

FINAL REPORT

Beyond Barriers: Advancing Research for Children with Disabilities

Insights, Challenges, and Opportunities from the UNICEF
Global Webinar Series on Inclusive Research with Children
with Disabilities

June 2025

Executive summary

This report synthesises key insights, persistent challenges, and significant opportunities identified during the UNICEF global webinar series, *Beyond Barriers: Advancing Research for Children with Disabilities*, held in April–May 2025—led by UNICEF Innocenti in partnership with the Altamont Group to tackle a critical challenge: how can we embed inclusion in the very process of research?

In recent years, global momentum has grown around strengthening disability-inclusive research, yet significant gaps remain in how children with (and without) disabilities are meaningfully engaged in the generation and use of research. Children with disabilities remain among the most under-researched and underserved populations, particularly in low- and middle-income countries and humanitarian settings and this is a critical issue—especially because they face persistent barriers to accessing education, healthcare, and social inclusion despite children with disabilities representing around 10 per cent of the global child population. The exclusion they experience in daily life must not be mirrored in how research is conceived, conducted, and used.

Rather than exploring research findings alone, the series focused squarely on methodologies, ethics, infrastructure, and partnerships that shape who gets to ask questions, who gets heard, and who benefits. It sought to move inclusion from the margins to the mainstream—establishing it not as an optional feature but as the foundation of credible, ethical, and transformative research. It focused on how inclusive research can and should be done.

Purpose and scope

The core aim of the series was to explore priority themes emerging from the *Global Research Agenda for Children with Disabilities* and generate actionable guidance—by convening experts to confront the structural, methodological, and ethical barriers that impede meaningful inclusion of children with disabilities in research.

Five thematic topics—early identification, violence prevention, assistive technology, children in emergencies, and ethical participation—were used as entry points to explore broader systemic issues. Each session addressed *how* research is planned, implemented, and governed, rather than only *what* is studied. Across the series, expert speakers brought lived experience and field-level knowledge to interrogate:

- What does it mean to design research that includes children with diverse disabilities and communication needs?
- How can we move beyond extractive approaches to participatory, child- and caregiver-led methodologies?
- What ethical frameworks are needed, particularly in low-resource or emergency settings?
- What are the funding and institutional shifts required to sustain inclusive practice?

It was emphasized in the opening session, “Participatory action research should include children with disabilities, families, and local communities — as co-researchers, not just informants.”

Key insights

If there is one overarching message emerging, it is this: inclusion is not a research outcome, but a principle of research design— it must be its foundation. Achieving it requires deliberate, coordinated change across multiple levels of the research ecosystem—from ethical review boards, advisory group composition, funding instruments, community partnerships and inclusive dissemination strategies.

The report challenges the misconception that inclusion is too difficult or too complex. Key insights from the series underscore that meaningful co-creation with children with disabilities is possible when adults build an enabling environment by including:

- Researchers skilled in accessible and ethical engagement with children.
- Caregivers and families who support trust, communication, and inclusion in research.
- OPDs and youth-led groups who scaffold agency and leadership.
- Flexible, child-friendly, and impairment-sensitive research methods.

This is not about tokenism or idealism. It's about interdependence—the collective act of building systems where children's voices carry real weight. Box 1 summarizes a number of common, perceived barriers to inclusive research identified throughout the series, along with opportunities to strengthen.

Moreover, participation without power is not real participation. The report warns against 'performative' inclusion: co-creation must involve children in shaping questions, tools, and interpretations—and must return findings in accessible formats. Children must be empowered to say, when things are working, "This reflects me" or when they feel otherwise, "this misses something important."

Ethical practice must evolve to foster protection *through* participation and moving beyond protection *through* participation. This necessitates dynamic assent, child-centred consent, and continuous, trust-based relationships. Crucially, inclusive research systems must:

- **Shift power towards OPDs, families, and communities** through long-term investment in participatory research
- **Embed OPDs in research governance** and accountability structures (e.g. research advisory groups)
- **Build capacity in the Global South** to lead evidence generation.
- **Remove structural and systemic barriers:** Strengthen ethical oversight, ensure accessible methods, and secure sustained funding for participatory research.
- **Innovate accessible and inclusive methods:** Embed creative tools like child-led interviews and digital storytelling to engage children with diverse needs.
- **The role of researchers, funders, and governments:** Inclusion requires coordinated efforts and accountability at every level—from inclusive funding mechanisms to institutionalized OPD participation in national research systems.

Box 1. Common inclusive research barriers and opportunities

Barriers

Exclusion of children with disabilities from study design and data collection

Lack of disaggregated data and weak national data systems

Limited disability expertise among researchers and enumerators

Ethical concerns about participation, especially for children with complex support needs

Overreliance on clinical or impairment-focused models

Short-term project cycles and donor pressure for rapid results

Insufficient partnerships with OPDs and communities

Research tools and methods not adapted to emergencies or low-resource settings

Research outputs not accessible or shared with participants

Opportunities

Engage children directly through inclusive, adapted, and participatory methods; co-create tools with children and caregivers, through OPDs

Use standardized tools (e.g. UNICEF Child Functioning Module) and build in disability-disaggregated data into research planning and budgets

Provide targeted training on inclusive methodologies, disability rights and safeguarding

Embed ethics as a continuous process; develop child-friendly consent/assent processes and work with caregivers as facilitators

Apply social and rights-based frameworks to examine barriers to inclusion and agency (CRPD compliance)

Advocate for multi-year, flexible funding to support longitudinal and context-responsive research

Strengthen collaboration with OPDs and local organizations as co-researchers and knowledge holders

Use remote and mobile technologies, accessible formats, and low-cost participatory approaches suited to context

Accessible formats are not expensive, so share findings back in accessible, visual, and local formats; include communities in dissemination strategies

Actionable recommendations

The report concludes with tailored, actionable recommendations to embed inclusive research as the norm, underscoring that these are not just technical but political, aiming to shift power and ownership toward children with disabilities and their representative organisations. To make research inclusive and impactful it should follow the six *core principles of inclusive research*, that were developed through the webinar series, not least the core principle that research must be co-created with children facilitated and supported by OPDs.

Core principles of inclusive research

1. Co-create from the beginning

Involve children, caregivers, OPDs, government agencies, and local providers in shaping research priorities, methodologies, and ethics protocols. Early engagement builds relevance, trust, and impact, including on research project advisory boards

2. Align funding with participation

Donors and funders support and work with NGOs, OPDs, and researchers to define shared standards for inclusive budgeting, ethical safeguards, and sustainability. Participatory research cannot be sustained on short-term or discretionary funding.

3. Bridge policy and evidence

Policymakers and researchers should create feedback loops that connect frontline data with system-wide change. NGOs and OPDs can play a vital role in translating findings for local uptake and national influence.

4. Develop shared ethical frameworks

Ethical boards, research institutions, and implementing partners should collaborate to define context-appropriate safeguarding, assent, and accountability mechanisms, especially in emergency or low-resource settings.

5. Recognize OPDs as bridges and brokers

OPDs are essential connectors across all stakeholder groups. They can facilitate community trust, represent lived experience in policymaking, support accessible dissemination, and evaluate research impact.

6. Promote inclusive research ecosystems

Academic institutions, research consultancies, and local partners each bring unique strengths. Building equitable partnerships among them, grounded in ethical rigor and mutual learning, enhances quality, accountability, and relevance across sectors

Building further on the webinar discussions several stakeholder-focussed recommendations and actions are presented, including:

- **Researchers:** should co-design research with representative organisations of children with disabilities (OPDs) to facilitate age-appropriate child engagement; integrate accessibility from the outset; are urged to use participatory and creative methods like drawing or storytelling; plan for accessibility in budgets as a standard element; and treat ethics as an ongoing relational process.
- **Funders** are called upon to invest in long-term, multi-year research and systems, not just pilots, and to mandate accessibility, appropriate participation, and safeguarding in budgets from the outset. They should also strengthen OPD leadership through capacity investment and co-granting model.
- **NGOs and implementers** are recommended to include building inclusive monitoring and evaluation (M&E) systems, training field staff on inclusive data collection, and involving caregivers and OPDs in interpreting findings and documenting innovative practices.
- **Policymakers** are advised to institutionalize OPD participation in national research governance, harmonize disability indicators using tools like the Washington Group Questions, and ensure that inclusive evidence informs national planning. Advocacy work is needed at multiple levels, including targeting donors and national governments

These recommendations are not only technical but political, aiming to shift power and ownership toward children with disabilities and their representative organizations.

The call to action

Disability-inclusive research is not a niche concern, it is a requirement for credible, rights-based, and impactful policies and accountability. When children with disabilities are co-creators of knowledge, research becomes more relevant, ethical, and transformative.

To shift the research paradigm, we must embed inclusion as the norm—not as an exception, not as an afterthought. This means rethinking funding, ethics, partnerships, and accountability. It means designing research from the onset that reflects the lived realities of children with disabilities—and equips policymakers and service providers with evidence that drives equitable change.

The research process must mirror the equity and dignity we seek to promote.

“Inclusion is not an outcome of research—it is the method, the measure, and the meaning.”

Dr. Gavin Wood
UNICEF Innocenti

Contents

Executive summary.....	2
Purpose and scope	2
Key insights.....	2
Actionable recommendations	4
The call to action	6
Contents.....	7
List of Tables	9
List of Figures	9
Introduction	10
Background and objectives.....	10
Overview of the webinar series	11
Description of the series, format and timeline.....	11
Audience and intended use.....	11
Thematic discussions: Building an inclusive research agenda for children with disabilities	13
Introduction.....	13
Webinar 1. Early identification and intervention for children with disabilities.....	14
Webinar 2. Preventing and protecting children with disabilities from all forms of violence and abuse.....	15
Webinar 3. Access to assistive technology in low-resource settings	15
Webinar 4. Children with disabilities in emergencies.....	17
Webinar 5. Ethical involvement of children with disabilities.....	18
Cross-cutting insights	19
Ethical inclusion and safeguarding	19
Gatekeeping and power imbalances	20
Stigma and societal attitudes	21
Methodological and data gaps	21
Structural and policy barriers	22
Financial and resource constraints	23
Participation, co-creation, and inclusion	24
Innovation and adaptation	25
Conclusion: from exclusion to co-creation and participation	26
Actionable insights.....	27
Conclusion: Advancing the agenda for inclusive research	31
Annex A. Webinar readout: Early identification and intervention for children with disabilities	35
Framing and Relevance.....	35
State of the art	36

Challenges in generating knowledge	37
Engaging children with disabilities in research	38
Recommendations.....	39
Annex B. Webinar readout: Preventing and protecting children with disabilities from all forms of violence and abuse	40
Framing and relevance	40
State of the art	41
Challenges in generating knowledge	43
Engaging children with disabilities in research.....	44
Recommendations.....	45
Annex C. Webinar readout: Access to assistive technology in low-resource settings	46
Framing and relevance	46
State of the art	47
Challenges in generating knowledge	48
Engaging children with disabilities in research.....	49
Recommendations.....	51
Annex D. Webinar readout: Children with disabilities in emergencies	53
Framing and relevance	53
State of the art	54
Challenges in generating knowledge	55
Engaging children with disabilities in research.....	56
Recommendations.....	58
Annex E. Webinar readout: Ethical involvement of children with disabilities in research	60
Framing and relevance	60
State of the art	60
Challenges in generating knowledge	61
Engaging children with disabilities in research.....	63
Recommendations.....	65
Annex F. Speaker and moderator list	67
Annex G. Full poll results (all themes).....	68
Annex H. Reference List	72
Annex I. Links to YouTube Videos.....	75

List of Tables

Table 1: Theme Overview	11
Table 2: YouTube Video Links	75

List of Figures

Figure 1: Barriers and opportunities to research discussed during Webinar 1	14
Figure 2: Barriers and opportunities to research discussed during Webinar 2	15
Figure 3: Barriers and opportunities to research discussed during Webinar 3	16
Figure 4: Barriers and opportunities to research discussed during Webinar 4	17
Figure 5: Barriers and opportunities to research discussed during Webinar 5	18
Figure 6: Cross-cutting insights	19
Figure 7: Principles of inclusive research	28
Figure 8: Priority dimensions underpinning future research directions.....	32
Figure 9: Recommendations for Webinar 1	39
Figure 10: Recommendations for Webinar 2	45
Figure 11: Recommendations for Webinar 3	51
Figure 12: Recommendations for Webinar 4	58
Figure 13: Recommendations for Webinar 5	65
Figure 14: Speaker and moderator list.....	67

Introduction

Background and objectives

In recent years, global momentum has grown around strengthening disability-inclusive research, yet significant gaps remain in how children with disabilities are meaningfully engaged in the generation and use of evidence—they remain among the most under-researched and underserved populations, particularly in low- and middle-income countries and humanitarian settings. This is a critical issue, especially because they face persistent barriers to accessing education, healthcare, and social inclusion despite children with disabilities representing around 10% of the global child population (UNICEF, 2021).

The Global Research Agenda for Children with Disabilities published by UNICEF Innocenti (UNICEF Office of Research – Innocenti (2025) identifies an urgent need for context-specific, participatory research to inform inclusive policy development and improving service delivery. In support of this agenda, UNICEF Innocenti in collaboration with Altamont Group, convened a webinar series in April–May 2025 titled *Beyond Barriers: Advancing Research for Children with Disabilities*.

The series covered five key topics:

1. Early identification and intervention
2. Protection from violence and abuse
3. Access to assistive technology
4. Children with disabilities in emergencies
5. Ethical involvement of children with disabilities in research

The series concluded with a validation workshop, 23 May 2025.

The webinar series aimed to operationalize the Research Agenda by exploring how to translate its inclusive priorities into practice. Grounded in participatory principles, the series provided a platform for experts, practitioners, and contributors with lived experience to critically examine how research can become more ethical, inclusive, and action oriented. While many initiatives aspire to be inclusive, children with disabilities, especially those with complex communication needs, living in humanitarian settings, or from under-resourced communities—continue to be excluded from the research cycle.

Discussions across the webinars highlighted that current practices often reinforce, rather than challenge, the marginalisation of children with disabilities. Key themes included the need to adapt consent processes, embrace participatory methods, and intentionally include children with diverse communication needs from the outset.

Overview of the webinar series

Description of the series, format and timeline

The *Beyond Barriers: Advancing Research for Children with Disabilities* was a five-part virtual webinar series designed to strengthen inclusive research practices by addressing structural, methodological, and ethical barriers that continue to exclude children with disabilities from evidence generation. Each 120-minute session was delivered online with full accessibility features, including International Sign, closed captioning, and speaker preparation guidance to support inclusive participation and accessibility.

Each webinar featured presentations from subject-matter experts, moderated panel discussions, and interactive audience engagement via live polls and Q&A segments. The series moved beyond research findings alone to examine how research is done—highlighting barriers to inclusion at each stage of the research cycle, from design and data collection to implementation and dissemination. Discussions emphasized practical solutions and included insights from researchers working in complex and under-resourced settings.

Each webinar generated actionable recommendations to inform more inclusive and impactful research practices with children with disabilities. The series concluded with a validation workshop on 23 May 2025 that brought together webinar speakers and key stakeholders to review and verify the findings presented in a draft version of this report, ensuring the report accurately reflects shared insights and priorities for advancing disability-inclusive research.

Table 1: Theme Overview

Webinar #	Date	Theme
1	22Apr2025	Early identification and intervention for children with disabilities
2	24Apr2025	Preventing and protecting children with disabilities from all forms of violence and abuse
3	30Apr2025	Access to assistive technology in low-resource settings
4	02May2025	Children with disabilities in emergencies
5	06May2025	Ethical involvement of children with disabilities in research

Audience and intended use

This report summarizes the discussions and content of a series of expert-led webinars aligned with the UNICEF-led Global Research Agenda for Children with Disabilities and is aimed at the same diverse stakeholders who helped shape that agenda.

Box 3: Audience and report aims

Audience

- Researchers designing and implementing inclusive and ethical studies
- Policymakers and technical advisors embedding evidence into national and global strategies
- Donors and foundations supporting sustainable, impactful, inclusive research
- Organizations of persons with disabilities (OPDs) as research partners and inclusion advocates
- NGOs and implementing agencies integrating research into programming and service delivery

Aims

- Provide practical insights for conducting inclusive, ethical, and participatory research
- Highlight persistent barriers to disability-inclusive research design, implementation and uptake and propose ways to address them
- Foster collaboration across sectors, including researchers, OPDs, donors, implementers and people with real-life experiences of disability
- Support evidence-informed programming and policymaking that actively involves children with disabilities
- Encourage long-term investment in inclusive research systems and capacity
- Contribute to the development of a global network committed to advancing disability-inclusive research and practice.

Thematic discussions: Building an inclusive research agenda for children with disabilities

Introduction

This chapter presents a synthesis of the five webinar themes held as part of the *Beyond Barriers* series. Each section includes a brief framing of the topic, a summary of insights from expert speakers and audience dialogue, and an analysis of challenges and opportunities for strengthening inclusive research. Across all sessions, speakers emphasized that while inclusive intent is growing, children with disabilities—particularly those with complex communication needs, in low-resource or humanitarian contexts—remain under-represented and underserved in the evidence base. Discussions revealed practical approaches to closing these gaps, with a focus on equity, participation, ethics, and system-level reform. Where participants identified specific research gaps, these are noted as opportunities for future inquiry, however, this was not the purpose of the webinars (for gaps and research priorities see: the [Global Research Agenda for Children with Disabilities 2025](#), related [Research Prioritization Exercise](#), and [EGMs](#)).

