quality, ethical data collection with children with disabilities
- be sensitive to the needs of children with disabilities and effectively support and value their participation (UNICEF, 2013). Letting participants define their needs improves the quality of inclusive evidence generation (van der Heijden et al., 2019)
- address individual adaptation needs (NDA, 2009; Jenkin et al., 2020) and factor the child's requirements into planning. This may include considering if the child experiences fatigue, pain or

difficulties concentrating/remembering, or needs specific assistive devices, adapted environments or assistance; or if extra time is needed to develop trust and to learn how the child communicates

- adjust their expectations of the nature and extent of information it is possible to collect. For example, shorter and possibly more frequent data collection sessions – and allowing more time when necessary, reducing distractions, allowing for rest periods or the rescheduling of appointments – may be required, particularly if working with children with intellectual disabilities (Kelly, 2007; Jenkin et al., 2020)
- listen and communicate in the language/communication format (including sign language) used by participants or be assisted by with someone who has these skills. Non-verbal communication methods are particularly important for children with intellectual impairments or those using alternative/augmentative communication methods (Noyes, 2000; Cameron & Murphy, 2007; Kelly, 2007; Wilson et al., 2016; Kyegombe et al., 2019)
- be aware of issues associated with collecting data in specific settings where certain roles and behaviours are expected. For example, collecting data in schools can reinforce expectations about adult-child relations, and many children with disabilities may not attend school, so this environment and culture may be unfamiliar to them. Gathering data in a hospital or in a residential care institution can pose ethical dilemmas. Some children may be too unwell to participate, may feel awkward or may be unable to communicate in private without support, which may pose a challenge to maintaining participant confidentiality (Oulton, Wray et al., 2016)
- be flexible and optimistic and adopt an inclusive, respectful approach that recognizes children with disabilities as having important and interesting things to say (Jenkin et al., 2020)
- build trust between children, families and researchers by developing an open and shared understanding of the research design and processes (Jenkin et al., 2020).

Organizations of people with disabilities can provide insights to strengthen researcher knowledge and can help to guide evidence generation processes that involve children with disabilities and their families. Where possible, the evidence generation team should include people with disabilities as researchers or as evidence generation consultants to act in an advisory capacity (NDA, 2009; Jenkin et al., 2020). This will facilitate rapport and develop a deeper understanding, especially if the participants' background is very different from that of the principal researcher (van der Heijden et al., 2019).

Researchers can benefit from wider experience of working jointly with children and engaging them in accordance with their evolving capacities. Young people and adults with disabilities are often skilled trainers and facilitators themselves and can learn to be role models for younger children (UNICEF, 2013).

3.1.6 Choice of methodologies for data collection and participant selection

Ethical issues

Rigid or heavily standardized, prescriptive approaches to involving children with disabilities in evidence generation can restrict the type of information collected, the emergence of unusual and unexpected data, and the reporting of the complexity in children's unique lives (Alderson & Goodey, 1996). Using methods that are not adapted to the children's needs can frustrate, intimidate or disempower the participants, and so their use is potentially unethical in and of itself. Such approaches may be dictated by the researcher's own disciplinary allegiances and may fail to appropriately explore and reflect the children's realities for them. Overemphasizing one aspect of a child's responses (informed by the researcher's discipline) can privilege certain types of findings and lead to biased or confused conclusions. Such approaches can lead to problems being attributed to the child, resulting in the medicalization and pathologization of their differences, rather than an understanding of how disability is also created or reduced through social context and structures. Including children with disabilities in evidence generation without making the appropriate and necessary methodological provisions in data collection is potentially unethical (Wickenden & Kembhavi-Tam, 2014).

Mitigation strategies

To ensure that no child with a disability is excluded from potential evidence generation, creative and adapted methodologies can be used to collect data from them and to understand their experiences. Researchers should select evidence generation approaches that allow for a diverse range of participants with different impairments to be included and represented (NDA, 2009).

The method, length and intensity of participation may need to be adapted to suit the children's needs. Communication methods must also be inclusive of all participants. The use of respondent-led (semi-structured or unstructured) interviews can reduce the risk of bias from more prescribed methodologies (Alderson & Goodey, 1996). Participatory approaches such as focus groups with a range of play-based activities can work well. While the approach for particular individuals or groups must match their needs, some adaptations that may be considered include:

- use of large print materials (or large font on a screen) or audio recordings
- use of easy-to-read or picture/symbol-based materials
- facilitation of lip-reading, provision of written materials and/or use of sign language interpretation
- use of physically accessible venues with suitable supportive seating, room to move around, accessible toilets, adapted equipment, etc.
- provision of a breakout space or quiet room to which children can retreat if necessary.

Verifying the participants' level of understanding can help to overcome under- or overestimations of children's abilities or suitability for a specific study (Kyegombe et al., 2019). It is important to ask adults (parents, caregivers, siblings, teachers) who know the child well what the child can understand, how she/he communicates best and what adaptations/support would be necessary to enable participation. UNICEF offers guidance on how to communicate with children with disabilities.⁴

⁴ Ibid., pp. 83–85.