More comprehensive webinar readouts can be found in Annexes A to E.

Box 4: Recap of the Global Research Agenda for Children with Disabilities

Launched at the Global Disability Summit in Berlin, April 2025, the *Global Research Agenda for Children with Disabilities* sets out priority areas to close critical evidence gaps and drive inclusive, rights-based research. Developed through a participatory process with over 400 global experts and stakeholders—including children and youth with disabilities—it calls for mainstreaming of disability in all research about children, inclusive research methods, and investment in scalable solutions.

The Agenda promotes a twin-track approach: integrating disability inclusion across all research on children, while addressing issues specific to children with disabilities—such as early intervention, assistive technology, protection from violence, inclusive education, and stigma reduction.

Building on this, the *Beyond Barriers* webinar series explored how research processes themselves can be more inclusive. Through five accessible, expert-led sessions, the series examined ethical, structural, and methodological barriers—generating practical recommendations and highlighting ways to strengthen participation, equity, and impact. Together, the agenda and series offer a roadmap for transforming research for all children.

<https://www.unicef.org/innocenti/reports/global-research-agenda-children-disabilities>

Webinar 1. Early identification and intervention for children with disabilities

This webinar explored research approaches to early identification, referral, follow-up, and early childhood intervention (ECI)—recognised as distinct but connected stages within a broader support continuum. Acknowledging that definitions of ECI and early identification vary across countries, the session took an inclusive view, while drawing on ECI frameworks to guide reflection. Through expert presentations and audience dialogue, speakers examined the dual role of early identification: to detect developmental delays and to act as a gateway to ongoing support services.

Speakers noted that many screening tools lack accessibility and cultural relevance, and that children and caregivers are often excluded from research design. The webinar also addressed the limitations of current research systems, pointing to fragmented service pathways, inconsistent definitions, and methodological gaps that undermine both quality and impact. Contributors called for research that is co-produced with families and caregivers, grounded in local realities, and responsive to the complex and often siloed environments in which early identification and intervention take place. The discussion underscored the need to centre community perspectives, strengthen inclusive research tools, and embed ethical practices across the entire research process.

Figure 1: Barriers and opportunities to research discussed during Webinar 1: Early identification and intervention for children with disabilities

Barriers to Inclusive Research	Opportunities for strengthening research processes	Opportunities for research include
<p>Lack of documented screening and referral pathways across health, education, and child protection sectors impedes research design.</p> <p>Incompatible definitions across sectors and countries.</p> <p>Poorly coordinated data systems limit ability to track longitudinal outcomes or compare across countries.</p> <p>Terminology and definitions for “screening” and “early intervention” vary widely, undermining comparability.</p> <p>Limited caregiver engagement in research development reduces contextual validity.</p>	<p>Conduct systems mapping and contextual analysis to understand how identification and referrals function in practice across different settings.</p> <p>Engage caregivers and front-line workers in co-developing research tools to reflect real-world processes.</p> <p>Develop shared terminology, definitions and common indicators .</p> <p>Pilot mixed-methods approaches that combine qualitative experience with quantitative data.</p>	<p>Mapping national screening and referral pathways.</p> <p>Evaluating low-cost, community-led screening, referral and intervention approaches to EII.</p> <p>Investigating caregiver experiences and barriers to accessing early identification and ECI services.</p>

See [Annex A](#) for a more detailed readout of the webinar on early identification and intervention for children with disabilities.

Webinar 2. Preventing and protecting children with disabilities from all forms of violence and abuse

This webinar focused on the urgent need to expand research on violence against children with disabilities—while also making research more ethical, participatory, and inclusive. Speakers, including practitioners and academics, shared evidence and field insights revealing how violence remains under-researched due to persistent ethical concerns, stigma, inaccessible methods, and a lack of disaggregated data. Speakers discussed how children with disabilities are often invisible within national protection systems that are designed not to include them and, thus, overlooked in research, despite their heightened risk of abuse and neglect. Current large-scale surveys often omit disability disaggregation or exclude children with intellectual or psychosocial disabilities. Research must reflect their lived experience not as a risk, but as a right. Drawing on audience questions and moderated exchange, speakers emphasized that disability inclusion must be built into broader institutional and national safeguarding frameworks and to engage representative organisations to support the co-design of research with children and youth with disabilities. The conversation pointed to both gaps in knowledge and practical strategies for safely involving children more directly in defining, detecting, and addressing violence in their lives.

Figure 2: Barriers and opportunities to research discussed during Webinar 2: Preventing and protecting children with disabilities from all forms of violence and abuse

Barriers to Inclusive Research	Opportunities for strengthening research processes	Research Priorities include
<p>Ethical and safeguarding concerns are often cited as barriers to including children with disabilities—especially in violence-related studies—but these are no more complex than other ethical issues and must be addressed to prevent exclusion.</p> <p>Limited disability disaggregation in surveys restricts analysis of risks and experiences; in small samples, this is sometimes deliberate to protect participant privacy.</p> <p>Assumptions about children’s ability to consent or disclose can discourage participatory approaches.</p> <p>Children with intellectual or psychosocial disabilities are often underrepresented in prevalence and prevention studies.</p> <p>Stigma, fear of institutionalisation, and communication barriers prevent disclosure, especially for children with complex needs—leading to serious underreporting.</p>	<p>Embed safeguarding protocols from the start, including accessible referral plans and child-sensitive disclosure mechanisms.</p> <p>Use adapted tools (e.g. vignettes, visual aids) to support communication and safety.</p> <p>Include children with disabilities through caregivers and OPDs in formative research stages to design ethically sound methodologies.</p> <p>Apply a twin-track research approach—mainstreaming disability inclusion in all research about children while also conducting targeted research on specific issues pertaining to children with disabilities.</p>	<p>Documenting how violence is both a driver and a consequence of family separation for children with disabilities.</p> <p>Investigating barriers to disclosure an reporting, including stigma, inaccessible reporting systems, and caregiver control.</p> <p>Expanding data on prevalence and protective factors, particularly disaggregated by disability type (and gender).</p>

See [Annex B](#) for a more detailed readout of the webinar on preventing and protecting children with disabilities from all forms of violence and abuse.

Webinar 3. Access to assistive technology in low-resource settings

This webinar focused on shifting the research lens from products to people. In this webinar speakers explored how research on assistive technology (AT) must shift from pilot studies and product-driven focused research toward inclusive, user-led approaches that reflect children’s lived realities. Presentations drew attention to the systemic barriers that undermine

research—such as weak integration of AT into education and health systems, poor user fit and limited follow-up or usability data. Contributors described how research has tended to prioritise device innovation over adoption, access, and long-term use.

During the discussion and Q&A, speakers and attendees highlighted the lack of contextual adaptation and the frequent exclusion of children with disabilities from research on the tools meant to support them. The conversation included examples from Ethiopia, India, and Kenya, where pilots have shown promise and underscored the need for interdisciplinary collaboration, community-based approaches, and participatory research models that value children and caregivers as experts in their own environments.

Figure 3: Barriers and opportunities to research discussed during Webinar 3: Access to assistive technology in low-resource settings

Barriers to Inclusive Research	Opportunities for strengthening research processes	Research Priorities include
<p>Research is concentrated in engineering and product development fields, not in education, health, or social inclusion disciplines, i.e. led primarily by technical rather than social sectors</p> <p>Minimal engagement with AT users (children and families) in study design undermines relevance.</p> <p>Short-term pilots often lack evaluation beyond initial uptake, limiting understanding of long-term use, abandonment, support needs or impact in relation to the demands of the growing child.</p> <p>Small, fragmented studies with weak methodological rigour limit generalizability.</p>	<p>Prioritize user-centered and participatory research, involving children and caregivers in defining success.</p> <p>Invest in longitudinal studies to assess adoption, abandonment, and real-life usage of AT over time.</p> <p>Develop mixed-methods approaches that combine usability testing with social and contextual inquiry.</p> <p>Build interdisciplinary research partnerships that bridge engineering with education, disability studies, and child development.</p>	<p>Generating evidence on what works across diverse impairment types and contexts.</p> <p>Evaluating user-centered design and service delivery models.</p> <p>Understanding barriers to adoption of AT in home, school, and community settings.</p>

See [Annex C](#) for a more detailed readout of the webinar on access to assistive technology in low-resource settings.

Webinar 4. Children with disabilities in emergencies

This webinar tackled the acute exclusion of children with disabilities from research conducted in humanitarian and emergency contexts. Speakers brought forward examples from conflict zones, displacement settings, and area impacted by natural hazards, to illustrate how these children are routinely excluded from assessments, monitoring, and evaluations. Despite progress in data systems, few studies intentionally included children with disabilities—and even fewer adapted tools or methods to ensure inclusion.

Speakers shared both personal field experiences and technical insights into the practical and ethical factors that shape research in crisis situations—including remote access and security. Moderated discussion and audience contributions highlighted adaptive research methods that are making inclusion more feasible, such as mobile data collection, remote interviews, flexible consent approaches, and participatory methods. However, it was also clear from the exchange that many research studies still lack the know-how, capacity, and tools to make inclusive research the norm. Speakers called for greater investment in inclusive methodologies, partnerships with OPDs, and the ethical integration of disability into the humanitarian research agenda.

Figure 4: Barriers and opportunities to research discussed during Webinar 4: Children with disabilities in emergencies

Barriers to Inclusive Research	Opportunities for strengthening research processes	Emerging innovations include
<p>Security risks, displacement, and access hinder data collection and research processes.</p> <p>Ethics review boards often lack frameworks for disability-inclusive research in emergencies.</p> <p>Disability inclusion is rarely embedded in humanitarian research agendas or funding priorities.</p> <p>Grey literature and local research can be excluded from evidence synthesis due to perceived lower quality.</p>	<p>Partner with local OPDs and researchers to enable remote or proxy data collection in fragile settings.</p> <p>Advocate for ethics boards to include expertise on disability and humanitarian contexts.</p> <p>Develop and validate flexible, rapid, and accessible methodologies tailored for emergencies and make existing tools more disability inclusive.</p> <p>Incorporate grey literature into all research, including evidence synthesis, e.g. systematic reviews, using clear quality-control standards for included primary studies.</p> <p>Incorporate participatory action research where appropriate.</p>	<p>Community-led, participatory research approaches that include children.</p> <p>Remote data collection, when appropriate, using tools adapted for accessibility and inclusion.</p> <p>Partnerships with organizations of persons with disabilities (OPDs) for recruitment, design, and interpretation.</p> <p>Investment in localized capacity, inclusive methodologies, and ethical guidance tailored to emergency settings.</p>

See [Annex D](#) for a more detailed readout of the webinar on children with disabilities in emergencies

Webinar 5. Ethical involvement of children with disabilities

This final webinar focused on ethics—reframing it as a relationship, not a checklist; not as a procedural requirement, but as a commitment to inclusive, respectful, and participatory research requiring trust, transparency, and continuous reflection. Drawing on examples from diverse contexts, speakers challenged prevailing assumptions that children with disabilities cannot give informed assent or participate meaningfully that too often leads to the exclusion of children with disabilities from research. Speakers shared practical models for inclusive consent and assent, using tools such as storytelling, images, and supported communication.

During the discussion and audience Q&A, the conversation turned toward the structural and attitudinal barriers within ethics review systems and research institutions themselves. The group emphasized that ethical inclusion is not optional, it is foundational. Researchers must proactively design for accessibility, respect lived experience as legitimate evidence, and engage children and caregivers as co-researchers, not just subjects. The webinar closed with a shared call to embed ethics as an ongoing relationship grounded in trust and shared accountability.

Figure 5: Barriers and opportunities to research discussed during Webinar 5: Ethical involvement of children with disabilities

Barriers to Inclusive Research	Opportunities for strengthening research processes	Good practice includes
<p>Persistent assumptions that children with disabilities, especially those with complex communication needs—cannot meaningfully participate in research.</p> <p>Gatekeeping by caregivers, researchers, or ethics committees is critical, but it can also lead to over-protection and exclusion of children with disabilities from study populations.</p> <p>Inaccessible or inappropriate ethics tools and methods reduce the ability to obtain valid consent or assent.</p> <p>Limited researcher training on disability-inclusive, ethical research methods and how to ensure standards are upheld throughout the project lifecycle.</p>	<p>Shift from only seeing ethics as a one-off review-board process, e.g. at the proposal stage, to ethical reflection that is continuous throughout the research lifecycle.</p> <p>Invest in researcher capacity to use supported communication, visual tools, and flexible consent/assent models.</p> <p>Involve caregivers and trusted adults not as proxies, but as enablers of children’s participation when safe, necessary and appropriate.</p> <p>Embed children and young people with disabilities as co-designers and advisors in research governance.</p>	<p>Planning for inclusion from the outset of research design.</p> <p>Using accessible communication tools, visual aids, and supported decision-making approaches.</p> <p>Recognizing and resourcing caregiver involvement while upholding children’s autonomy and voice.</p>

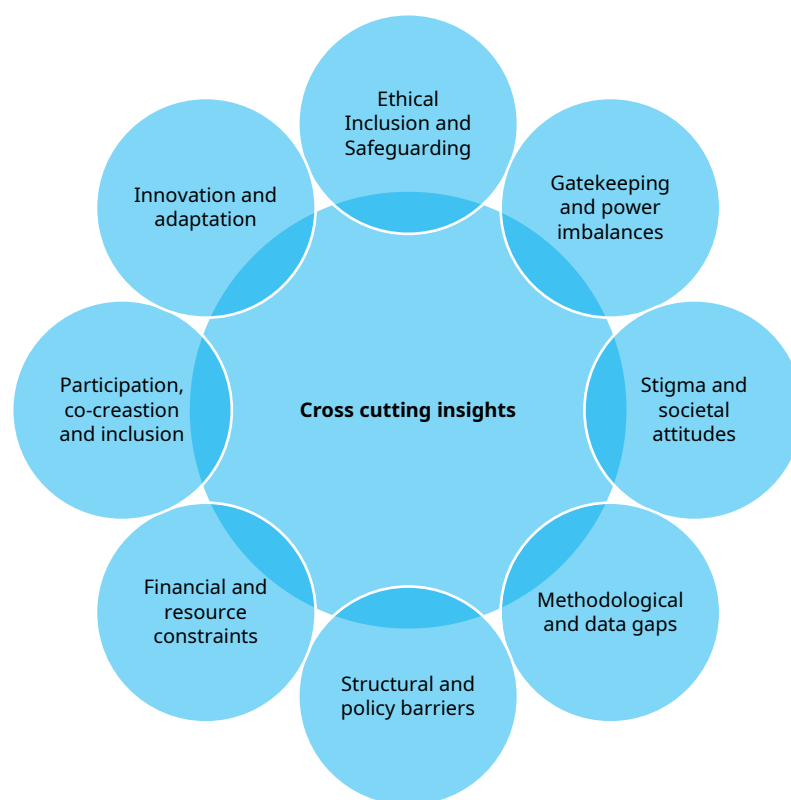
See [Annex E](#) for a more detailed readout of the webinar on ethical involvement of children with disabilities in research

Cross-cutting insights

Across all webinars in the *Beyond Barriers* series, speakers identified recurring challenges that continue to limit how research involving children with disabilities is designed, conducted and used. These issues were not confined to a single topic—they emerged across discussions on early identification, violence prevention, assistive technology, humanitarian settings, and ethical research practices.

This section brings together where inclusive research often gets stuck: in the systems, assumptions, and practices that fail to account for diversity and reinforce exclusion. But it also points to how researchers, funders, and practitioners are finding ways to move forward—adapting methods, challenging norms, and creating more inclusive, ethical, and effective research approaches. What follows is a shared map of the research barriers that persist—and the strategies that are helping to dismantle them.

Figure 6: Cross-cutting insights



Ethical inclusion and safeguarding

Speakers emphasized that ethical inclusion is not a secondary consideration—it is a foundational obligation for all research about children with disabilities, especially those with cognitive or communication support needs, who are often routinely excluded from research participation due to inappropriate (inaccessible) consent and assent protocols, inaccessible research tools, or incorrect assumptions about capacities of children with disabilities. These exclusions often reflect structural issues within research systems and ethics frameworks that have not been designed with diversity in mind.

Throughout the webinar series, there was broad agreement that consent, and assent must be understood as dynamic, relational processes—i.e. not only seeing ethics as a one-off review-board process, but also to embed ethical reflections and protocols throughout the research lifecycle. Speakers shared a range of inclusive practices—such as modified consent scripts, image-based tools, and the use of behavioural or non-verbal cues to support active and periodically repeated

assent—that allows children to agree actively to participate meaningfully and safely in research studies, including the possibility to opt out at any stage.

Several speakers observed that well-intentioned ethical safeguards can unintentionally create barriers when not tailored to individual needs. For example, rigid institutional review processes may prevent researchers from adapting consent materials or engaging children with high support needs, even when appropriate safeguards are in place.

The webinar also challenged the assumption that some children are “too difficult” to include in research, arguing that exclusion based on impairment or communication style constitutes an ethical failure. Speakers emphasized the importance of engaging gatekeepers—i.e. caregivers, professionals, and ethics boards—as allies in inclusion by equipping them to *support* rather than *limit* safe, appropriate participation.

Inclusive research requires preparation—not just invitation. Ethical frameworks must be designed to protect rights and enable participation simultaneously—not trade one off against the other. Children with disabilities should be protected by no less stringent ethical standards than others. However, the tools, processes and methods used to uphold these standards should be adapted to support different forms of engagement. And committees must be trained and skilled to support these adaptations without lowering standards. When ethical protocols are adapted in this way, they can help to reduce harm, widen participation, build trust, and ensure that children with disabilities can contribute fully and safely to research that affects their lives.

“Ethics is not just a box that you tick at the beginning—it’s a thread that you carry through every conversation and every adjustment.”

Dr. Tracey Smythe
(06 May 2025, Webinar)

Gatekeeping and power imbalances

Briefly introduced above, parents, caregivers, teachers, clinicians, ethics boards, organizations of persons with disabilities (OPDs)—collectively known as gatekeepers—hold significant influence over whether children with disabilities participate in research. Often acting from concern or caution, their decisions can inadvertently limit children’s agency and visibility.

Speakers across the series described the complex and often under-acknowledged role of gatekeepers in shaping whether and how children with disabilities are involved in research, excluded from research opportunities or having their participation heavily filtered by adults’ assumptions about vulnerability, risk, or competence.

In discussions on violence prevention and humanitarian response, gatekeeping by institutions, caregivers, and OPDs was identified as a key barrier—particularly in contexts of trauma, stigma, or instability. In early identification work, building trust with families was described as essential to enabling inclusive research. Trust was repeatedly emphasized as a condition for participation, not simply a by-product of it.

Several speakers encouraged researchers to consider the critical role of gatekeepers as essential partners in inclusive research. They play a key role in requiring, supporting, and identifying opportunities for safe, ethical and meaningful inclusion during the research design phases. This means engaging them early, clearly explaining the objectives and safeguards of the study, and equipping them with the tools and confidence to support children’s involvement. When adults are included as allies—not just permission-givers and potential barriers—they can play a powerful role in enabling children’s voices to be heard and respected.

The webinar on ethical involvement reinforced the idea that gatekeepers can enable or restrict participation depending on how they are engaged and supported. Gatekeeping is not inherently harmful—but when it is unexamined, it can limit children’s agency and deny them opportunities to shape the knowledge that affects their lives.

“Whoever the gatekeepers are, it’s about making sure they feel part of the process and that they understand and feel safe about the children that are going to be involved.”

Dr. Mary Wickenden
(06 May 2025, Webinar)

Stigma and societal attitudes

Stigma surrounding disability distorts every phase of the research process—from who is invited to participate to how results are interpreted.

Speakers noted that stigma operates at every level of the research process—from how children are recruited to how results are interpreted. Stigma shapes assumptions about who is “capable” of participating, whether families will feel safe disclosing sensitive information, and whether certain topics—like violence or exclusion—are even investigated in the first place.

In many cases, children with disabilities are hidden from view, especially in crisis contexts. Families may worry that research participation will expose them to community judgment or reinforce discriminatory labels. In humanitarian settings, this invisibility can be especially acute, as families may feel they must shield children due to perceived social risk or a belief that services won’t accommodate their needs. As one speaker shared:

“In some communities, children with disabilities are hidden during crises—they’re not just forgotten, they’re actively erased from the public eye.”

Dr. Israel Balogun
(02 May 2025, Webinar)

At the same time, researchers may avoid including children with higher support needs because of uncertainty about methods or fear of ethical missteps. This can lead to exclusion by default—driven not by ill intent, but by unchallenged assumptions or a lack of preparation to engage with complexity.

Speakers called for deliberate strategies to counter stigma in research: using inclusive and empowering language, involving communities in research design, and ensuring that research outputs reflect the value and dignity of all children—regardless of impairment or context. They also encouraged researchers to reflect on how stigma may influence not only participant selection but also the interpretation and dissemination of findings, calling for more participatory approaches that confront exclusionary narratives and shift the framing of disability in both policy and practice.

Methodological and data gaps

In many countries, children with disabilities are largely absent from programme and data systems, making them invisible not only in service delivery but also in the evidence base that guides it. Many commonly used research tools and methods (surveys, forms, interview techniques, etc.) are not designed with their needs in mind. Children who use non-verbal communication, or need sensory supports, or process information differently are often excluded simply because the research tools don’t work for them—or because researchers don’t know how to adapt them to make them accessible to all children. Even when children with disabilities are included, the methods used are not always tested or adjusted to make sure they work well for different impairment types.

Speakers pointed out that in many countries, disability data is still not broken down (disaggregated) in useful ways. Where disability is recorded, it is often done in a very basic way—simply noting whether a child has a disability or not—without showing what kind of disability they have (e.g. not using the Child Functioning Module – but not only), how it affects their abilities, or what kind of support they might need. That kind of data tells us little about the real experiences of children with disabilities.

One clear entry point for strengthening data systems raised during the webinars was the potential to improve case management and frontline service systems. These systems—used in areas like social work, education, and child protection—already collect data about children in contact with services. Yet disability status is often missing, inconsistently recorded, or framed in ways that reinforce stigma. For example, a child’s disability might only be noted as a reason for separation from family care, without further detail about type, support needs, or interventions provided. This represents a missed opportunity to both tailor services and generate practical, inclusive evidence. Strengthening routine data collection within such systems—by standardising definitions, including functional assessments, and supporting ethical use—could significantly improve both practice and policymaking.

In emergencies, the challenges are even greater. Crises can disrupt systems, limit access to ethical review processes, and make it harder to use tools that are already limited in their ability to include all children.

One example came from the discussion on violence prevention research:

“Only three out of 160 school-based violence prevention studies included children with disabilities in their analysis—and none of them adapted their interventions to include them meaningfully.”

Emily Eldred
(referring to a Systematic Review: Eldred et al., 2025)

Speakers also noted that some research measure what’s easy, not what’s important. For example, in assistive technology research, data systems often count how many devices are distributed—but not whether they’re used, whether they meet the child’s needs, or whether they help children be more included in school or their community. Important things like social inclusion, dignity, and emotional wellbeing are often left out because they are harder to measure.

Several contributors emphasized that many of the tools and methods used in research assume that participants can speak, write, or sit through standard interviews. This excludes children with complex communication needs or cognitive impairments. These oversights have far-reaching implications—not just for current research, but for emerging technologies as well. As one speaker noted, tools like artificial intelligence can inadvertently deepen exclusion:

“There’s a whole raft of challenges around ethics and exclusion. Most AI algorithms are built on existing datasets. And if children with disabilities aren’t there in the first place, they’re not going to be in those AI data sets.”

Prof. Maria Kett
(02 May 2025, Webinar)

To move forward, speakers called for much greater investment in data collection and analysis tools that work for more children. These include participatory approaches such as drawing, mapping, storytelling, peer interviews, and mobile-based data collection. They also stressed the importance of image-based consent, simplified language, and flexible ways of giving assent. These kinds of tools not only improve accuracy—they help make sure that research reflects what matters to children and families, and not just what’s easy for researchers to count.

Structural and policy barriers

Despite progress on global disability rights frameworks, several systemic barriers emerged as significant obstacles to conducting inclusive research. These include fragmented service delivery systems, limited coordination between ministries, insufficient investment in national research infrastructure, and weak regulatory mechanisms that fail to enforce inclusive policies.

Across the webinars on early identification and intervention, violence prevention, assistive technology, and children with disabilities in emergencies, speakers described how even when national strategies reference inclusion, they often lack clear implementation mechanisms, funding lines, or accountability structures. This disconnect between aspiration and execution makes it difficult to embed inclusive research into program cycles or decision-making frameworks.

In the discussion on assistive technology, speakers noted that policies might mention the need for inclusive education or disability access, yet provision remains siloed across ministries of health, education, and ICT. As a result, data systems are not shared, service models are not integrated, and research remains disconnected from practice.

Early identification and intervention (EII) were highlighted as an area where policy limitations directly affect research visibility. Without integrated developmental monitoring or national child disability registries, researchers struggle to identify participants or follow up over time. Dr. Wickenden pointed out that many children—particularly in LMICs—never access formal assessments or structured support services. Rolling out basic skills and tools to families and frontline workers was emphasized as a pragmatic way to expand reach and inclusion.

Dr. Toby Long also emphasized the need to better bridge the gap between research and practice:

“We have often kept all our services in a more siloed environment, and we now know how important it is to integrate services and supports throughout multiple systems.”

Dr. Toby Long
(22 April 2025, Webinar)

Speakers discussing protection and emergencies emphasized that even strong inclusive education policies are undermined when safeguards, data-sharing protocols, and intersectoral coordination are missing. Emergencies only heighten these risks. Displacement, conflict, and institutional breakdown further fracture already-weak systems—yet they may also offer opportunities to rebuild with inclusion in mind, if evidence is mobilized and policy tools are responsive.

Financial and resource constraints

Limited and inflexible funding remains one of the most persistent and widespread barriers to conducting inclusive research (any research). It affects not only what is studied, but who is included, how the research is carried out, and whether the findings are usable by the people who need them most—or whether research is funded at all.

When budgets are tight, participatory and inclusive methods are often the first to be deprioritized. Tools such as visual aids, alternative communication formats, transport stipends, and caregiver support may be seen as additional or non-essential, especially in short-term projects or emergency settings. Yet these practices are essential to ensure ethical inclusion, high-quality participation, and research that reflects diverse realities.

“We were supposed to screen 60,000 children, but because of funding, they asked us to stop. By the time we screened 10,000 students, we realized that about 4,000 of them really need AT—different types, varieties... I felt bad because it was an ethical dilemma for me.”

Dr. Israel Balogun
(30 April 2025, Webinar)

Speakers across the series noted that many inclusive adaptations are not expensive—they simply take a little more time and require early planning and commitment. Incorporating flexible consent processes, ensuring materials are readable and culturally relevant, or budgeting for caregiver involvement can often be done at minimal extra cost. The issue is not always a lack of money, but a lack of recognition and prioritization in research design and proposal development—and tight deadlines. Without intentional budgeting for accessibility and participation, inclusive research remains aspirational.

To move forward, inclusive design must be embedded from the start—reflected in funding calls, proposal guidelines, and review criteria. Donors and institutions should not only support but require that research proposals demonstrate how they will ensure accessibility, participation, and ethical inclusion. These should not be optional enhancements, but core eligibility requirements. Proposals should clearly outline how accommodations such as communication support, caregiver engagement, accessible formats, and inclusive consent processes will be incorporated. Without this level of expectation and accountability, inclusive research will continue to rely on goodwill rather than being recognised as a non-negotiable standard of quality.

Participation, co-creation, and inclusion

Too often, children with disabilities are invited to participate only at the point of data collection. Across the webinar series, speakers repeatedly drew attention to the gap between the rhetoric of participation and its actual practice in research involving children with disabilities. While participation is widely recognised as both a right and a methodological imperative, the role of children with disabilities is frequently limited to visibility rather than influence. They might appear in consultations, photos, or pilot tests, but rarely shape research priorities, methods, or analysis. As a result, inclusion can become procedural rather than meaningful.

Speakers in webinars on assistive technology, ethical involvement, and research in emergencies stressed that logistical, institutional, and attitudinal barriers routinely restrict participation. These include limited timeframes, inaccessible tools, untrained staff, and a reluctance to engage children perceived as having higher support needs.

Despite these challenges, several speakers shared strong examples of more meaningful engagement. These included co-designed studies, caregiver-led validation processes, and feedback loops that returned results in accessible formats. In the webinar on assistive technology, speakers described participatory research as both ethically necessary and operationally advantageous. When families, organisations of persons with disabilities (OPDs), and children are involved from the outset, tools are more likely to be relevant, feasible, and trusted. Yet many studies continue to treat users as informants, rather than collaborators.

“Participatory action research should include children with disabilities, families, and local communities – as co-researchers, not just informants.”

Dr. Gavin Wood
(30 April 2025, Webinar)

In the webinar on ethical involvement, Dr. Tracey Smythe shared case studies illustrating how families co-facilitated research activities and identified inclusive methods such as play and storytelling to support children’s meaningful engagement. These examples also highlighted the importance of building trust, planning for feedback, and treating research as a relationship—not just a transaction.

“Ethical failure isn’t always about what we do. It’s often about what we don’t do... If we’re collecting data, we need to plan our return before we even start.”

Dr. Tracey Smythe
(06 May 2025, Webinar)

Effective participation requires time, trust, and tools that support shared ownership. Research becomes truly inclusive when children with disabilities and their caregivers help shape what questions are asked, how data is collected, and how findings are interpreted and used. Co-creation does not just improve ethics—it strengthens relevance, accountability, and the real-world impact of evidence. At the same time, several speakers acknowledged that OPDs may differ in their familiarity with child-led research and participatory approaches.

While OPDs are essential partners in inclusive research, some may require targeted support or orientation—particularly when their prior experience has focused primarily on adult advocacy. Strengthening OPDs’ capacity to engage in child-focused research processes is critical to ensuring their contributions reflect evolving rights-based and participatory standards.

Innovation and adaptation

Some of the most effective inclusive research practices shared during the series emerged from contexts of crisis, constraint, or uncertainty. In emergencies or under-resourced systems, speakers showcased a shift toward more adaptive, user-centred research approaches—especially where traditional models have historically failed. These approaches were not only necessary but often more effective in reaching children and families who are typically excluded.

Speakers emphasized the importance of designing research that is flexible, co-owned, and responsive to the lived realities of children with disabilities. In the webinar on children with disabilities in emergencies, crises were described not only as challenges but also as catalysts for innovation. The urgency and disruption of humanitarian settings prompted researchers to abandon rigid, extractive models in favour of inclusive, context-sensitive methods.

Examples shared included participatory photography, visual storytelling, mobile interviews, and remote consent protocols. These were not only practical adaptations—they reflected a deeper shift in research values: from standardized to responsive, and from detached observation to co-production and trust-building.

In the webinar on assistive technology, speakers underscored the importance of designing research ecosystems—not just tools—that sustain participation. Speakers highlighted promising initiatives like [Baby Ubuntu](#), which integrates developmental screening, caregiver coaching, and assistive technology referrals to public health systems. Innovation was also framed as a systemic challenge. It requires shifting focus from testing individual products to embedding inclusive practices across procurement, data collection, and service delivery.

Speakers also called for more intergenerational and lifecycle-based approaches to research—recognizing that the needs of children with disabilities shift as they grow, and that research about inclusive systems must reflect those evolving experiences.

The final webinar on ethical involvement contributed to this conversation by illustrating how ethical inclusion itself can be a form of innovation. Speakers shared strategies for adapting research protocols to align with children’s diverse communication styles, support needs, and evolving capacities. Examples included image-based consent, storytelling, simplified language, and assent based on body language or behavioural cues. Family-led adaptations—such as caregivers co-shaping methodology and guiding participation through everyday routines—were highlighted as powerful enablers of inclusion.

Ultimately, these insights reframed adaptation not as a compromise, but as a pathway to research that is more ethical, more relevant, and more empowering. Many speakers noted that inclusion is itself a form of innovation—it challenges assumptions about who can generate knowledge and how it is used.

“We can include them [children with disabilities] if we adapt our methods to suit the children’s needs—their support needs, their impairment-specific needs, their ages, their interests, their ways of participating.”

Dr. Mary Wickenden
(06 May 2025, Webinar)

Conclusion: from exclusion to co-creation and participation

Across the Beyond Barriers webinar series, speakers consistently emphasized a clear and urgent truth: inclusion is not an innovation—it is an imperative. Exclusion is not inevitable; it is the result of choices, systems, and environments that fail to accommodate human diversity. Research involving children with disabilities cannot be considered ethical, participatory, or even credible unless inclusion is embedded from the start—not as an afterthought or accommodation, but as a core principle.

As one speaker reminded us:

“Children with disabilities have the right to be involved—not because it’s nice or because it’s innovative, but because it is their right to have a say in what affects them.”

Speaker
(24 April 2025, Webinar)

Despite progress in visibility and intent, too many research systems still operate in ways that exclude children—whether through rigid consent protocols, inaccessible tools, short-term funding models, or unexamined biases about capacity and risk.

These are not isolated technical challenges. They are systemic and structural in nature—shaped by stigma, resource constraints, weak policy mandates, and institutional gatekeeping. In many cases, exclusion is not deliberate but the consequence of research systems that have not been designed with disabled children in mind.

To move forward, speakers called for a shift in both mindset and power: from extractive to co-produced models of research; from treating accessibility in research as a cost to recognizing it as a right; and from relying on institutional proxies to meaningfully engaging children, families, and communities as central actors in knowledge creation.

Throughout the series, ethical involvement was reframed as a dynamic and ongoing process—something that begins before consent forms are signed and continues through feedback, co-analysis, and dissemination. Some of the most powerful innovations shared during the webinars came not from ideal conditions but from moments of disruption: emergencies, under-resourced systems, and humanitarian contexts. These settings pushed researchers to adapt, listen, and innovate—not despite the challenges, but because of them.

Speakers emphasized that inclusive research is not about perfect conditions. It is about commitment, preparation, and the willingness to shift power. Inclusive research requires more than methods—it requires values, relationships, and systems that are built to listen and act. As framed in the introduction:

“Inclusion is not an outcome of research—it is the method, the measure, and the meaning.”

Dr. Gavin Wood
UNICEF Innocenti

Ultimately, the series called for a research culture that does not treat children with disabilities as subjects, but as collaborators of knowledge. Inclusive research is not a niche practice. It is essential to the credibility, relevance, and impact of evidence.

Actionable insights

Building on the webinar discussions and cross-cutting insights, this section consolidates key recommendations into targeted, stakeholder-specific recommendations and action. While earlier sections summarised systemic, ethical, and methodological barriers that continue to undermine inclusive research—particularly for children with disabilities in low-resource and humanitarian contexts—this section focuses on solutions. It translates the series' findings into practical entry points for those designing, funding, implementing, or governing research.