Inclusive approaches should be tailored to the individual to support children's different abilities. Such approaches may include:

- artistic and writing activities
- use of drawings/symbols or objects to aid the child's understanding or expression of ideas (although beware the overuse of drawing, which is not suitable for all) and storytelling/story games (including narrative approaches using visual support)
- use of photography (e.g., photovoice method) and video-making
- sign language, natural gestures and body language (including eye-pointing)
- computer-aided approaches (e.g., for drawing, writing, talking, picture selection) with access adaptations such as increased font size or special keyboards or controls.

Researchers should not assume, however, that alternative/augmentative communication methods (e.g., methods that use signs, symbols or photographs or which are technology-aided) will be enough to make the experience meaningful for all potential participants. The needs of individual participants must be assessed and responded to/provided for (Lewis & Porter, 2004).

3.2 Implementation

3.2.1 Consent

Ethical issues

The concepts of informed consent and assent are of vital importance to ethical evidence generation activities in general but are particularly pertinent to evidence generation with children with disabilities (Jenkin et al., 2017). For evidence generation involving children with disabilities to be conducted ethically, the children themselves must understand what they are being invited to do and want/agree to participate (assent) and either the children or their parents – or a responsible adult, depending on context – must approve or authorize their participation (consent) (Graham et al., 2013; Wilson et al., 2015; Jenkin et al., 2015). The age at which a person can independently give consent to participate varies according to national context (Bennett et al., 2016).

Using age as the sole threshold factor to determine whether consent can be independently given can be problematic, however (Oulton, Gibson et al., 2016). For example, the age of a child with disabilities, as is the case for the general child population, may be relatively meaningless in terms of conveying a sense of her/his comprehension and abilities. Judgements made in relation to capacity are more likely to be helpful, but such judgements should be framed in relation to the relevant guiding principles of the:

- Convention on the Rights of Persons with Disabilities – such as respect for individual autonomy, including the freedom to make one's own choices, and respect for the evolving capacities of children with disabilities
- Convention on the Rights of the Child – such as non-discrimination and the right of the child to be heard.

Requesting children's informed consent or assent can give them a sense of empowerment and acknowledges children's competence and decision-making abilities, thus signifying recognition of their agency and ownership throughout the evidence generation process (Ajodhia-Andrews, 2016).

It is debatable and individually variable whether children can have a full understanding of both a research study and their role within it. If they cannot fully understand the research, they cannot provide fully informed consent. Characteristics associated with children with intellectual impairments (a perceived lack of understanding/communication) may be regarded as barriers to informed consent and assent (Oulton, Gibson et al., 2016).

It is often assumed that children are unreliable research subjects. Consequently, they may be excluded from research, instead of the researcher exploring whether the relevant barriers lie in the way the evidence generation is conducted (Kelly et al., 2000). Widespread and internalized attitudes about the capacity of children with disabilities to make decisions may not only result in their exclusion from evidence generation, but can also deprive them of their basic rights. Assumptions that children with severe communication difficulties or learning impairments are unable to understand research protocols can lead to their exclusion. While children may be unable to demonstrate the necessary competencies to make independent decisions about research, they may be able to express their opinions about being involved. They may understand enough to exercise choice about whether or not to take part (Oulton, Gibson et al., 2016). Linking consent to rigid definitions of competence can inadvertently exclude children with disabilities (such as those with intellectual impairments) from the evidence generation agenda (Cocks, 2006). If sufficient safeguards are in place and children understand enough to participate safely with support, and know that they can opt out at any time, they may give assent through their demonstrated desire to join in and participate.

Informed consent must evolve beyond an understanding of childhood that is age-focused and must consider more than a single means of communication such as written or spoken language. Whether or not a child has a disability, individual capacities and a variety of communication strategies should be considered.

Unless the researcher is doing research on her/his own child, it is likely that someone will act as a gatekeeper – consenting to, or withholding, access to the child. In most cases, this will be the parent or caregiver (or responsible adult, depending on context). Someone else may, in turn, act as an indirect (secondary) gatekeeper (such as a head teacher). Depending on the focus of the evidence generation activity and on the child's situation, the gatekeeper could also be a health, legal and/or social service agency (Lewis, 2002).

Consent and privacy

The presence of an intermediary can limit equal participation by children with disabilities and limit the degree of confidentiality possible (van der Heijden et al., 2019). In some cases, parents under- or overestimate, or otherwise misrepresent, their child's abilities (Kelly, 2007). Generally speaking, however, parents and caregivers are likely to be the adults best placed to accurately understand their child's capacities and needs.

Researchers must obtain the trust and confidence of the adults who have responsibility for the children's welfare. The attitudes of parents and caregivers, advocates and educationalists are powerful in determining what can be researched and whose voices can contribute and be heard.

Over-concern among gatekeepers to protect the vulnerable can paradoxically be harmful because it can result in unwarranted exclusion (NDA, 2009). Denying access can be in the best interests of the child, but it may also be driven by other considerations such as cost, inconvenience, time limitations, staff resources, lack of skills, and even an unwillingness for the child to participate in any evidence generation activities of which the gatekeeper disapproves. Refusal may be based on the gatekeeper's concerns about being scrutinized and criticized (Loveridge & Meyer, 2010).

The caregivers of a child with disabilities may underestimate or misconstrue their child's abilities (Kyegombe et al., 2019). Whether operating with good or bad intentions, parents may interfere with or dismiss a child's view, obscuring the child's own voice (Oulton, Gibson et al., 2016). Third parties will have their own views about the value of the evidence generation activity and who should, or could, contribute to it. Such views can shape what is researched and whose voices are heard – in essence, acting as a gatekeeper by controlling access to the population. Parents may be more willing to take part in the evidence generation activity themselves than to let their child take part (Lewis & Porter, 2004). They may see representing their child as part of their role, not appreciating that the child's perspective is also important and may differ from their own.

Parents, caregivers or families members may wish to accompany their child during evidence generation activities, to counter risks of exploitation that stem from power imbalances between the researcher and the child. Also, parents may wish to influence how the child responds. Children have a right to privacy, however (*see sections 3.2.2 and 3.2.3*) (Jenkin et al., 2015). Children with disabilities are particularly at risk of the denial of privacy, especially if they are reliant on others for physical or communication support. NDA (2009) warns that use of coercion, manipulation or undue influence to secure others' participation in evidence generation is unethical and potentially harmful. Participation should always be chosen voluntarily by the individual, after she/he has been fully informed of the key aspects of the project (UNICEF, 2013; Jenkin et al., 2015; Kyegombe et al., 2019).

Issues of privacy and consent are particularly pertinent to evidence generation involving older children, as adolescents may wish to disclose information that is unknown to their parents and/or that they would not say in front of a parent. Also, young children may feel uncomfortable participating in evidence generation activities without the company of their parents. These requirements and concerns may be conflicting. A balance needs to be found by researchers, who must consider the concerns of parents while respecting the choices of children. For children with disabilities, signalling dissent may be more difficult than it is for other children. Consent, assent and dissent must be ongoing processes throughout the evidence generation process (NDA, 2009; Jenkin et al., 2015; Harden et al., 2016; Jenkin et al., 2020). Children should be able to cease involvement with the evidence generation activity at any stage (UNICEF, 2013).

Mitigation strategies

Consent and assent processes should be designed to be accessible for children with diverse impairments, and enough time must be allowed for them to make a decision before the actual data collection activities begin (Rumney et al., 2015; Wilson et al., 2015; Harden et al., 2016; Oulton, Gibson et al., 2016). If children are to be involved and included in the consent, assent and dissent processes, strategies built on trust between the researcher and participant must be devised to facilitate this (Scott et al., 2006). The researcher must remain constantly vigilant and sensitive to the responses of the child (Cocks, 2006).

Children with disabilities must be provided with:

- full, accessible, disability-inclusive and age-appropriate information about their potential contribution to an evidence generation activity and the expectations of them
- information about how the evidence generation activity will proceed and about its scope, purpose and potential impact
- sufficient time and support to enable individuals to make the decision to participate (or not), bearing in mind that children with disabilities have been shown to be more likely to acquiesce than other children and so are vulnerable to coercion (Lewis, 2002; Scott et al., 2006; Cameron & Murphy, 2007; NDA, 2009; Jenkin et al., 2015)
- information about the voluntary nature of the invitation and about the right to withdraw from the activity (Lewis, 2002).

This information must be provided in formats to match the children's cognitive, physical, sensory and communication competencies (UNICEF, 2013; Wickenden & Kembhavi-Tam, 2014). While some children may not understand consent/assent or the concept of research, most will be able to gain a basic appreciation of the activity and make informed decisions if relevant information is made available and accessible to them (Jenkin et al., 2015).

Explanations about the evidence generation activity should be clear, informative and engaging, and materials should opt for simplicity in both language and layout (Kelly et al., 2000; Jenkin et al., 2015; Jenkin et al., 2020). Consent, assent and dissent processes must be inclusive and accessible. Such approaches can be informed by the existing literature on inclusive communications for children with disabilities (Snelgrove, 2005; Scott et al., 2006; Cameron & Murphy, 2007; NDA, 2009; Jenkin et al., 2015; Oulton, Wray et al., 2016; Kyegombe et al., 2019; Jenkin et al., 2020).

The communication of consent, assent or dissent can be verbal or non-verbal (Graham et al., 2013). Children's facial expressions and body language can be valuable ways for researchers to ascertain assent or dissent. Respecting children's ability to indicate signs of interest and engagement in evidence generation requires ongoing attention to their modes of expression and to their behaviour. An explicit request to withdraw from evidence generation activities may not be very obvious, but researchers should be aware of verbal and behavioural signs that indicate when a child does not wish to continue. Behavioural indicators of dissent (Graham et al., 2013; Jenkin et al., 2015; Jenkin et al., 2020) may include:

- passivity
- lack of cooperation
- silence
- fussiness
- crying
- puckering of the mouth

- constantly looking towards the door
- lack of eye contact with the researcher
- signs of boredom (such as multiple yawns).

Verbal indicators of dissent (Graham et al., 2013) may include phrases such as:

- 'I don't know' (in response to direct and age-appropriate questions)
- 'I want to go to the toilet'
- 'I'm tired'
- 'When will I be done?'

Researchers must determine if it is likely that a potential participant will have trouble communicating a refusal (Burke, 2005). Researchers should be aware that children with physical impairments and very young children may be physically unable to move themselves out of situations that make them feel uncomfortable. Listening to children should be regarded as an active process of observation and interpretation that is not limited to the spoken word (Graham et al., 2013; Jenkin et al., 2020).