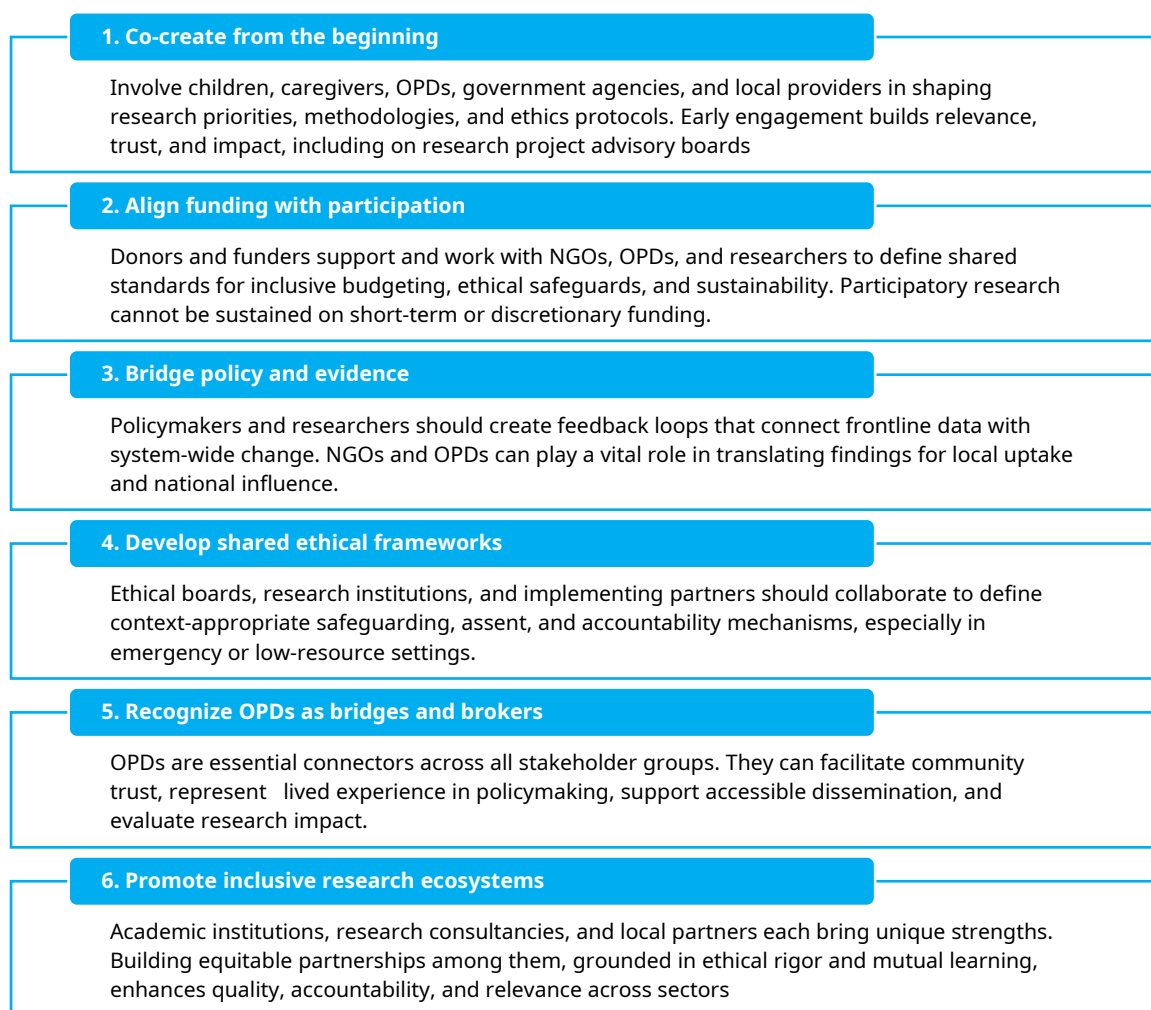
A consistent message emerged: inclusive, participatory research must become a norm, not the exception. Inclusion must be embedded from the outset—in research priorities, ethics protocols, budget frameworks, and in designing participatory methodologies. To make research inclusive and impactful it should follow the six core principles presented in Figure 7, starting with the core principle that research must be co-created with children facilitated and supported by OPDs.

Effective inclusion is not a matter of good intentions alone, but of sustained, coordinated action. Signposts in this section underscore the importance of investing in accessible infrastructure, enabling meaningful child and caregiver participation, resourcing, including training, OPDs as co-leaders in research. The series made clear: inclusion is only achieved through deliberate, coordinated, and accountable systems change.

Next steps for researchers

- **Center children's voices from the start:** Co-develop research priorities, tools, and ethics frameworks with children and families to ensure relevance and respect.
- **Collaborate meaningfully with OPDs:** Engage OPDs in the co-production, validation and then translation of research findings into community action and policy influence—be prepared to provide some research training and orientation.
- **Co-analyse and set agendas with OPDs:** Beyond data collection, engage OPDs in interpreting findings and define future research priorities that reflect community concerns and lived experience.
- **Use participatory and creative methods:** Use child-led approaches (e.g. drawing, storytelling, peer-to-peer interviews) to enable participation across disability types and settings.
- **Plan for accessibility:** Budget for sign language, Easy Read, transport, and other accommodations as standard—not optional—element.
- **Adapt to challenging contexts:** Employ flexible, adaptive research protocols that pass ethics approval (e.g., remote consent, trauma-informed tools).
- **Broaden measurement frameworks:** Move beyond implementation and delivery metrics (outputs) to include measure of meaningful outcomes and impact defined by children and families (e.g., belonging, learning, self-expression).
- **Treat ethics as an ongoing practice:** Go beyond one-off consent forms. Embed dynamic, child-centred assent and safeguarding throughout the research process. Develop protocols that are responsive to children's communication preferences, safeguard their wellbeing, and support transparent feedback loops.
- **Invest in accessible dissemination:** Budget for accessible reporting formats, social-media dissemination and uptake strategies.

Figure 7: Principles of inclusive research



For donors and funders

- **Invest in systems, not just pilots:** Shift from short-term project funding to multi-year, systems-aligned investments that enable national ownership.
- **Support longitudinal and mixed-methods research:** Enable follow-up beyond baseline and endline surveys to understand long-term outcomes for children with disabilities.
- **Require accessibility from the start:** Require all grantees to include accessibility measures, inclusive engagement protocols and safeguarding in budgets.
- **Standardise inclusion criteria:** Require inclusive data collection in all research proposals about children, encourage accessible reporting, require inclusive safeguarding protocols, and call for inclusive, context-specific consent/assent procedures.
- **Fund ethical safeguards:** Fund training and accountability structures for ethical research—including safeguarding, consent, assent and feedback mechanisms.
- **Strengthen OPD leadership:** Move beyond engagement to support OPDs as research partners—through long-term capacity investment, co-granting models, and infrastructure that enables their participation in national and global research ecosystems.

“If you plan carefully in advance and write into budgets that you need that extra money, then it’s possible to do—if you plan it ahead rather than having to do it on the hoof.”

Dr. Mary Wickenden
(06 May 2025, Webinar)

For NGOs and implementing organisations

- **Design research-ready programs:** Build M&E systems that are participatory, disability-inclusive, and ethics-approved from the start.
- **Train field staff:** Equip implementers with tools and skills for inclusive data collection, trauma-informed engagement, and respectful facilitation.
- **Include children and caregivers in validation:** Involve communities in interpreting results and shaping next steps—especially those often excluded (e.g., children with intellectual disabilities).
- **Document and share innovation:** Capture lessons from community-driven approaches and humanitarian adaptations (e.g., photo voice, co-analysis).
- **Strengthen OPD partnerships:** Partner with OPDs on programme design, tool development, and humanitarian response—ensuring representation of marginalized subgroups (e.g., under-14s, caregivers, people with communication support needs).

“There needs to be much greater engagement of parents, caregivers and the wider community and this is not actually happening—particularly at home and at the community level.”

Dr. Paul Lynch
(30 Apr 2025, Webinar)

For policy and advocacy actors

- **Embed inclusive research into systems:** Use inclusive research findings to shape national education, protection, health, and disability policy frameworks.
- **Standardize definitions and indicators:** Promote the use of harmonized disability measures (e.g., Washington Group Questions) across sectors and ministries to ensure comparability, reduce duplication, and strengthen accountability.
- **Mandate OPD involvement:** Mandate meaningful OPD participation in national research review boards, ethics committees, and disability data governance bodies. Establish transparent criteria for representation and mechanisms to elevate voices of marginalized subgroups within the disability movement.
- **Scale inclusive service models:** Embed tested models—like routines-based early intervention or integrated AT provision—into national policies and implementation frameworks.
- **Set inclusive research standards:** Require inclusive data collection in all research about children, encourage accessible reporting, inclusive safeguarding protocols, and inclusive consent/assent procedures in state-funded research.

“Advocacy work needs to be happening at multiple levels. In donor countries, there needs to be advocacy efficacy aimed at donors, at the mainstream organizations working on it also. But also, within the countries it needs to be aimed at national government, at the humanitarian organizations operating in these places.”

Brigitte Rohwerder
(02 May 2025, Webinar)

To support practical action and policy engagement, the symposium findings can be grouped into two interlinked categories:

Box 5: Symposium findings interlinked into two categories

Positive Developments

Greater awareness of disability inclusion in research and data systems

Emerging inclusive research tools and methods (e.g., peer interviews, image-based consent, participatory analysis)

Growing engagement of OPDs and caregivers in co-design and validation

Movement toward ethical and rights-based research frameworks

Evidence of what works in inclusive early intervention models

Use of innovative dissemination strategies to reach families and communities

Persisting Gaps

Disability still inconsistently defined and under-reported in national and local systems

Limited uptake of inclusive methods across mainstream research practices

Children with disabilities still often excluded from direct participation and co-research roles

Ethics review boards often apply rigid or risk-averse assumptions that exclude children with complex needs

Fragmented referral pathways and poor integration between screening, follow-up, and services

Research findings often not translated into formats accessible to decision-makers or frontline workers

This framing aims to surface both what's working and where further investment, research, and systems change are urgently needed. It also offers policymakers and practitioners a clear structure for engaging with the symposium's core takeaways.

Conclusion: Advancing the agenda for inclusive research

The Beyond Barriers webinar series convened a series of conversations on what it takes to meaningfully include children with disabilities in research—to make research inclusive of children with disabilities. Across five thematic areas—early identification, violence prevention, assistive technology, emergencies, and ethical engagement—speakers highlighted both progress and persistent challenges. While diverse in focus, each discussion pointed to a shared truth: children with disabilities remain systematically excluded from the data, decisions, and systems that shape their lives.

Reflections from the series

This report has highlighted recurring challenges such as fragmented service systems, inaccessible tools, weak consent protocols, and underfunded participatory approaches. However, it has also surfaced a groundswell of innovation and practical solutions. The series showcased creative and adaptive research tools, including visual methods such as participatory photography, storytelling, and drawing, effectively engaging children with non-verbal communication styles. In hard-to-reach and emergency settings, mobile interviews and remote consent protocols allowed for continued inclusion despite physical or logistical constraints.

Speakers emphasized inclusive consent and ethical engagement, with innovations such as image-based consent forms, simplified language, and the use of behavioural or non-verbal assent for children with diverse cognitive and communication needs. Co-development of ethical approaches with families and caregivers was presented as essential, ensuring ethics is not a one-time step but an ongoing, responsive process. Examples of co-design and family-led research highlighted how families helped shape research tools and topics, resulting in greater relevance and accessibility. Tools such as co-designed checklists and child-led interviews demonstrated how collaborative design can strengthen both methodology and inclusion.

Importantly, the series advanced a vision of system-level innovation, advocating for inclusive research ecosystems rather than isolated tools. One example is the Baby Ubuntu model, which integrates early intervention, screening, and assistive technology into existing community health systems—demonstrating the importance of embedding inclusive research in broader service structures. The series also addressed the realities of inclusive research in humanitarian settings, where peer-led focus groups, community-based data collection, and mobile platforms or satellite imagery were deployed to ensure continued inclusion in crisis contexts.

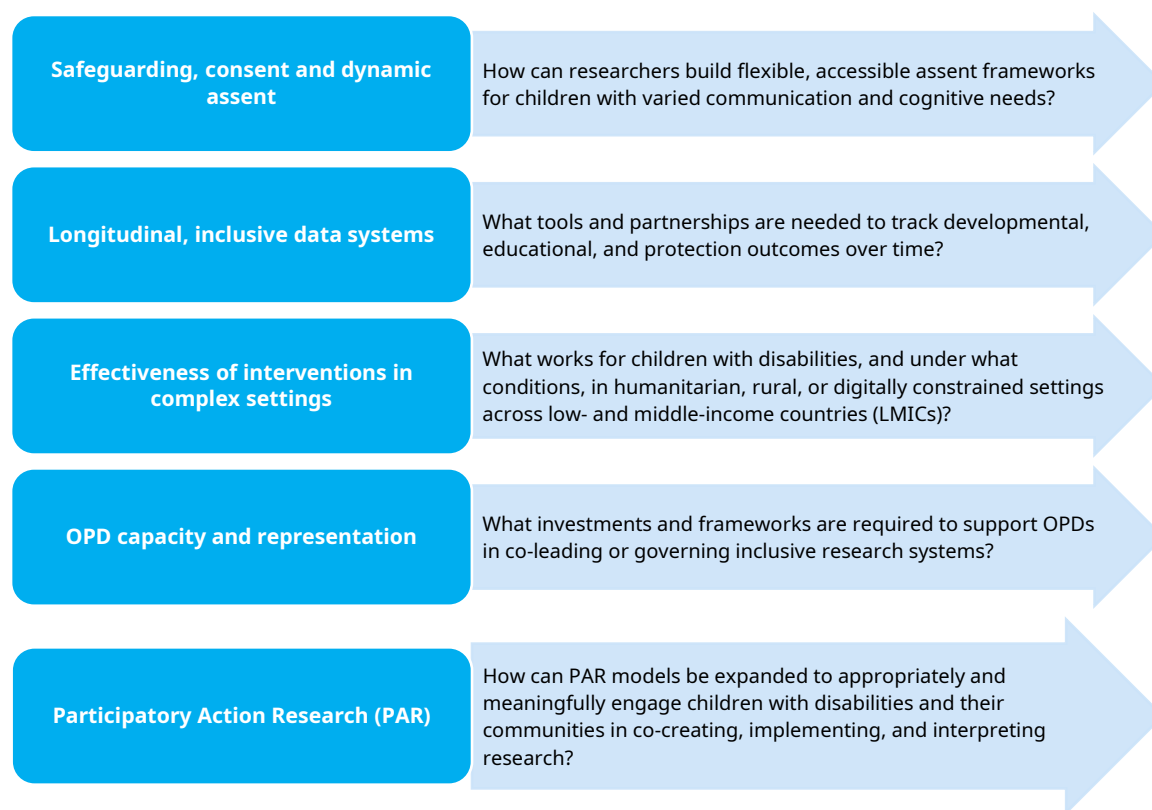
Ultimately, the series challenged traditional power dynamics by advocating the positioning of children with disabilities as co-creators of knowledge, not merely research subjects. It underscored the critical importance of leadership by Organisations of Persons with Disabilities (OPDs) and deep caregiver involvement as prerequisites for valid, ethical, and impactful research. Achieving such a shift requires more than symbolic gestures or aspirational ideals—it demands systemic change grounded in collaboration and shared responsibility. Building inclusive research systems means creating structures in which children's voices are not only heard but meaningfully shape research priorities, methods, and outcomes.

Important dimensions for future research

Speakers emphasized the importance of embedding disability inclusion and ethical safeguarding throughout all stages of research design and implementation. These priorities reflect the direction set by [UNICEF's Global Research Agenda for Children with Disabilities](#) (UNICEF Office of Research – Innocenti, 2025) and the [Disability Research Prioritization Exercise \(DRPE\) 2025](#), both of which underscore the need for rigorous, participatory, and contextually grounded evidence to inform inclusive policies and programmes. The intersection of violence, disability, and child-care systems was identified as a

particularly urgent and underexplored area for future research. Speakers and participants identified several priority areas for further inquiry (Figure 8).

Figure 8: Priority dimensions underpinning future research directions



The role of inclusive, participatory research

At its core, this series reaffirmed that inclusive research is not a technical exercise—it is a rights-based, political, and relational process. When children with disabilities participate not just as informants, but as co-creators of knowledge, the quality, credibility, and usefulness of research improves. Participation is not only an ethical imperative—it is an enabler of relevance, resilience, and gives a better chance to making change.

A call to action

The exclusion of children with disabilities from mainstream research systems is not merely a data gap—it is a structural failure that undermines the development of equitable policy and practice. This series has underscored the imperative to reposition children with disabilities as central participants in the research ecosystem, not peripheral subjects. Advancing disability-inclusive research requires a shift in both practice and paradigm: from extractive to participatory, from fragmented to systemic, and from aspirational to actionable.

We call on researchers, funders, policymakers, implementers, and organizations of persons with disabilities (OPDs) to embed inclusive research as a standard—not a specialized add-on. This requires:

Box 6: Actionable outlines

- Co-designing research priorities and tools with children, caregivers, and OPDs
- Allocating resources for accessibility and meaningful participation
- Applying ethical safeguards as continuous, dynamic, and child-centred practices
- Ensuring accountability to communities, including children with intersectional identities
- Aligning all efforts with human rights-based frameworks and international obligations

Disability-inclusive research is not a peripheral concern. It is the foundation of credible, rigorous, and transformative evidence. Research that excludes children with disabilities risks reinforcing the very inequities it seeks to address. To move forward, we must reframe inclusion not as an outcome of research—but as its ethos and method.