Other important considerations for mitigating ethical issues related to consent include the following:

- The decision not to consent to participation must be documented to allow researchers to reflect on the validity of their consent procedures (Cameron & Murphy, 2007).
- A child's assent must be an explicit, affirmative agreement to participate, not merely the absence of objection (Jenkin et al., 2015; Jenkin et al., 2020).
- Researchers may need to make a judgement on what has been consented to. For example, children and young people with disabilities may be able to consent to a researcher meeting with them, but not to the information about them being used in the research.
- Researchers should establish in advance the age at which a child is legally old enough to give consent in the location where the research is based (Brus, 2015).
- Researchers should be mindful, however, that age may not be an appropriate determinant of the ability to give consent (Oulton, Gibson et al., 2016). Judgements about capacity to consent/assent to participation should be framed by the principles of the Convention on the Rights of Persons with Disabilities (respect for individual autonomy and respect for the evolving capacities of children with disabilities) and the Convention on the Rights of the Child (non-discrimination and the right of the child to be heard).
- Adopting the social model of disability to frame the research allows researchers to understand how decisions made about the evidence generation process and choice of methods are crucial in avoiding potential barriers to inclusion. Children with disabilities can participate in research if given appropriate support. For example, the participation of children with learning impairments can be facilitated with the assistance of appropriate communication support (Oulton, Gibson et al., 2016).

- Consent processes should be accessible and, where possible, formally documented. A degree of flexibility may be required, with appropriate communication methods adopted according to the child's needs (for example, consent documentation may be written, recorded audially or on video as appropriate) (Dalton & McVilly, 2004; Kyegombe et al., 2019). If a witness is required, careful thought about who is suitable for this role may be necessary, as the behaviour of certain children may be unpredictable in the presence of an unfamiliar person (Snelgrove, 2005).

In accordance with a participatory rights agenda, in contexts where parental consent is required, children should also be engaged in an informed assent process (Lewis & Porter, 2004; Graham et al., 2013; Rumney et al., 2015; Kyegombe et al., 2019; Jenkin et al., 2020). The Convention on the Rights of Persons with Disabilities advocates for 'supported' decision-making (where individuals are supported to make decisions for themselves) as opposed to 'substituted' decision-making (where someone else makes the final decision and the individual concerned can either be involved or not). Supported processes give primacy to a person's will and preferences (Kyegombe et al., 2019); substituted processes may involve the person with a disability, but they do not deliver autonomy.

Whenever a proxy is used to represent a child during data collection, this should be documented and considered during analysis, as the data may differ from those which might have been collected directly from the child (Lewis, 2002; Kyegombe et al., 2019). To respect children's autonomy, the use of proxy informants for consent should be minimized (NDA, 2009; Graham et al., 2013).

If an adult is needed to give consent on behalf of a child, the researcher must make a judgement about whether or not the adult is deemed to be protecting the child's best interests appropriately (see *section 3.1.3*) (Morris, 2003).

Parents and caregivers can provide additional information to help the researcher to personalize and adapt interviews for each child and to avoid asking children inappropriate questions or using the wrong communication format with them (Jenkin et al., 2020). It is also important, however, to value the views of children and not be unduly influenced by the information provided by parents (Kelly, 2007). A communication partner/interpreter should be able to accurately interpret the child's communication and is ideally chosen by the child (Lewis, 2002; Kyegombe et al., 2019; Jenkin et al., 2020). This could be another child – for example, a sibling or close friend – if the role is clearly explained to her/him.

Consent processes should be treated as an ongoing, iterative conversation running throughout the evidence generation process (Rumney et al., 2015). Consent will need to be revisited regularly during the research in response to any changes that occur or additional data collection activities proposed (Lewis & Porter, 2004; Cameron & Murphy, 2007; Oulton, Gibson et al., 2016).

Children must be informed that they have a right to cease involvement with the evidence generation at any stage and may need practical support to enable them to express their desire to stop (Lewis & Porter, 2004; UNICEF, 2013). This is particularly significant for studies that involve repeated and prolonged involvement by children or young people (Oulton, Gibson et al., 2016). The explicit continuation of procedures to gain and periodically reacquire assent serves to affirm the corresponding right to withdraw at any point (Kelly et al., 2000; Lewis, 2002).

3.2.2 Confidentiality and anonymity

Ethical issues

Anonymity of participants, and processes for de-identifying data, are common ethical requirements in nearly all evidence generation projects (Wilson et al., 2015). Processes applied to anonymize data may, however, result in some views being excluded from research. For example, if one child in a sample group has particularly identifiable characteristics, a reference reflecting her/his perspective may be traceable back to that individual, which could be problematic (Lewis, 2002). Ensuring anonymity is a particular challenge when dealing with minority populations with rare and noticeable or prominent characteristics. It is sometimes possible to change some characteristics of participants to obscure their identity, in order that their data may be used to illustrate an important point, as long as this does not distort the interpretation of the data.