Research that excludes children with disabilities risks perpetuating the very inequities it seeks to address. The path forward requires a research culture where children with disabilities are collaborators in knowledge creation, leading to evidence that is credible, relevant, and truly transformative. The process must mirror the equity and dignity we seek to promote

ANNEXES

Annex A. Webinar readout: Early identification and intervention for children with disabilities

Webinar Date: 22 April 2025

Moderator: Dr. Aleksandra Karovska, Ss. Cyril and Methodius University & RISE Institute

Opening Remarks: Dr. Gavin Wood, UNICEF Innocenti

Speakers: Dr. Hollie Hix-Small, Portland State University; Dr. Mijna Hadders-Algra, University of Groningen; Dr. Toby Long, Georgetown University.

Framing and Relevance

Early Identification and Intervention (EII) refers to a continuum of processes designed to recognize, respond to, and support children at risk of or experiencing developmental delays and disabilities. It begins with early identification—typically through screening and monitoring—followed by referral to appropriate services, and continued follow-up to ensure that support is accessible, appropriate, and sustained over time. Each stage plays a critical role and must be designed to function in an integrated and coordinated way.

When well implemented, this continuum enables children to access timely support—such as early childhood intervention (ECI) programs, therapies, assistive devices, inclusive education, and family support—often before a formal diagnosis is in place. ECI, in this context, refers to the broader, ongoing delivery of services, while EII emphasizes the importance of the initial entry points and pathways into care.

This webinar was framed by the broader process that links screening, referral, and follow-up into ongoing early childhood intervention (ECI) programs. It also recognized that definitions of ECI, early identification, and screening are not universally agreed upon across countries and sectors. For this reason, the session adopted a broad and inclusive view of the continuum—while many of the discussions were guided by established ECI frameworks, the intention was to reflect the diversity of systems and practices represented by participants and speakers, and more importantly, to reflect on the challenges and opportunities for strengthening research in this area.

It was opened by **Dr. Gavin Wood**, Manager of Disability Inclusion Research at UNICEF Office of Research–Innocenti, who emphasized the urgency of building equity-centred, data-driven systems to address the persistent invisibility of children with disabilities in policy and practice. Moderated by **Dr. Aleksandra Karovska** (Ss. Cyril and Methodius University and the RISE Institute), the discussion stressed that inclusive systems must be participatory, culturally responsive, and grounded in the lived experiences of children and caregivers.

Three expert speakers presented a progression of insights, moving from definitions to implementation:

- **Dr. Hollie Hix-Small** introduced foundational concepts like “screening,” “monitoring,” and “referral,” and made the case for aligning EII efforts across sectors.

- **Dr. Mijna Hadders-Algra** shared insights from the Standardized Infant Neurodevelopmental Assessment (SINDA), showing how early developmental monitoring tools can be implemented in diverse contexts.
- **Dr. Toby Long** focused on embedding ECI within everyday family routines and strengthening the capacity of caregivers through coaching.

Together, these contributions reinforced the idea that EII is not only a clinical function but a rights-based obligation—essential to ensuring visibility, access, and inclusive development for children with disabilities.

“Missing early windows of intervention can have lasting effects, which is why early intervention and identification is critical.”

Dr. Aleksandra Karovska
(22 April 2025, Webinar)

State of the art

What we know

There is growing evidence that early identification tools—such as the ASQ (Ages and Stages Questionnaire), MDAT (Malawi Developmental Assessment Tool), BSID (Bayley Scales), and SINDA—can improve developmental outcomes when used appropriately. Tools like SINDA have been implemented in some LMICs and adapted for community and caregiver use. However, broader implementation is hindered by lack of training, weak system integration, and inadequate cultural or linguistic adaptation.

Speakers highlighted tiered models of support that build from universal services (e.g., nurturing care and early stimulation) to more targeted and individualized interventions. These models are promising because they rely on the people closest to the child—families, teachers, and community health workers—but they are only as strong as the systems that support them. Tools that incorporate caregiver observation, video coaching, and routine-based assessment are gaining traction, especially when designed to work in low-resource settings.

The webinar underscored that integration into health and education systems remains a major challenge. Promising pilot efforts often fail to scale due to lack of coordination across sectors or unclear pathways for referral and follow-up. Building systems that centre caregivers, recognize their expertise, and embed support into daily life can improve both uptake and outcomes—but only if those systems are inclusive from the start.

Limitations and gaps in knowledge

Despite progress, large gaps remain. Speakers pointed to ongoing confusion in how EII and ECI are defined across disciplines and countries, with terms often used interchangeably or inconsistently. This impedes coherence in both policy and research. They also highlighted the lack of longitudinal studies tracking outcomes across domains (education, health, social inclusion), and a general underuse of participatory methods that elevate the voices of children and families.

Many tools used today have not been validated for diverse populations or adapted for local use. In some settings, services are available in theory, but families cannot access them due to stigma, cost, transport barriers, or unclear referral processes. Others face exclusion due to diagnosis-dependent eligibility criteria that can reinforce bias and delay support.

Audience members also questioned the alignment of current practices with the CRPD. Several speakers responded that EII is still often framed within deficit-based or medical models, and that rights-based approaches must go further in embedding participation, dignity, and local ownership.

A key challenge in assessing interventions for children with disabilities is the reliance on tools based on “normal” development or activities of daily living. These measures may not accurately capture progress or functional change for

children with diverse needs. There is a need to **develop and adapt measurement tools** that go beyond normative models to more appropriately assess **individual progress and functional outcomes over time**.

Challenges in generating knowledge

Barriers to Data

In many LMICs, data relevant to early development—such as screening results, health histories, and family risk factors—are not shared across systems or integrated into national data platforms. Sectoral silos and vertical programming result in duplicated efforts or children falling through the cracks. This severely limits the potential to generate scalable, practice-relevant evidence.

Methodological and Ethical Challenges

Children with disabilities are often excluded from EII research due to inaccessible consent processes or research tools that assume standard verbal or cognitive capacities. Consent and assent procedures are frequently rigid or absent altogether, and ethics boards may restrict participation out of over-cautiousness rather than need for protection. These barriers limit both the quantity and quality of research, especially for children with complex needs.

Systemic Constraints

Research priorities are rarely co-developed with children, caregivers, or OPDs. Local researchers are underfunded or excluded, particularly in LMICs. Donor-driven projects often emphasize short-term outcomes over sustained, family-centred systems of support. Fragmented systems and vertical programming constrain the ability to test what works across settings and systems.

“We want to build integrated, family-centred systems—systems that allow us to share data, support caregivers, and promote cross-sector training.”

Dr. Toby Long
(22 April 2025, Webinar)

Engaging children with disabilities in research

Opportunities for engagement

The webinar highlighted strategies for engaging children and caregivers in research—from co-designing tools to conducting caregiver-led assessments. Speakers stressed the value of embedding participation within program development and evaluation, not just as a research method but as a principle of system strengthening.

Methods that use drawing, polling, mobile platforms, or storytelling were seen as promising in enabling children to express their needs and priorities in age-appropriate, culturally grounded ways. Local ownership—especially in LMICs—was emphasized as essential to ethical, inclusive practice.

Barriers to participation

Many research instruments are not accessible. In LMICs, few surveys include local language versions, Easy Read formats, or visual aids. Children with intellectual or communication disabilities remain severely underrepresented, especially where participation is viewed as too complex or too risky. Assumptions about capacity, combined with logistical constraints, often result in default exclusion.

“We need to recognize that for many communities, research has not been a positive experience. If we are serious about inclusion, we must rethink how we involve families and ensure their voices shape the research.”

Dr. Hollie Hix-Small
(22 April 2025, Webinar)

Dr. Hix-Small’s contributions throughout the series repeatedly underscored the importance of not just co-designing research tools with caregivers but also building systems that empower them as data contributors and early detectors of developmental risks.

Illustrative practices and case reflections

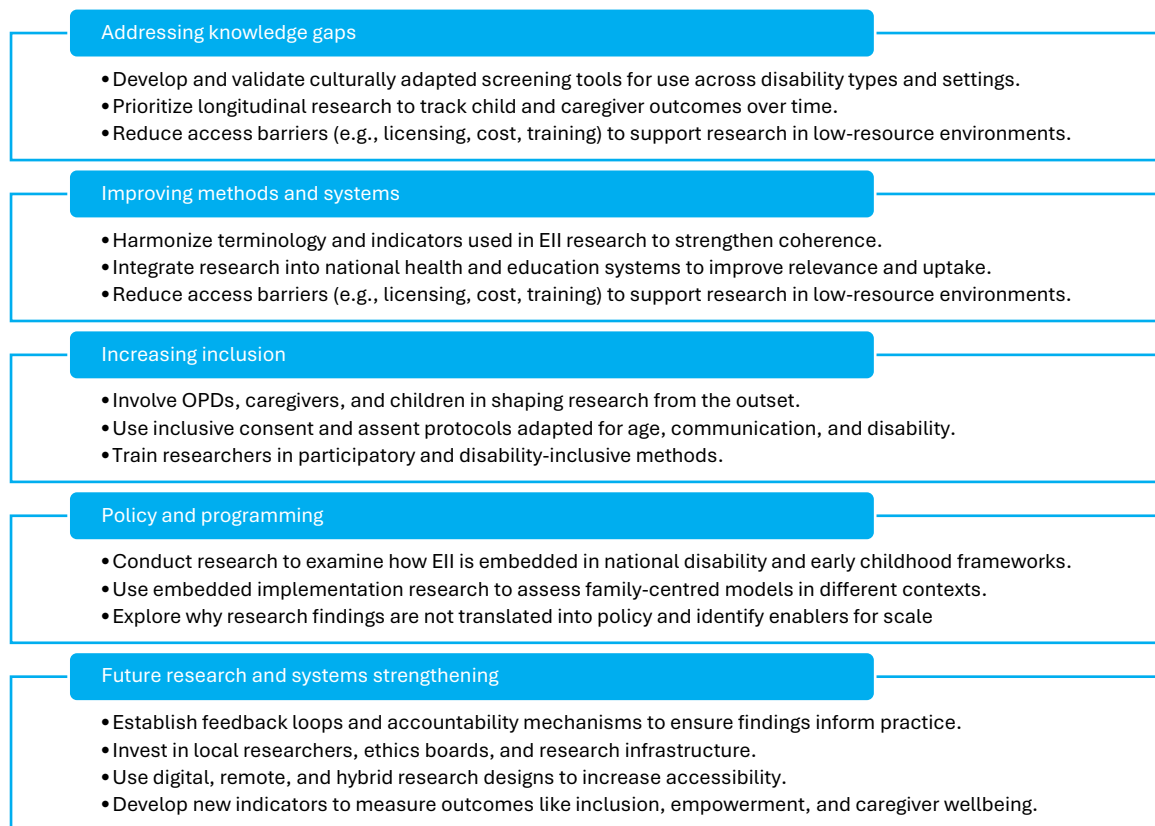
While no formal case studies were presented, examples of practice included:

- Family-centred coaching models that treat caregivers as partners and data contributors.
- SINDA implementation in community settings using video training and structured feedback loops.
- Community outreach strategies that align screening with immunization visits or early learning programs.

Speakers advocated for these strategies to be documented and scaled with attention to inclusivity, contextual adaptation, and cost-effectiveness. They called for research that bridges the gap between technical feasibility and ethical obligation.

Recommendations

Figure 9: Recommendations for Webinar 1: Early identification and intervention for children with disabilities



Annex B. Webinar readout: Preventing and protecting children with disabilities from all forms of violence and abuse

Webinar Date: 24 April 2025

Moderator: Lucy Marie Richardson, UNICEF Child Protection Programme, New York

Opening Remarks: Dr. Gavin Wood, UNICEF Innocenti

Speakers: Emily Eldred, London School of Hygiene & Tropical Medicine'; Dr. Claudia Arisi, Global Policy and Advocacy Advisor, SOS Children's Villages International; Dr. Cecilie Moesby-Jensen, University College Absalon; Maryam Ehsani, Founder, Child Safe Me Middle East.

Framing and relevance

The second webinar in the *Beyond Barriers* series focused on one of the most urgent and under-addressed human rights concerns in disability-inclusive research: the pervasive risk of violence and abuse faced by children with disabilities. Moderated by **Lucy Marie Richardson** (UNICEF Child Protection Programme, New York Headquarters), the webinar opened with a compelling reminder that children with disabilities must be recognised not only as rights holders but as children first—entitled to safety, nurturing care, and protection from all forms of harm.

" We know that children with disabilities are subjected to violence and abuse in all settings, including in their homes, schools, and communities, and in both humanitarian and development contexts. The perpetrators of this violence can be anyone, including their peers, family members, intimate partners, caregivers and services staff, and they experience the same types of violence and abuse as their peers without disabilities, along with violence directly related to their disabilities. Some of the drivers of this violence ...are community exclusion and isolation, stigma and discrimination, and lack of inclusive child protection systems and services. But we still don't know enough because there are gaps in the research, and we are still lacking the kind of evidence that could inform our actions to protect children with disabilities from violence and abuse and uphold their right to safety."

Lucy Marie Richardson
(24 April 2025, Webinar)

Yet children with disabilities are nearly twice as likely as their peers to experience violence across all settings—homes, schools, communities, and institutions—and in both development and humanitarian contexts. This violence may take many forms, including physical, emotional, and sexual abuse, neglect, institutionalization, or harmful practices disguised as care. Despite this elevated risk, the voices and experiences of children with disabilities remain largely absent from research and policy frameworks—particularly in low-resource and crisis-affected settings.

The webinar explored why children with disabilities remain both under-protected and under-researched, highlighting the methodological, ethical, and systemic barriers that prevent their inclusion in evidence-generation and protection systems. A live poll conducted during the webinar underscored the salience of these issues, with 46% of attendees identifying stigma

as the greatest barrier to preventing violence against children with disabilities—followed by data gaps, policy incoherence, and underfunding.

Four expert speakers built on this framing to offer diverse, practice-based insights:

- **Emily Eldred** reviewed the definitional and measurement challenges in researching violence against children with disabilities, including the persistent exclusion of children with communication and cognitive impairments.
- **Dr. Claudia Arisi** shared research findings across multiple countries showing how violence, stigma, and systemic neglect are often mischaracterized as protection or care, particularly within institutional settings.
- **Dr. Cecilie Moesby-Jensen** presented a participatory research model co-developed with children, using visual tools and storytelling to enable safe and meaningful engagement. She emphasized the importance of adapting research to children—not the other way around.
- **Maryam Ehsani** distinguished safeguarding from child protection, arguing that ethical safeguards must be integrated from the outset of research, not applied post hoc. She called for researchers, institutions, and ethics boards to embed inclusive safeguards as a core research standard.

Together, these voices made a powerful case: violence against children with disabilities is not merely a pattern of individual harm—it is a systemic failure, sustained by underinvestment, ableism, fragmented systems, and outdated research norms that exclude the very children they aim to protect.

“Violence doesn’t just happen to children with disabilities—it happens through systems that claim to protect them.”

Dr. Cecilie Moesby-Jensen
(24 April 2025, Webinar)

State of the art

What We Know

There is now broad consensus that children with disabilities are at significantly higher risk of experiencing violence and abuse—and that the forms of harm they face are often normalized, mischaracterized, or invisible within existing protection systems. These harms span the social ecological model, occurring at the individual (e.g. disability-related vulnerability), relational (e.g. caregiver violence), community (e.g. school bullying), and structural (e.g. systemic neglect) levels.

Findings presented during the webinar drew on data from Uganda, Zambia, Malawi, and other contexts, showing that children with cognitive disabilities face particularly high rates of violence—while those with sensory impairments often experience bullying and social exclusion from peers. The violence children face is compounded by stigma and isolation, and in some cases, justified as therapeutic or disciplinary care, particularly in institutional settings where monitoring and safeguards are weak.

Children with disabilities in many low- and middle-income countries face multiple, interlinked barriers to care and protection. A study in Uganda and Malawi confirmed widespread challenges, including limited accessibility of services, financial barriers to accessing care, and stigma related to disability. These issues contribute to a heightened risk of family separation, placement in alternative care, and exposure to violence and neglect.

Across several countries—such as Lebanon, Indonesia, Kenya, Kyrgyzstan, and Uruguay—positive practices have emerged, particularly community-based mental health and psychosocial support (MHPSS) services, which have helped reduce institutionalization and harmful practices.

The global study on children’s care and protection piloted a co-designed methodology in Lebanon and El Salvador, fostering trust among children and researchers. It highlighted that states have both the responsibility and capacity to respond

through cross-sectoral coordination and greater investment in child protection, social protection, and family-strengthening services.

Systemic challenges span across social protection, health, education, and justice sectors, often leading to inadequate or inaccessible services. At the family and community levels, caregiver stress, poor parenting practices, violence, poverty, labour migration, and life events like divorce or remarriage contribute significantly to children's vulnerability.

Ultimately, addressing these issues requires not just better services, but also a shift in societal attitudes, stronger legal and policy frameworks, and inclusive support systems that prioritize family-based, community-rooted care for children with disabilities. Speakers presented results from a Systematic Review of over 160 school-based violence prevention trials: only three studies considered the experiences of children with disabilities, and none included meaningful adaptations to intervention design or data collection protocols (Eldred *et al.*, 2025). These findings reflect a wider pattern of exclusion in research and programming, even in domains that explicitly aim to prevent harm.

Increasingly, there is recognition that effective prevention must be intersectional and inclusive—from the research tools and data collectors to the design of referral systems and ethics protocols. Participatory and child-led methodologies are essential to capture children's lived experiences and to challenge the biases and assumptions that underpin both research and protection failures.

“Our tools are built around the idea that children must speak to be counted. What happens when they can't?”

Emily Eldred
(24 April 2025, Webinar)

Limitations and gaps in knowledge

Despite increasing awareness, research on violence against children with disabilities remains fragmented. Significant knowledge gaps persist across multiple domains:

- **Disaggregated data are rare:** Even when disability is recorded, data systems often fail to account for impairment type, gender, or intersectional risk factors—masking the complex realities that all children face.
- **Forms of violence are mischaracterized or omitted:** Practices like overmedication, restraint, and neglect are often normalized as caregiving and omitted from formal datasets and policy narratives.
- **Longitudinal research is lacking:** There is little evidence on the long-term impacts of violence on children with disabilities, or on the sustained effectiveness of prevention interventions for them.
- **Children's voices are missing:** Most studies rely on caregiver reports or institutional perspectives. Children with intellectual or communication disabilities are rarely included as participants—despite practice demonstrating effective participation approaches.
- **Safeguarding procedures are often inadequate:** Referral plans, and ethical protections are frequently absent, especially in low-resource or humanitarian contexts.

As Dr. Arisi stressed, failing to collect meaningful data risks perpetuating a false narrative—one that obscures children's protection needs, weakens accountability, and undermines the design of services meant to safeguard their rights.

“Many national data systems still fail to systematically identify children with disabilities. Even when data are disaggregated, the questions often miss the complexity of their experiences. Involving them meaningfully is not just a moral or rights-based imperative—it enriches our understanding by generating more informative data. Without this, we risk false narratives about their protection needs, which undermines both research and the planning and delivery of services they rely on”

Challenges in generating knowledge

Barriers to obtaining and synthesizing data

Children with disabilities are routinely excluded from mainstream data systems. Violence research often overlooks disability altogether or categorizes children under broad vulnerability groupings without capturing the nuances of their experience. Tools used to collect data—such as interviews or surveys—tend to be inaccessible, relying heavily on verbal communication or assuming cognitive competence that excludes many children with intellectual or communication disabilities. As a result, findings may be skewed, incomplete, or biased toward adult or institutional perspectives.

Stigma and fear of reprisal can suppress disclosure, particularly in contexts where violence is normalised or institutions lack accountability. These dynamics influence how children respond to researchers, how families permit participation, and how researchers interpret findings.

Issues with national data systems

Even where protection protocols exist, they are rarely adapted for disability inclusion or crisis contexts. National data systems often fail to identify children with disabilities, and when they do, disaggregation tends to be superficial or incomplete. Safeguarding violations—such as restraint, seclusion, or over-medication—are often omitted from reporting frameworks, while service providers may not be trained to identify or record these as forms of violence.

Fragmented systems across sectors—child protection, health, and education—undermine consistency in reporting and follow-up. A lack of shared indicators, incompatible data platforms, and minimal investment in inter-agency coordination limit the ability to synthesise or respond to patterns of violence against children with disabilities.

Research methodology and ethical challenges

Speakers highlighted that research in this area continues to be dominated by prevalence-focused studies that are rarely participatory and often methodologically exclusionary. Standard tools do not account for assisted communication, alternative literacy needs, or behavioural cues as forms of expression. Few studies are designed with meaningful involvement of children as co-researchers, despite the growing body of literature and practice showing how participatory and child-led approaches can improve both rigor and ethical integrity.

Ethical concerns—particularly fears of re-traumatization or triggering distress—often discourage researchers from engaging directly with children, especially those with prior exposure to violence or institutionalisation. While these concerns are valid, an overly cautious approach can lead to the systematic silencing of the very children most affected. Informed consent and assent procedures are also frequently inaccessible or overly rigid, failing to accommodate children's diverse cognitive, communicative, or emotional support needs.

Moreover, there remains a lack of clear guidance on how to respond when children disclose violence, express discomfort, or signal dissent—especially through non-verbal means. Safeguarding protocols, where they exist, often target adult populations or fail to account for the additional supports required to uphold the dignity, safety, and agency of children with disabilities in research contexts. Without stronger ethical infrastructure, the field risks perpetuating exclusion in the name of protection.

Systemic and structural constraints

Research on violence against children with disabilities is underfunded and fragmented. In low-resource settings, local researchers and organizations of persons with disabilities (OPDs) are frequently excluded. Structural stigma and systemic

bias further entrench exclusion. Adults—including parents, teachers, researchers, and policymakers—may internalize assumptions about the vulnerability or incapacity of children with disabilities engage in research.

Stigma may also cause children to fear disclosure—especially where institutionalisation or disbelief are likely consequences—while safeguarding mechanisms remain poorly adapted or under-resourced. Without proactive investment in inclusive, trauma-informed, and locally grounded research systems, the cycle of invisibility and under-protection is likely to persist—limiting ownership, contextual relevance, and the sustainability of research outcomes.

Engaging children with disabilities in research

Opportunities for engagement

The webinar highlighted a wide range of inclusive approaches already being used to engage children with disabilities in ethical and empowering ways. Examples included child-led inquiries, co-designed visual tools, photo-voice methodologies, tactile prompts, and storytelling formats that allow expression beyond spoken language.

Speakers emphasised that children with disabilities are not too difficult to include—rather, adults must adapt their methods, attitudes, and expectations. Participatory research was described as both ethically essential and methodologically sound, producing richer, more relevant insights than extractive approaches. Involving local researchers and OPDs was also highlighted as a way to ensure tools are responsive to real-world conditions and that findings are more likely to be trusted and used.

One presentation drew from the Global Report on Children’s Care and Protection by SOS Children’s Villages and ten academic partners”, which engaged children in designing trauma-informed research tools. These included co-created safety protocols, accessible checklists, and feedback loops that enabled children to shape the process and outputs of the research.

Barriers to participation

Despite growing examples of inclusive practice, children with disabilities—particularly those with high support needs—continue to face systemic barriers to research participation. Informed assent processes are often designed without input from children or caregivers and may be inaccessible or inappropriate. Tools rarely include Easy Read formats, supported decision-making processes, or sensory-friendly adaptations.

Gatekeeping was identified as a major issue. Adults acting as protectors—parents, clinicians, ethics committees—may deny access to children out of concern for their safety, fear of stigma, or discomfort with the topic. These forms of gatekeeping can prevent the inclusion of children most at risk of violence and silence those with the most critical insights into protection failures.

Funding was another significant barrier. Participatory research often requires more time, training, and support than standard designs—yet these elements are rarely included in project budgets. Without flexible resources for interpreter support, accessible materials, or follow-up mechanisms, inclusion becomes aspirational rather than achievable.

“... too often children with disabilities are excluded from research, even when it concerns their own lives... Our guiding philosophy throughout the entire project has been children should not be adapted to research—we should adapt the research to the children.”

Dr. Cecilie Moesby-Jensen
(24 April 2025, Webinar)

Recommendations

Figure 10: Recommendations for Webinar 2: Preventing and protecting children with disabilities from all forms of violence and abuse

Addressing knowledge gaps

- Prioritise data disaggregation by age, gender, disability type, and setting to reveal hidden risks and structural disparities
- Conduct longitudinal studies to understand the long-term impact of violence and the effectiveness of prevention strategies.
- Expand research into under-explored areas, including caregiving violence, institutional harm, and long-term trauma.
- Strengthen evidence on institutional practices—such as restraint and over-medication—that are often omitted from standard protection frameworks

Improving methodology and data systems

- Integrate mixed-methods and participatory approaches to reflect the nuanced, lived experiences of children with disabilities.
- Design and validate inclusive, child-sensitive tools using visual, assisted communication, and simplified language formats.
- Embed trauma-informed, child protection safeguards into every stage of the research process, from design to dissemination.
- Harmonise indicators across sectors to support more coherent disability-inclusive violence prevention monitoring and accountability.

Increasing inclusion in research

- Involve children with disabilities as co-researchers, not just respondents—ensuring their perspectives shape both tools and priorities.
- Use accessible, supported communication formats to ensure informed assent and ongoing participation.
- Provide comprehensive training in inclusive ethics, trauma sensitivity, and child rights to build researcher capacity and confidence.
- Train and equip ethics boards to review inclusive research protocols using child-rights-based benchmarks—moving beyond default assumptions about capacity, risk, or vulnerability that can lead to exclusion.

Policy and programming integration

- Use research to document and expose harmful practices—such as over-medication, isolation, and seclusion—that are often normalised or invisible within protection systems.
- Integrate disability into national and organisational safeguarding frameworks, researcher protocols, and funding requirements to institutionalise inclusive practices.
- Link research to policy change through applied studies and operational research that inform real-time improvements in safeguarding and protection systems.

Enablers and future research

- Strengthen political will and funding mechanisms to support sustained, disability-inclusive research
- Validate and scale participatory methodologies that can be applied across regions and adapted to various support needs.
- Promote cross-sector and cross-regional collaboration—including with OPDs—to ensure inclusive violence prevention is grounded in lived experience and shared accountability

Annex C. Webinar readout: Access to assistive technology in low-resource settings

Webinar Date: 30 April 2025

Moderator: Dr. Deborah Taub, OTL Education Solutions

Opening Remarks: Dr. Gavin Wood, UNICEF Innocenti

Speakers: Israel Balogun, University College London; Dr. Paul Lynch, Reader (Culture, Literacies, Inclusion & Pedagogy) University of Glasgow; Fernando Botelho, AT Programme Specialist, UNICEF HQ.

Framing and relevance

Assistive technology (AT) plays a vital role in enabling children with disabilities to participate fully in education, communication, play, and everyday life. When appropriate and available, it supports independence and inclusion—and is key to realizing children’s rights. However, in many low-resource and humanitarian settings, access to AT remains severely limited. Devices are often unavailable, unaffordable, or poorly matched to children’s needs.

This webinar explored how research can bridge those access gaps. It positioned AT not just as a tool, but as a pathway to equity. It emphasized the need for more inclusive, sustainable systems and underscored the lack of rigorous, context-sensitive research—especially studies that reflect the lived experiences of children with disabilities in low-income settings.

Moderated by **Dr. Deborah Taub**, the webinar opened with a powerful reminder of AT’s transformative potential:

“AT can make the difference between an individual having a say in their life and that same individual being the subject of other people’s decisions.”

Dr. Deborah Taub
(30 April 2025, Webinar)

Three expert speakers framed the discussion:

- **Dr. Israel Balogun**, a disability advocate and medical practitioner, introduced key frameworks and emphasized rights-based approaches to AT. He outlined systemic barriers such as workforce shortages, weak supply chains, poor planning, and data gaps that constrain access in LMICs.
- **Dr. Paul Lynch** distinguished AT from edtech and emphasized the importance of tailoring AT solutions to the individual needs of children. His review of literature highlighted significant gaps, particularly around communication disabilities and user involvement.
- **Fernando Botelho**, AT Programme Specialist at UNICEF, critiqued overreliance on product innovation, when innovations in areas such as business models can be just as important in their impact on improving access to AT. He urged researchers to focus on practical impact—calling for longitudinal, user-centred research that informs scalable, sustainable solutions.

Across their presentations, speakers drew attention to persistent challenges in AT systems: mismatches between available products and user needs; a lack of demand-driven planning; fragmented provision across education, health, and social

welfare sectors; and weak follow-up and repair services. Although global frameworks such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD), the UN Disability Inclusion Strategy, and the WHO/UNICEF Global Report on Assistive Technology provide clear direction, many countries lack coordinated operational plans and investments.

Speakers also critiqued the dominance of high-tech, one-off innovations—arguing instead for context-appropriate, service-driven models that prioritise caregiver engagement, training, and sustainability. They called for a shift from deficit-based research to practical, user-informed studies that can drive real-world improvements, including the adaptation of existing tools and services in LMICs.

“Perhaps the most shocking finding shown in the Global Report on Assistive Technology was that more than 90 % of children in low- and middle-income countries do not have access to the assistive technology they need... Before we decide on what questions are most important, before we decide on what approaches are most effective, I think we need to acknowledge that we need to approach these challenges with an attitude of humility because whatever we have tried so far, it is not working.”

Fernando Botelho
(30 April 2025, Webinar)

State of the art

What We Know

Assistive technology (AT) is increasingly recognised as a cornerstone of inclusive development for children with disabilities. It enables access to education, mobility, communication, and social participation. Evidence confirms that in low- and middle-income countries (LMICs), the gap between need and provision is stark: fewer than 10% of individuals have access to the assistive products they require—with even lower rates among children.

Speakers drew heavily on findings from the *Global Report on Assistive Technology*, which documents persistent disparities in access, the inadequacy of one-off device handouts, and the urgent need for sustained, system-level investment. Most national AT systems in LMICs are underfunded, fragmented, and heavily reliant on donor support.

We also know that assistive technology provision in many low-resource contexts is poorly integrated across education, health, and rehabilitation services. Devices are often imported without local adaptation, distributed without training or follow-up, and prescribed without child or caregiver input—contributing to high rates of device abandonment. Evidence consistently shows that successful AT provision depends not just on the availability of suitable products, but on well-coordinated systems that include user training, community engagement, and ongoing maintenance.

Community and caregiver involvement are increasingly recognised as critical to effective implementation. Where co-design and local repair systems exist, they improve contextual relevance, support sustainability, and reduce abandonment. Concerns about the quality of AT prescription are also well-founded: mismatched or inappropriate devices routinely result in user frustration and exclusion from learning.

While some technological innovations receive attention, speakers noted that low-tech or training-based innovations often yield better outcomes. There is clear recognition that innovations in service delivery—rather than in the technology itself—often hold the key to scale and sustainability. Evidence supports the need for greater investment in child-centred, longitudinal studies that measure real-world impact, including modest gains that can drive system reform over time.

Limitations and gaps in knowledge

Despite progress, major evidence gaps persist—particularly in LMICs and humanitarian settings—where research remains limited, fragmented, or overly focused on devices rather than systems or outcomes. One critical gap is the lack of research on children’s lived experiences with AT. Studies rarely explore how children use, adapt, or feel about AT in daily life, and even fewer examine perspectives from families, educators, or communities.

Research remains disproportionately focused on device performance. Systemic barriers such as supply chain breakdowns, limited human resources, and mismatches between devices and user needs are acknowledged in practice but not well studied. The long-term developmental, educational, and social outcomes of AT use are similarly under-researched.

Speakers highlighted the ongoing lack of disaggregated data. Few countries systematically track AT access by age, impairment type, or context. Where data systems do exist, they often exclude classroom-based technologies and fail to monitor continued use or impact after device distribution. There is also minimal evidence on the appropriateness and adaptability of AT developed in high-income countries when applied in low-resource environments. Questions remain about usability, sustainability, and fit with local norms and infrastructure.

Research design itself presents challenges. Studies often rely on proxy indicators or short-term measures, lacking direct evaluations of child outcomes. There is insufficient exploration of the timing of AT provision—despite growing consensus that earlier access improves results. Similarly, the long-term functionality and user satisfaction with digital AT, particularly in LMICs, remain poorly documented.

In humanitarian and crisis contexts, research is even more limited. While low-cost and portable devices are increasingly deployed in emergencies, few studies evaluate their long-term impact, durability, or integration into broader protection or education systems.

Finally, while participatory design is widely promoted, its practical application in AT research remains rare. Few studies include meaningful engagement of children with disabilities in the design, testing, or evaluation of AT. Until these voices are central to the research cycle, children with the most complex needs will continue to be excluded from both the evidence base and the programmes that result from it.

Challenges in generating knowledge

Barriers to obtaining and synthesizing data

A major barrier to advancing inclusive AT systems is the lack of comprehensive, disaggregated, and longitudinal data. Most national data systems track only distribution—not whether devices are appropriate, used, or beneficial to children’s development. Speakers noted that geographic dispersion, insufficient funding, and the lack of trained personnel often hinder data collection, especially in rural, low-resource, and humanitarian settings.

Additionally, stigma and discrimination can suppress participation in research or lead to underreporting. Inaccessible research tools frequently exclude children with communication, cognitive, or neurodevelopmental disabilities—due to narrow eligibility criteria, inaccessible formats, or assumptions about capacity. Teachers and community members may also be unaware of existing AT options, further limiting data visibility and uptake.

Issues with national data systems

National AT data systems often lack integration across sectors. Ministries of education, health, and social protection typically operate in silos, leading to duplicated efforts and inconsistent provision. Although tools like the WHO AT Capacity Assessment (ATA-C) and UNICEF’s Child Functioning Module (CFM) exist, they are not widely applied or harmonized. Regulatory and bureaucratic barriers also limit efficient data sharing and tracking, and few systems include monitoring mechanisms to assess whether AT devices remain functional or meet evolving needs of the growing child.

Research methodology and ethical challenges

Many AT studies in LMICs are short-term, narrowly focused on devices, and lacking in user engagement. Research often fails to explore broader impacts on learning, participation, or well-being. Ethical approval processes frequently exclude children with disabilities, based on unproven assumptions about risk, communication limitations, or consent complexity. This form of "ethical gatekeeping" contributes to exclusion, especially in low-resource or emergency contexts.