As well as individual characteristics (such as disability) that may lead to the identification of a participant, geographical factors may enable the location of the evidence generation activity to be identified (Lewis & Porter, 2004). Children who have rare disabilities may also be easy to identify if characteristics of their impairments are either directly or indirectly reported in the data. Researching innovative, high-profile programmes may also render participants identifiable (Loveridge & Meyer, 2010).

In some situations, children may ask to be identified, as they may be proud to have been involved in the research and want their information to be known and understood by others. This presents an ethical dilemma, as there is a tension between a child's right to decide that she/he wishes to be identified and ensuring that the child is not put at risk through identification. In choosing to be identifiable, participants may not have considered all of the potential consequences or may be anticipating particular findings (Haines, 2017). Some institutional ethics guidelines may prevent the identification of child participants; others may not.

Mitigation strategies

A dialogue is required between researcher, child and parents/guardians (or responsible adult) to explain to the child the risks and benefits of identification, both in the present and in the future (Jenkin et al., 2015; Jenkin et al., 2020).

Where a child requests to be identified, a compromise arrangement can sometime be arrived at. For example, children can be named in the report without attributing individual quotes or photographs to them, thus ensuring that it is not possible to identify who is who and who said what.

To address the challenge of anonymity in research, pseudonyms may be used. As part of the evidence generation process, children can be involved in developing their own pseudonym (Jenkin et al., 2020). It may be necessary to set aside time to teach participants about the concept of pseudonyms. This can be done in a pragmatic learning context involving elements of surprise, humour and competition (Snelgrove, 2005). An example of such a process to encourage the use of pseudonyms when working with children with intellectual disabilities is detailed below.

Case study: Teaching children with intellectual disabilities about pseudonyms through humour

“The children are sitting in a semicircle with myself and Mary, a teacher aide, who is wearing a blindfold so that she cannot see. I have two ‘grab bags’ containing boys’ and girls’ names, different to those of the children, written on check tickets. The children take turns to take a ticket from the bag, unfold the paper and read the names quietly. Tim helps those who have difficulty reading. Rosie unfolds her paper. She has drawn the name ‘Jane.’ When all the children have a name, they hold them up and I talk to them using their ‘different’ name. Then I ask Mary if she knows who Jane is. She says that she does not. The children find this a huge joke.” (Snelgrove, 2005, p. 317)

3.2.3 Privacy and security*Ethical issues*

Children also have a right to privacy. In research, this may involve participating without their parents or other people being present. When undertaking evidence generation activities in certain contexts, family members and sometimes neighbours may want or expect to join in. This may reflect not only a lack of physical space but also a sociocultural understanding of space as ‘collective’ rather than ‘individualized’, with the notion of privacy unfamiliar. In such circumstances, accessing private/individual experiences may be challenging (Jenkin et al., 2015).

Privacy is a concept that is understood in particular ways in the global North and may not necessarily apply similarly elsewhere. Privacy considerations will need to be carefully discussed and planned for in LMICs and used in a way that simultaneously respects local cultural and norms while recognising safety considerations and the potential for self censorship.

Privacy may be particularly pertinent if the evidence generation involves older children, who may wish to disclose information that is unknown to their parents or caregivers, but feel unable to do so in their presence. Children and young people with disabilities who are dependent on personal assistance may be especially sensitive about lack of privacy, because they are so reliant on others. They are likely to have strong views about how they like to be assisted and who they can trust. Privacy is also relevant to young children, who may feel uncomfortable participating in evidence generation activities and communicating their thoughts and ideas if their parents are *not* present. Confidentiality and privacy must be considered alongside potential safety concerns and respect for individual autonomy and choice (Jenkin et al., 2020).

Mitigation strategies

Mitigation strategies to address privacy concerns include:

- discussing the concept of privacy with family members who support children with disabilities (Jenkin et al., 2015), with explicit discussion of the impact of parents being present or not
- inviting children with disabilities to participate in evidence generation participation (with the consent of a parent/guardian where necessary) on the basis of either participating in private or with a family member, assistant or another child present. This choice should be respected throughout the evidence generation process

- in circumstances where parental consent is not required, observing the good practice of asking the young people for permission to contact their parents if needed. The young people should be given the choice whether to allow any parental contact during the evidence generation process (apart from in the event of an emergency). This approach signifies an awareness of power disparities between young people with disabilities and their parents, and between young people and researchers (Brady & Franklin, 2019).

A child may choose to participate in evidence generation activities without their parents or with other people present. According to Jenkin et al. (2015), while the right to privacy must be respected, the researcher must consider various factors before agreeing to the child's unaccompanied participation, including the:

- 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
- the nature of the information being sought.

Researchers must acknowledge that different results may emerge depending on whether children participate alone or with their parents. The possible consequences of this should be considered during analysis of the data (Jenkin et al., 2015).

3.3 Research communication and uptake

Ethical issues

Even when all data collection activities are complete there are still ethical issues to consider.

Evidence generation activities must do no harm, even after the study has ended (Kyegombe et al., 2019). Safeguarding risk assessment must ask what will happen when the project is over. Expectations must be managed and an exit strategy planned (Brady & Franklin, 2019). Children involved in evidence generation activities may have expectations of continued friendship with the researchers, and thus feel hurt or confused when participation in the evidence generation process ends. This can be particularly true of children with disabilities as they often have smaller social networks and friendship groups. Often, involvement in a project may be the first time that children's perspectives are sought and valued, and they may then not want the contact to end.