Other constraints include underfunded projects, prioritization of life-saving interventions over AT-related studies, and a lack of inclusive or trauma-informed research frameworks. Few studies are co-produced with children, caregivers, or local service providers—missing critical insights and perpetuating top-down models that may not reflect lived realities.

Systemic and structural constraints

AT is still widely viewed as a medical or charitable intervention, rather than a development priority or human right. National budgets often lack dedicated lines for procurement, repair, or training, relying instead on short-term donations or externally funded projects. Multi-sectoral collaboration remains weak, and education and social protection actors are often absent from AT planning and research.

Governments may resist research that highlights systemic failures, particularly in settings where resources are constrained. This contributes to inertia and reinforces gaps in access, provision, and evaluation. In conflict-affected and low-income contexts, the absence of trained rehabilitation professionals and supporting infrastructure deepens these inequities.

Engaging children with disabilities in research

Opportunities for engagement

Speakers emphasized that children with disabilities must be recognised as active users—not passive recipients—of assistive technology. Their insights are essential to understanding how AT functions in everyday life, including at home, school, and in the community. Participatory research models that engage children and caregivers from the outset—through co-design, peer-to-peer learning, and storytelling methods—offer practical and ethical advantages.

Caregiver involvement was also highlighted as crucial, especially in settings where formal systems are weak. Local knowledge can enhance device fit, support long-term use, and strengthen uptake. Collaboration with teachers and frontline workers further builds capacity and improves the relevance of findings.

Speakers stressed the importance of applying participatory research in inclusive school environments—not only in special settings—where the needs of children with disabilities are more likely to be overlooked without intentional design.

Barriers to Participation and Representation

Despite growing momentum for participatory approaches, children with disabilities—particularly those with communication, neurodevelopmental, or multiple disabilities—remain largely excluded from assistive technology (AT) research and planning. While children with sensory impairments are somewhat better represented in existing studies, those with communication, cognitive, or multiple disabilities continue to be consistently underrepresented. This imbalance is reinforced by methodological limitations, adult-oriented research tools, and prevailing assumptions about capacity or communication that hinder inclusive design.

Ethical gatekeeping was identified as a barrier. Speakers noted that ethics review boards often view disability-inclusive child research as high-risk, leading to restrictive protocols or outright exclusion—especially in low-resource or humanitarian settings. They also emphasized that in times of crisis, AT programmes are frequently among the first to be deprioritized, reinforcing the perception that inclusion is optional. In many low- and middle-income countries, governments tend to prioritise basic needs over research, creating additional barriers to funding or prioritising disability-related studies.

Audience questions reflected concerns about this systemic neglect, with several asking whether national AT systems could be more intentionally linked to early childhood intervention and inclusive education. These reflections highlighted the need for a shift away from top-down service models and toward approaches grounded in the engagement of children and caregivers.

Illustrative Practices and Case Reflections

Throughout the webinar, speakers shared practical examples to ground the discussion on assistive technology (AT) in low-resource settings and LMICs. Israel Balogun highlighted systemic gaps using global tools such as:

- The UNICEF Inclusive Products Catalogue and the WHO 5P Framework

Paul Lynch presented case studies illustrating the importance of tailoring technology to individual needs, including:

- The Baby Ubuntu programme for children with cerebral palsy
- Mobile-based sign language education during COVID-19

Fernando Botelho offered critical insights on the limitations of digital AT pilots, stressing the need for sustained investment in services, user training, and:

- Community-led repair models and peer support networks

Together, these examples reinforced that effective AT solutions require more than just devices—they need scalable, sustainable systems tailored to real-world use. Speakers emphasized the need for inclusive research that can inform how AT approaches are adapted and scaled across diverse LMIC contexts. Research must include children with a wide range of disabilities—including those with communication, neurodevelopmental, and multiple impairments—and account for varied social, cultural, and environmental settings.

The webinar underscored the urgent need for studies that evaluate not only product efficacy, but also delivery systems, user experiences, physical environment, and long-term outcomes. A one-size-fits-all approach to research risks reinforcing exclusion. Instead, research must be co-designed with users, flexible across contexts, and grounded in the daily realities of children and families using AT.

“It doesn’t matter if it’s a screen reader or a wheelchair—the AT will be only as effective as the level of accessibility of the environment where it is used.”

Fernando Botelho
(30 April 2025, Webinar)

Recommendations

Figure 11: Recommendations for Webinar 3: Access to assistive technology in low-resource settings

Addressing Knowledge Gaps

- Conduct user-centered studies on AT adoption and relevance that reflect the perspectives of children, families, and educators. Traditional methods often fail to capture lived experience or contextual needs, limiting their real-world applicability.
- Investigate the frequency of inappropriate AT prescriptions and device abandonment, ensuring children receive the right tools and support to thrive.
- Embed participatory methods that centre children's and caregivers' voices in research design—particularly for groups traditionally excluded from studies.

Improving Methodology and Data Systems

- Integrate feedback throughout the AT lifecycle—from needs assessment and co-design to implementation, evaluation, and maintenance—to ensure research remains responsive and relevant.
- Develop shared data protocols across education, health, and social protection sectors to reduce fragmentation and support more holistic evidence generation.
- Train researchers and ethics committees in disability-inclusive and trauma-informed research practices to reduce exclusion and uphold ethical standards.
- Strengthen longitudinal tracking of AT outcomes in national education and child protection systems to improve continuity, comparability, and insight into long-term impacts.
- Expand national data systems to disaggregate by age, disability type, AT usage, and educational outcomes—enabling more equitable planning and analysis.

Increasing Inclusion

- Co-design research methodologies with children using accessible, child-sensitive, and participatory approaches that reflect their lived experiences.
- Involve caregivers at every stage of research design, implementation, and analysis, recognising their essential role in daily AT use and support.
- Adapt research tools and protocols to reflect language, cultural context, and routines—particularly for children with multiple and communication-related disabilities, who are often excluded from conventional study designs.

Policy and Programming

- Mandate interministerial research coordination and data sharing, ensuring AT research aligns with national priorities and facilitates cross-sector learning.
 - Integrate AT into national research agendas across education, health, and social protection sectors. Support this with dedicated funding for long-term, mixed-methods, and implementation-focused studies.
 - Support research into AT procurement, delivery, and maintenance, including comparative studies of local manufacturing and repair networks in diverse LMIC contexts.
- Fund research focusing on children with cognitive, psychosocial, and multiple disabilities, who are systematically excluded from current datasets and evaluation frameworks

Enablers and Future Research

- Secure long-term political and financial support for inclusive AT research, reducing dependency on fragmented, donor-driven projects.
- Build research capacity among caregivers, frontline workers, and technicians, who play critical roles in co-design, data collection, and evaluating AT impact.
- Strengthen innovation ecosystems for locally adapted, low-cost AT solutions by addressing gaps in infrastructure and applied research capacity.
- Establish inclusive governance mechanisms that embed children's and caregivers' voices in research planning, implementation, and review processes.
- Evaluate AT effectiveness and sustainability in humanitarian contexts, where service disruption and infrastructure gaps remain major barriers to long-term use.
- Develop ethical, child-centred research frameworks that ensure meaningful and safe participation of children with disabilities, particularly in feedback and monitoring.
- Explore cross-sector cost-sharing and procurement models, improving efficiency and ensuring consistent AT access by coordinating efforts across education, health, and social protection.
- Conduct longitudinal studies on AT's impact on learning, participation, and life outcomes—especially for children with high support needs in resource-constrained settings.

“There needs to be much greater engagement of parents, caregivers, and the wider community—but this is not actually happening, particularly at the home and community level.”

Dr. Paul Lynch
(30 April 2025, Webinar)

“We’d like to have more research that is child-centred in the types of measurements that they use—instead of using proxy indicators—with more longitudinal studies and larger samples.”

Fernando Botelho
(30 April 2025, Webinar)

Annex D. Webinar readout: Children with disabilities in emergencies

Webinar Date: 02 May 2025

Opening remarks and moderator: Dr. Gavin Wood, UNICEF Innocenti

Speakers: Prof. Maria Kett, Professor, University College London; Israel Balogun, University College London; Brigitte Rohwerder, Institute of Development Studies.

Framing and relevance

Children with disabilities in emergencies is an especially important and often overlooked topic. If you've been reading this report from start to finish, you will have noticed a recurring phrase: "*Children with disabilities are among the most marginalized groups affected by...*". In the context of humanitarian crises, this is particularly true. Yet research on their experiences—and on what inclusion looks like in these settings—remains limited and fragmented.

UNICEF Innocenti recently updated its Evidence and Gap Map on inclusive interventions for children with disabilities and identified a striking absence of literature and research related to humanitarian contexts. This lack of traditional evidence makes it even more urgent to learn from those working directly in the field.

This fourth webinar in the *Beyond Barriers* series examined persistent evidence gaps, structural barriers, and methodological challenges that constrain disability-inclusive research in emergencies.

The webinar approached the topic through a rights-based and participatory lens. Speakers called for ethical, timely, and actionable evidence that reflects the lived experiences of children with disabilities in contexts of conflict, displacement, and disaster. Presenters highlighted how inaccessible infrastructure, lack of disaggregated data, and heightened security risks further limit the visibility of children with disabilities in humanitarian systems. Yet they also emphasized that humanitarian settings can be spaces of opportunity—where new research approaches can disrupt exclusion and reframe how knowledge is produced and applied.

Moderated by **Dr. Gavin Wood** (Global Research Manager, UNICEF Innocenti), the webinar built on priorities in the *Global Research Agenda for Children with Disabilities*, launched earlier at the Global Disability Summit. The agenda emphasizes inclusive research across education, early childhood intervention, and humanitarian contexts. Three experts contributed diverse perspectives:

- **Prof. Maria Kett** (University College London) argued for reframing humanitarian research through a social justice lens. She warned against treating tools like the Washington Group Questions as evidence of inclusion in themselves, stressing that measurement without participation does not equal equity. She advocated for twin-track approaches that both mainstream disability and pursue disability-specific research, with greater use of creative dissemination—such as storytelling and exhibitions.
- **Dr. Israel Balogun** (UCL/Commonwealth Scholar) shared grounded examples of community-led and participatory research, including co-design with OPDs and peer research in insecure contexts. He underscored the need for flexibility, ethical preparedness, and continuity in emergency research environments.
- **Brigitte Rohwerder** (Institute of Development Studies) reviewed findings showing how aggregated data, stigma, and methodological assumptions render children with disabilities invisible. She advocated for peer-led focus groups, creative tools, and inclusive analysis processes to shift ownership and strengthen relevance.

“We’ve focused a lot on policies—and that’s important—but much less on the underlying assumptions that lead to exclusion. Without examining those mechanisms, we can’t achieve transformational change.”

Prof. Maria Kett
(02 May 2025, Webinar)

State of the art

What we know

While international frameworks—such as the IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (2019) and UNICEF’s Global Guidance on Including Children with Disabilities in Humanitarian Action (2017)—have laid important foundations, research on how these frameworks are implemented remains limited. As Prof. Maria Kett emphasised, tools like the Washington Group Questions are often used as a proxy for inclusion, yet their use alone does not guarantee meaningful participation or equity. Without critical reflection or participatory engagement, data collection risks becoming a technical exercise that fails to capture children’s lived experiences.

There is a growing recognition that humanitarian research must examine not only whether disability is mentioned in policies, but whether inclusion is being translated into real change on the ground. However, limited funding, insufficient disability expertise among humanitarian actors, and poor integration of local researchers and organisations of persons with disabilities (OPDs) continue to restrict the quality, reach, and sustainability of disability-inclusive research.

Traditional research methods—especially those relying solely on caregiver input—have been shown to fall short in capturing the complex realities of children with disabilities in humanitarian contexts. In response, more inclusive, participatory approaches are emerging. These include child-led tools, community-driven research, and collaboration with local OPDs, all of which help build more equitable and responsive research relationships.

Creative, non-traditional methods are also gaining traction. These include storytelling, film, drawing, and visual exhibitions—tools that not only foster trust and safety but also expand the reach and accessibility of research. These innovations point to the need for more context-sensitive, culturally grounded, and mixed-method strategies that reflect the diversity of disability and promote meaningful inclusion throughout the research process.

Limitations and gaps in knowledge

Disaggregated data on children with disabilities in humanitarian settings remains extremely limited. Much of the available data either aggregates children with adults or merges disability with other vulnerability indicators—such as poverty or displacement—making it difficult to isolate the distinct experiences of children with disabilities or monitor their inclusion in humanitarian responses. This lack of specificity hampers both research and programming efforts aimed at equitable and accountable service delivery.

Few studies include children with disabilities as direct participants—especially those with intellectual or communication disabilities. Ethical concerns, methodological limitations, and lack of training among researchers often result in reliance on adult or caregiver perspectives, thereby excluding children’s own voices and agency.

Additionally, little research has explored the underlying structural causes of exclusion. There is a need to better understand how state-led systems and humanitarian responses contribute to marginalisation, and through what mechanisms that exclusion is produced and sustained.

While evidence exists on the negative effects of emergencies—such as increased violence, disrupted services, and social isolation—very few studies assess the effectiveness of interventions designed to address these challenges. Most research focuses on describing exclusion rather than evaluating inclusive practices or outcomes. Even where promising approaches are underway, they are rarely documented or shared widely. This lack of visibility makes it difficult for humanitarian actors to replicate or scale what works.

Finally, structural barriers remain. Short-term funding cycles limit follow-through. Humanitarian agencies often lack staff with disability expertise. And local researchers and OPDs are frequently excluded from research design and implementation. These constraints reduce the potential for long-term, inclusive research systems that are locally relevant and sustainable.

Challenges in generating knowledge

Despite increasing recognition of the importance of disability-inclusive research in emergencies, significant challenges remain. These challenges affect the rigour, ethics, and reach of research, particularly where children with disabilities are concerned. Barriers exist at multiple levels—technical, structural, institutional, and methodological—and disproportionately impact those with the highest support needs.

Data gaps and visibility

Disability-disaggregated data remains limited across most humanitarian contexts. Emergencies often disrupt national data systems, making it difficult to obtain timely or reliable information on children with disabilities. In many cases, disability is grouped under broad vulnerability labels or aggregated with adult data, reducing visibility and weakening accountability.

Existing data collection tools are rarely adapted for use in crisis situations. Where tools are deployed, they are often inaccessible or unsuitable for identifying children with disabilities—especially those with cognitive or communication support needs. This invisibility undermines inclusive programming and limits the ability of agencies to track progress or adjust interventions effectively. It was noted by the moderator that UNICEF is soon rolling out a humanitarian version of the Child Functioning Module.

Research methodology and ethical challenges

Conventional data collection methods are frequently impractical in emergency settings due to security concerns, logistical constraints, and population displacement. These conditions demand flexibility, but most standard research protocols are rigid and designed for stable environments. As Israel Balogun noted, researchers must be prepared to adapt in real time to shifting contexts.

“And oftentimes when you are carrying out research in emergency, there is a need for you to be dynamic, and have urgency in decision making processes...You realize that the situation might just change suddenly. And for you as a researcher, you need to be innovative, you need to think quick, you need to pre-empt some of these potential challenges so that when you set the ball rolling, you won't have challenges.”

Dr. Israel Balogun
(02 May 2025, Webinar)

Inclusion in research design and leadership

Local researchers and organisations of persons with disabilities (OPDs) are frequently left out of research design and implementation in emergency settings. Tight timelines, inflexible funding, and externally driven agendas often lead to extractive research that is disconnected from local realities. Even when local actors are included, it is often tokenistic—limiting opportunities for shared ownership, capacity strengthening, and longer-term impact.

This exclusion undermines the relevance and quality of research. It also means that promising innovations developed by local actors—such as community-based data collection or peer-led enquiry—are less likely to be recognised, documented, or scaled.

Funding and structural constraints

Short-term humanitarian funding cycles rarely prioritise research, let alone research focused on marginalised subgroups. Even where disability-inclusive research is commissioned, it is often constrained by limited duration, a narrow scope, and a lack of follow-through beyond the emergency phase.

Some humanitarian actors lack in-house expertise on disability inclusion, making it difficult to design and deliver inclusive studies. Additionally, researchers often face disrupted or restricted access to populations, particularly in insecure or rapidly evolving contexts. These factors contribute to a fragmented evidence base and limit opportunities for learning and sustained system change.

Engaging children with disabilities in research

Opportunities for engagement

Speakers emphasized that meaningful engagement of children with disabilities in research is both feasible and essential, even in humanitarian contexts. Participatory methods—particularly those that use creative, accessible, and rights-based tools—were highlighted as key enablers. These included drawing, digital media, storytelling, child-friendly interviews, and visual mapping exercises, all of which support expression beyond verbal communication.

The role of organizations of persons with disabilities (OPDs), caregivers, and older children was underscored as vital in shaping participatory research tools and approaches. When designed with local input and adapted to diverse communication needs, these tools can help children participate safely and meaningfully in research. Embedding local knowledge into the process improves both the relevance and ethical quality of research in emergency settings.

“We’ve focused a lot on policies and that’s really important, but it has been much less focused on the underlying assumptions of why children with disabilities are left out. What are the impacts of these state actions on children with disabilities and what are those mechanisms of exclusion? Whilst there’s been progress, it perhaps hasn’t led to the transformational change we might have liked to have seen across the sector.”

Prof. Maria Kett
(02 May 2025, Webinar)

Barriers to participation and representation

Despite growing interest in participatory approaches, significant barriers remain. Research tools are often not designed with children with disabilities in mind—especially those with intellectual or communication support needs. For example, safeguarding protocols are typically structured around adult participation, with limited accommodations for children.