Researchers should take care to manage the expectations of children with disabilities involved in evidence generation activities, particularly young children or those with learning impairments. Researchers need to signal clearly to children how long the meetings will go on, when they will stop and what will happen next. Robust and detailed information and consent protocols must be used to manage and mitigate expectations and potentially unrealistic perceptions of beneficial outcomes or continued contact and involvement (*see section 3.2.1*) (Graham et al., 2013). Participants can be linked to self-advocacy groups or organizations of people with disabilities that may be able to provide ongoing support.

For evidence generation to be ethical, its benefits must be distributed justly. Researchers must consider how their research findings will be communicated and, ultimately, what impact they would like the findings to have (NDA, 2009).

When considering the impact of research on policy and on practice, consideration should also be given to the impact on those who have experienced being researchers, particularly those who belong to a marginalized group such as children with disabilities. Young researchers and participants may feel responsible/accountable for success/failure in terms of whether or not the research findings and recommendations are heeded or acknowledged as important (Brady & Franklin, 2019).

Further, explicit consideration should also be given to communication and feedback to mobile populations as triangulation and/or sharing findings with participants who move around geographically can be challenging. (Lewis, 2002).

Certain methodologies are accompanied by ethical dilemmas when it comes to research communication. For example, with photo-elicitation, communication is an essential part of the research, providing the opportunity to gather views about, reactions to and interpretations of the photographs, but anonymity and confidentiality can be difficult to navigate (Woolhouse, 2019). A particular challenge with regard to photographs is how they are used when the evidence generation process has concluded. Consent must be obtained on an ongoing basis (*see section 3.2.1*) and parameters for future usage require careful consideration.

Mitigation strategies

Communication activities must be an integral part of any evidence generation activity and not just an 'add-on' (Brady & Franklin, 2019). As with any research, evidence generation involving children with disabilities should include a research communication or uptake plan devised at the outset to help ensure the effective use of findings. Research uptake plans should consider that:

- children who participate in the evidence generation process must be able to validate and/or challenge the interpretation of the findings
- all participants should have the opportunity to access details of the outcomes of the study (Lewis, 2002; Brus, 2015; Bennett et al., 2016)
- children with disabilities should be given the opportunity to contribute to the research uptake plan, as they may have important ideas about the formats and media that should be used and with whom the information should be shared
- evidence should be communicated in inclusive and accessible formats (Oulton, Wray et al., 2016; Kyegombe et al., 2019). This should be done throughout the research cycle to build engagement and ownership with participants and relevant stakeholders
- research communication activities should take place at different levels (e.g., local, national, international) so that the findings can contribute to improving the lives of children with disabilities in varied settings (Kyegombe et al., 2019)

- the results and information may need to be ‘translated’ and reformatted according to the target audience. Different groups will have different understandings and potentially use different terminology (Brus, 2015)
- when publishing and communicating research, care must be taken not to report information that allows identification of either the location of evidence generation activities or individual participants, unless this has been explicitly agreed to by all (*see sections 3.2.2 and 3.2.3*)
- evaluation of the effectiveness and inclusivity of the approaches and methods used in evidence generation programmes should be collected in collaboration with children with disabilities themselves in appropriate ways (UNICEF, 2013)
- to ethically communicate evidence involving photographs or video, extra steps may need to be taken to anonymize it, such as turning the photographs or video into cartoons (Woolhouse, 2019).

4. CONCLUSION

To include children with disabilities in evidence generation activities is ethically desirable, yet it simultaneously raises many ethical dilemmas and uncertainties. Researchers must explicitly consider mitigation strategies to overcome these challenges and to ethically and respectfully involve children with disabilities in evidence generation activities. For meaningful participation, the individual capacities of each child involved must be considered at all stages of the research cycle, to ensure that processes are suitable for the diverse competencies, knowledge, interests, access, needs and contexts of all children involved.

APPENDIX 1: CHECKLIST OF THE KEY CHALLENGES AND MITIGATION STRATEGIES

Drawing on the literature reviewed in this working paper, the following checklist summarizes the key challenges and suggested mitigation strategies (there may be others) to consider to involve children with disabilities ethically and inclusively in research, evaluation or data collection processes.

Preparation phase	
Child protection	
Key challenge	Mitigation strategies
<p>If children with disabilities participate in evidence generation activities, they must be protected and kept safe, but their right to participate in evidence generation activities must also be protected.</p>	<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>Child 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"> ■ researcher police/reference checks ■ clear rules about behaviour (adult-child ratios and interactions – e.g., regarding solo working) ■ supervision of researchers ■ discussion of support options for children ■ researcher training in inclusive child protection/safeguarding policies and processes ■ a formal complaints procedure. <p>Children should be informed of their right to be protected from harm.</p> <p>Organizations should develop child safeguarding policies. These policies should directly inform individual protection /safeguarding protocols developed for evidence programmes.</p>
<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>	<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.</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.</p>

<p>Power imbalances between the (adult) researcher and the (child) participant can increase risks of disempowerment and vulnerability for children with disabilities.</p>	<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.</p>
<p>Protection protocols</p>	
<p>Key challenge</p>	<p>Mitigation strategies</p>
<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 protocol and referral pathways (both discretionary and mandatory) must be planned in advance, with input from local service providers (e.g., statutory service providers, non-governmental 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 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.</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.
<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 and/or community-based rehabilitation programmes.</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 their data. Older children and young people with disabilities can learn to be role models for younger children.</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 should be avoided. Even within the 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.</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 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
<p>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>	<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>

<p>Children with disabilities are under-represented in the evidence generation process.</p>	<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 ■ 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.
<p>Children with disabilities with particular characteristics can be over-enrolled in evidence generation activities (leading to research fatigue).</p>	<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.</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 evidence generation activities.</p>
<p>Restrictive or inflexible methodologies can be exclusionary and affect how a child with disabilities is portrayed.</p>	<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.</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.</p>	<p>When considering the privacy of a child with a disability, 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
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>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 perceptions of safety	
Key challenge	Mitigation strategies
Confidentiality must be maintained as far as possible, but it must never replace the need to protect children and ensure that they and their carers feel safe.	<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.</p>
Confidentiality/privacy may be understood differently in some families or contexts.	The concept of confidentiality must be discussed with family members who support children with disabilities. The reasons why protecting privacy may be important, even if the concept is unfamiliar, will require sensitive explanation.
Research communication and uptake	
Key challenge	Mitigation strategies
Evidence generation teams must consider how to communicate their research and 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 photo-based methods), masking techniques can be used to anonymize subjects (e.g., turning the photographs into cartoons).

APPENDIX 2: THE NATURE OF THE LITERATURE REVIEWED

	Study	Geographical location of focus	Disability/ impairment focus	Specific focus on ethics?	Child-focused?	Research type	Research design	Additional information
1	Ajodhia-Andrews (2016)	Canada	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	
2	Alderson and Goodey (1996)	United Kingdom	Physical, emotional and learning impairments	Yes	Yes	Primary	Observational	Does not specify an exact location, but a UK focus is inferred
3	Bélanger and Connelly (2007)	Canada	Socio-affective needs, literacy/numeracy difficulties, attention-deficit hyperactivity disorder (ADHD ⁵), psychosocial impairments, and behavioural problems	No	Yes	Primary	Observational	Impairment type is not specifically listed
4	Bennett et al. (2016)	United Kingdom	Neurological conditions and mental health impairments	No	Yes	Primary	Experimental	Study protocol
5	Bradbury-Jones et al. (2018)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	No	Yes	Secondary	Non-systematic literature review	Reviews papers from Canada, Finland, India, Papua New Guinea, South Africa, Sri Lanka, United Kingdom and United States
6	Brady and Franklin (2019)	United Kingdom	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	
7	Brus (2015)	Non-specific	Disability-focused, but does not focus on a specific impairment	Yes	No	Conceptual/theoretical	Guidance note	Guidance provided draws on field experience, reference documents and scientific articles
8	Burke (2005)	United Kingdom	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Quasi-experimental	
9	Cameron and Murphy (2007)	United Kingdom	Learning and communication impairments	No	No	Primary	Observational	Does not specify an exact location, but a UK focus is inferred
10	Child Protection Monitoring and Evaluation Reference Group (2012)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Secondary		
11	Clavering and McLaughlin (2010)	United Kingdom	Not disability-focused, but does include relevant information on children with disabilities	No	Yes	Secondary	Non-systematic literature review	
12	Cocks (2006)	United Kingdom	Learning impairments	Yes	Yes	Primary	Observational	
13	Cologon et al. (2019)	Non-specific	Disability-focused, but does not focus on a specific impairment	No	Yes	Conceptual/theoretical	Reflections on previous research	Authors are based in Australia

5 There is some debate as to whether ADHD is to be considered a disability.

	Study	Geographical location of focus	Disability/ impairment focus	Specific focus on ethics?	Child-focused?	Research type	Research design	Additional information
14	Daley et al. (2013)	Low- and middle-income countries (LMICs), with a particular focus on India	Autism spectrum disorders (ASD)	Yes	No	Conceptual/theoretical	Descriptive study	Draws on the experience of two organizations that have been involved in conducting and collaborating on ASD research in India
15	Dalton and McVilly (2004)	Non-specific	Intellectual impairments	Yes	No	Conceptual/theoretical	Position statement	
16	Ellery et al. (2011)	Burundi, Madagascar, Mozambique and United Republic of Tanzania (Zanzibar)	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	Also includes a global-level literature review
17	Feinstein and O'Kane (2008)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Conceptual/theoretical	Guidance note	
18	Flynn (2019)	Non-specific	Intellectual impairments	No	Yes	Conceptual/theoretical	Narrative review	Commentary draws out broad themes from existing literature
19	Glantz (1996)	Non-specific	Intellectual impairments	Yes	Yes	Conceptual/theoretical		Focuses on "mentally disabled children", although it is inferred to mean children with intellectual impairments
20	Graham et al. (2013)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Conceptual/theoretical	Guidance note	
21	Haines (2017)	United Kingdom	Intellectual impairments	Yes	No	Conceptual/theoretical		Draws on field experience of undertaking qualitative research with people with intellectual impairments
22	Harden et al. (2016)	Non-specific	Epilepsy	No	Yes	Secondary	Systematic review	
23	Hill (2005)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Conceptual/theoretical		
24	Iacono (2006)	Non-specific	Intellectual impairments	Yes	No	Conceptual/theoretical		
25	Jenkin et al. (2020)	Papua New Guinea and Vanuatu	Disability-focused, but does not focus on a specific impairment	Yes	Yes	Secondary	Non-systematic literature review	
26	Jenkin et al. (2017)	Papua New Guinea and Vanuatu	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	
27	Jenkin et al. (2015)	Papua New Guinea and Vanuatu	Disability-focused, but does not focus on a specific impairment	No	Yes	Conceptual/theoretical	Guidance note	The guidance draws on academic literature and the experiences of researchers
28	Karellou (2017)	Greece	Intellectual impairments	No	Yes	Primary	Observational	

	Study	Geographical location of focus	Disability/ impairment focus	Specific focus on ethics?	Child-focused?	Research type	Research design	Additional information
29	Kellett and Nind (2001)	United Kingdom	Learning impairments	Yes	No	Primary	Quasi-experimental	Does not specify an exact location, but a UK focus is inferred
30	Kelly (2007)	United Kingdom	Learning impairments	No	Yes	Conceptual/theoretical		Based on the author's previous research experience
31	Kelly et al. (2000)	United Kingdom	Learning impairments	No	Yes	Primary	Observational	
32	Koelch and Fegert (2010)	Non-specific	Mental health impairments	Yes	Yes	Secondary	Non-systematic literature review	
33	Kyegombe et al. (2019)	LMICs, with a particular focus on Uganda	Disability-focused, but does not focus on a specific impairment	Yes	Yes	Conceptual/theoretical	Guidance note	Guidance on how to conduct good quality, ethical and inclusive research on violence against children with disabilities
34	Lewis (2002)	Non-specific	Learning impairments	No	Yes	Conceptual/theoretical		
35	Lewis and Porter (2004)	Non-specific	Learning impairments	No	Yes	Secondary	Non-systematic literature review	
36	Loveridge and Meyer (2010)	Non-specific (partial focus on New Zealand)	Not disability-focused, but does include relevant information on children with disabilities	No	Yes	Secondary	Non-systematic literature review	
37	Morris (2003)	United Kingdom	Communication and/or cognitive impairments	No	Yes	Secondary	Non-systematic literature review	Draws on four research projects. Does not specify an exact location, but a UK focus is inferred
38	National Disability Authority (2009)	Ireland	Disability-focused, but does not focus on a specific impairment	Yes	No	Conceptual/theoretical	Guidance note	
39	Nicolaidis et al. (2015)	United States	Developmental disabilities	No	No	Primary	Observational	
40	Noyes (2000)	United Kingdom	Ventilator-dependent children	No	Yes	Primary	Observational	Not specifically focused on children with disabilities, but contains relevant sections
41	Oulton, Gibson et al. (2016)	United Kingdom	Not disability-focused, but does include relevant information on children with disabilities	No	Yes	Primary	Observational	
42	Oulton, Wray et al. (2016)	United Kingdom	Learning impairments	No	Yes	Primary	Quasi-experimental	
43	Richards et al. (2015)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Conceptual/theoretical		
44	Rumney et al. (2015)	Canada	Disability-focused, but does not focus on a specific impairment	Yes	Yes	Secondary	Non-systematic literature review	

	Study	Geographical location of focus	Disability/ impairment focus	Specific focus on ethics?	Child-focused?	Research type	Research design	Additional information
45	Schenk and Williamson (2005)	Non-specific	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Conceptual/theoretical	Guidance note	
46	Scott et al. (2006)	United Kingdom	Learning impairments	No	Yes	Primary	Observational	
47	Snelgrove (2005)	Australia	Intellectual impairments	No	Yes	Conceptual/theoretical		
48	Solyom and Moreno (2005)	United States	Psychiatric impairments	No	Yes	Conceptual/theoretical		
49	Tucker and Govender (2016)	South Africa	ADHD	Yes	Yes	Primary	Observational	
50	UNICEF (2013)	Non-specific	Disability-focused, but does not focus on a specific impairment	No	Yes	Conceptual/theoretical	Guidance note	
51	van der Heijden et al. (2019)	South Africa	Disability-focused, but does not focus on a specific impairment	Yes	No	Primary	Observational	Informed by a case study
52	Whyte (2006)	Ireland	Disability-focused, but does not focus on a specific impairment	No	Yes	Secondary	Non-systematic literature review	
53	Wickenden and Kembhavi-Tam (2014)	LMICs, with a particular focus on India and Sri Lanka	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	
55	Wilson et al. (2016)	Papua New Guinea and Vanuatu	Disability-focused, but does not focus on a specific impairment	No	Yes	Primary	Observational	
54	Wilson et al. (2015)	Papua New Guinea and Vanuatu	Disability-focused, but does not focus on a specific impairment	Yes	Yes	Primary	Observational	
56	Woolhouse (2019)	United Kingdom	Not disability-focused, but does include relevant information on children with disabilities	Yes	Yes	Primary	Observational	
57	Yan and Munir (2004)	Non-specific	Developmental disabilities	Yes	Yes	Conceptual/theoretical		

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