Even when caregivers are not intentionally excluding their children, the stress and trauma of crisis conditions can leave them overwhelmed, making it harder to support or facilitate their children’s participation in research. As a result, children with disabilities may remain unseen or excluded—not due to lack of interest, but because the realities of emergency contexts make engagement significantly more difficult.

Illustrative practices and case studies

The webinar highlighted a range of inclusive, context-sensitive approaches to researching with children with disabilities in humanitarian settings in countries such as Ethiopia, Burkina Faso, Kenya, Jordan, Palestine, and Nepal. Examples included:

- Peer-led focus groups and co-researcher models with persons with disabilities
- Accessible tools like storytelling, body mapping, and visual prompts
- Collaborations between international NGOs, local actors, and caregivers in contexts like Syrian refugee camps and the Rohingya crisis
- Innovations such as mobile data collection, satellite imagery, and remote interviews to reach hard-to-access populations
- The *Oxford Young Lives Project*, though not a disability-focused project, was cited as a strong research framework for engaging children in longitudinal research

Across these examples, the meaningful involvement of children, caregivers, and communities not only improved the relevance of the research but also helped shift attitudes among humanitarian staff. Collectively, the case studies underscored the transformative potential of co-produced, socially just research.

Recommendations

Figure 12: Recommendations for Webinar 4: Children with disabilities in emergencies

Addressing knowledge gaps

- Disaggregate data more precisely: Ensure children with disabilities are identified in humanitarian data by age, gender, and disability type— rather than grouping children within broad vulnerability categories or combining them with adult or caregiver data.
- Focus on underrepresented subgroups: Prioritize research on children with intellectual and communication disabilities, as well as those in rural or conflict-affected areas.
- Capture community-led innovation: Document real-time, inclusive practices led by OPDs, caregivers, or local actors that often go unrecorded but hold practical value for inclusive response.

Improving methodology and data systems

- Adapt research tools for emergencies: Ensure research instruments are accessible (e.g., Easy Read, sign-supported, audio-based where appropriate), context-specific, and usable in crisis conditions.
- Expand use of creative and participatory methods: Encourage expression through storytelling, drawing, body mapping, or technology when traditional surveys are not viable.
- Embed ethical safeguards into all stages of research: Include flexible consent, trauma-informed protocols, and ongoing assent processes to ensure participant safety and comfort throughout the research cycle.

Increasing inclusion

- Engage OPDs, caregivers, and children as co-producers of research, from priority-setting through tool development and interpretation of findings.
- Invest in local partnerships: Strengthen collaboration with researchers and local research institutions, and with lived experience of disability.
- Ensure intersectionality: Account for how disability intersects with gender, displacement, poverty, and other factors that shape exclusion in emergencies.
- Support children's roles as co-researchers: Facilitate their active involvement in shaping questions, collecting data, and communicating findings—building long-term pathways for participation and advocacy.

Policy and programming integration

- Translate evidence into action: Use research findings to inform inclusive preparedness, response plans, and humanitarian monitoring frameworks.
- Incorporate disability indicators in IASC Cluster coordination systems: Ensure inclusion is visible and tracked through needs assessments and cluster-level planning.
- Advocate for integrated funding mechanisms: Promote mechanisms that support long-term, cross-sectoral research instead of fragmented project cycles.

Enablers and future research priorities

- Build collaborative ecosystems: Foster long-term partnerships among global and local researchers, OPDs, humanitarian agencies, and communities. Use grey literature and lived experience to co-create relevant, actionable knowledge.
- Evaluate intervention outcomes: Research what inclusive humanitarian programming looks like in practice—what works, for whom, and under what conditions.
- Explore longitudinal impacts: Study the long-term effects of inclusive (or exclusive) responses on learning, health, safety, and participation.
- Support storytelling and arts-based methods: Use visual, performative, and narrative forms (e.g. film, photography, theatre) to elevate the voices of children with disabilities and shift perceptions.

“One area of increasing research is into the role of organizations of persons with disabilities in humanitarian response. However, again, there is very little research that focuses on children with disabilities inclusion and humanitarian programming, making it harder to understand the specific barriers and ways to overcome them that children with disabilities face. The available research indicates that despite progress on disability inclusion and humanitarian responses, there are still substantial gaps in implementation amongst those delivering humanitarian and emergency responses. More research is needed into why these implementation gaps exist, what are the institutional barriers to disability inclusion and how to overcome these, including in relation to the effects on and inclusion of children with disabilities and humanitarian and emergency response. In addition, more research and dissemination is needed on lessons learned from examples of disability inclusive humanitarian responses. More is going on than is publicly available, but it is harder for the wider sector to learn from such efforts if they are unaware of them.”

Brigitte Rohwerder
(02 May 2025, Webinar)

“We need to frame our research with a social justice lens. It genuinely has to be co-produced—not just with the children, but with their caregivers, their families, and their communities.”

Prof. Maria Kett
(02 May 2025, Webinar)

Annex E. Webinar readout: Ethical involvement of children with disabilities in research

Webinar Date: 06 May 2025

Moderator: Professor Bronagh Byrne, Queen’s University Belfast

Opening remarks: Dr. Gavin Wood, UNICEF Innocenti

Speakers: Dr. Mary Wickenden, Institute of Development Studies; Professor Sheffali Gulati, All India Institute of Medical Sciences; Dr. Tracey Smythe, London School of Hygiene & Tropical Medicine and Stellenbosch University

Framing and relevance

The final webinar in the UNICEF *Beyond Barriers* series took a deep dive into one of the recurring issues: the ethical dimensions of conducting research with children with disabilities. Framed around a central call to shift from research *on* children with disabilities to research *with* them, the webinar underscored that ethical research is not simply procedural—it is about rights, dignity, inclusion, and empowerment.

Speakers emphasized that ethical failure occurs not only when harm is caused, but also when children with disabilities are systematically excluded from research. Formal ethical approvals, while important, are insufficient on their own. Ethical practice must be continuous, relational, and grounded in humility, transparency, and responsiveness to power dynamics and overprotection.

The webinar was moderated by **Professor Bronagh Byrne** (Queen’s University Belfast), who describes herself as a profoundly deaf academic and Professor of Disability and Children’s Rights. Professor Byrne, who co-directs the Centre for Children’s Rights and serves on UNICEF Innocenti’s Global Research Agenda Advisory Group, opened the discussion by highlighting the ethical complexities that arise in disability-inclusive research. She emphasized the need for researchers to approach their work with care—particularly in relation to informed consent, power dynamics, and inclusive methodologies. The three expert speakers contributed powerful reflections:

- **Dr. Mary Wickenden** challenged pervasive myths that exclude children from research—such as assumptions about capacity, cost, or communication barriers. Drawing on participatory work in Kaduna, Nigeria, she illustrated how children co-developed a wellbeing and inclusion checklist using drawing, games, and stickers to express their priorities.
- **Dr. Sheffali Gulati** addressed practical and ethical dilemmas faced by researchers working with children with neurodevelopmental conditions. She provided clinical case examples showing how adapted consent processes, non-verbal communication cues, and safeguarding can enable inclusion even in low-resource settings.
- **Dr. Tracey Smythe** emphasized that ethical research must be grounded in relationships—not just rules. Through the *Juntos* project in Brazil and Colombia, she showed how active listening to families’ concerns and needs co-designed tools, and caregiver facilitation transformed hesitant families into research collaborators.

State of the art

What we know

Exclusion of children with disabilities from research is not only a missed opportunity—it is an ethical failure. Speakers emphasized that ethical research must recognise children with disabilities as experts in their own real-life experiences, not as passive subjects. Speakers stressed, when inclusion is sidelined, evidence risks becoming incomplete, unrepresentative,

and misaligned with the realities it seeks to inform. Nonetheless, exclusionary practices in research on children with disabilities remains common, and the absence of direct engagement produces incomplete or invalid evidence.

Speakers shared growing recognition of the value of participatory and non-verbal methods—such as storytelling, visual mapping, drawing, modelling, and co-developed checklists—which enable children to communicate in ways that suit them. These approaches are most effective when paired with caregiver facilitation and thoughtful adaptations to the research environment. Speakers highlighted how ethical, family-centred practices can help shift caregivers from initial fatigue or scepticism toward active co-leadership in research. Involving children early—such as in the co-creation of research tools and design—enhances both the inclusivity and relevance of the research process.

Importantly, ethical engagement is increasingly seen as a continuous process, rather than a one-time consent procedure. Feedback loops, ongoing assent, and attention to participant wellbeing are emerging as key pillars of ethical research. Family-centred methods—like those shared through the *Juntos* and Kaduna case studies—show how caregivers, when supported, can shift from gatekeepers to co-researchers, helping to shape both tools and outcomes.

Limitations and gaps in knowledge

Despite progress, the discussion recognised that inclusive research with children with disabilities remains rare, inconsistent, and often tokenistic. Many studies still rely on caregiver or professional proxies—even when children could meaningfully participate through adapted approaches. Such exclusion is particularly true for children with high support needs or those in institutional, humanitarian, or rural settings.

Speakers highlighted persistent gatekeeping by adults as a barrier—especially parents, teachers, and clinicians—who may act out of concern but end up silencing children “for their own good.” These dynamics, while well-meaning, can reinforce an assumption that inclusion in research studies is too risky, too complex, or not feasible.

Another gap lies in how ethics is interpreted and applied. Review boards often treat inclusion as an optional enhancement, and participatory tools (such as drawing or visual prompts) may be flagged as unconventional or unsuitable—especially in contexts unfamiliar with disability-inclusive practices. In low- and middle-income countries, ethical infrastructure remains weak, and inclusive methodologies lack clear guidance or institutional support.

Crucially, speakers noted the lack of documentation on how to navigate dissent—especially non-verbal dissent—and how to operationalize child-led decision-making in formal protocols. Many research processes continue to be extractive: children are engaged for data, but not for analysis, reflection, or follow-up. Without co-created indicators and transparency around outcomes, ethical intent is easily lost.

Challenges in generating knowledge

Despite growing recognition of the need for ethical, inclusive research, significant barriers remain in generating rigorous, representative evidence involving children with disabilities. These challenges are multidimensional—spanning technical, ethical, institutional, and cultural domains—and often intersect in ways that disproportionately exclude children with the highest support needs.

Barriers to obtaining and synthesizing data

Speaker noted that many existing research tools rely heavily on verbal, written, or structured formats that exclude children with communication or cognitive disabilities. Standardised approaches—such as verbal surveys or written consent forms—are often inaccessible, leading to the statistical invisibility of these children.

Dr. Tracey Smythe highlighted that exclusion often starts at the design stage. In a review of 100 early childhood development trials, Smythe, Zuurmond, Tann, Gladstone, and Kuper (2021) found that:

- **50%** explicitly excluded children with disabilities;
- **30%** were designed only for children with disabilities;
- **20%** did not specify inclusion criteria.

(Smythe T, 2021 Apr 27)

This reflects how exclusion becomes embedded from the outset, resulting in gaps in evidence, broken trust, and inadequate services for those most in need. Participatory alternatives—such as drawing, visual cards, simplified consent materials, or behavioural observation—are essential to making research tools more inclusive but remain underused.

Research methodology and ethical challenges

Traditional research designs, especially large-scale or clinical studies, are often ill-suited for the diverse needs of children with disabilities. Ethical safeguards, while essential, are sometimes applied in ways that default to exclusion—prioritising risk avoidance over inclusive participation. Children with intellectual disabilities or high support needs are frequently deemed “too complex” to involve, particularly in emergency or institutional settings.

Even where participation is possible, research teams often lack the tools or training to recognise and respond to non-verbal dissent, or to implement ongoing assent processes that uphold children’s autonomy. In some settings, ethics protocols require consent to be obtained once and in writing—an approach ill-matched to the lived realities of many children with disabilities.

There is also a legacy of extractive research in this space. Children and families may contribute data without ever seeing how it is used, what results it produces, or how their contributions shape change. Without feedback, research becomes one-sided, eroding trust and reinforcing patterns of exclusion.

Inclusion in research design and leadership

Research priorities, design processes, and tools are often developed without input from children with disabilities or their representative organisations. Local researchers, OPDs, and caregivers are frequently excluded due to funding constraints, administrative barriers, or assumptions about expertise.

As a result, commonly used tools— such as verbal surveys, written questionnaires, standard consent forms, or ‘unadapted’ interview protocols — may be inaccessible to children with communication or cognitive disabilities, may fail to reflect children’s lived experiences, cultural contexts, or modes of communication. The webinar highlighted the need for co-creation—not only of tools, but of research agendas—so that children’s priorities shape what gets studied and how.

“Research is not just a method—it’s a relationship. And if we approach that relational process with humility and intention, we can shift from studying families to standing with them. This builds dignity and equity in each research step [Referring to a recent project in Juntos] We kept asking ourselves how we could do better. We listened, we learned, and we stayed curious together. Let that be our standard: equity not only in outcomes, but in every interaction along the way.”

Dr. Tracey Smythe
(06 May 2025, Webinar)

Funding and structural barriers

Short-term project timelines and inflexible budgets hinder researchers' ability to build trust, adapt methods, or sustain engagement with children and families. Inclusion often requires modest resources—interpreters, accessible materials, flexible scheduling—but these are rarely prioritised in planning or costed adequately.

Speakers stressed that inclusion is too often treated as an optional enhancement rather than a core design element. Unless funders and institutions shift their expectations and invest in ethical infrastructure, inclusive research will remain sporadic and inconsistent.

Engaging children with disabilities in research

Opportunities for engagement

Speakers emphasised that children with disabilities must not only be included in research but meaningfully engaged through accessible, respectful, and rights-based methods. Participatory approaches—such as drawing, role-play, storytelling, miming, visual mapping, and co-designed checklists—allow children, particularly those with intellectual or communication support needs, to express themselves in ways beyond conventional verbal or written responses.

Dr. Sheffali Gulati shared inclusive strategies for enabling consent and assent, including the use of body language, simplified explanations, visual prompts, and paraphrasing to confirm understanding. She underscored the importance of creating a supportive environment in which children feel safe and empowered to indicate both agreement and dissent.

Speakers also noted that engaging parents and caregivers in the research process strengthens both ethical safeguards and data quality. Caregivers can help interpret children's needs and preferences, co-develop research tools, and facilitate ongoing communication. Their involvement also provides insight into broader contextual realities—including stigma, time constraints, or stressors—that shape children's capacity to participate.

A recurring theme was the need for continuous, rather than one-off, consent and engagement. Ethical research should be iterative and built on trust, reciprocity, and transparency. Dr. Tracey Smythe explained: this includes building feedback loops, creating space for children to revisit or withdraw assent, and embedding mechanisms for reflection at each stage of the process.

“The assumptions that they're [children with disabilities] not capable of participating is just not true. We can include them if we adapt our methods to suit the children's needs, their support needs, their impairment-specific needs, their ages, their interests, their ways of participating... It's unethical to exclude them. It's the adults' responsibility to find ways to include them.”

Dr. Mary Wickenden
(06 May 2025, Webinar)

Barriers to participation and representation

Despite increased interest in inclusive approaches, children with disabilities continue to face significant barriers to participation in research—particularly those with higher support needs or non-verbal communication styles. Many research tools and safeguarding frameworks are not designed with these children in mind. Standard protocols may assume verbal fluency, literacy, or the ability to engage on fixed timelines, inadvertently excluding children who require more flexibility or support.

Gatekeepers have a legitimate role to identify and block participation in poorly designed, unsafe research. However, there are concerns when gatekeeping becomes overly restrictive, and children are excluded from research they could safely participate. Parents, teachers, clinicians, institutions, or even OPDs may unintentionally restrict children's participation based on assumptions that it is too risky, burdensome, or potentially stigmatising. While often well-intentioned, these

protective actions contribute to a pattern of structural exclusion. It requires both education of gatekeepers and an improvement of the research proposals and design.

Speakers reiterated that ethical inclusion is not only about who is invited to participate, but who is consistently left out of view. True engagement requires actively identifying and dismantling these barriers, not simply extending invitations to a predetermined few.

Illustrative practices and case studies

Speakers shared a range of compelling examples demonstrating how children with disabilities can meaningfully participate in research when inclusive practices are embedded from the outset. These cases underscored that ethical research is not only feasible in diverse contexts—including low-resource and clinical settings—but stronger and more impactful when built on trust, flexibility, and mutual respect.

- **Dr. Mary Wickenden** shared insights from a participatory study in Kaduna, Nigeria, where children with disabilities co-developed a school inclusion and wellbeing checklist. Using games, drawings, stickers, and visual prompts, children were able to express their priorities and ideas without relying on conventional verbal methods. These non-verbal techniques respected diverse communication styles and honoured children’s agency.
- **Dr. Tracey Smythe** described how the Juntos programme in Brazil and Colombia reframed ethics as a continuous, relational process. Initially, caregivers were hesitant about their children’s participation. However, by introducing, regular feedback loops, co-creation of images (where caregivers described how they would like to be portrayed, commented on drafts and approved final images) and creation of a space for collaborative reflection, caregivers became advocates for their children’s involvement. The programme demonstrated that trust-building and co-design can enhance both ethical rigour and research quality.
- **Dr. Sheffali Gulati** shared clinical case studies from India where visual aids, simplified consent materials, and attention to behavioural cues helped ensure meaningful inclusion of children with cognitive or communication-related impairments. Her work illustrated how adapting research protocols to accommodate children’s support needs—especially in clinical and low-resource contexts—can uphold dignity while yielding more reliable data.

Across all examples, speakers emphasised that ethical research with children with disabilities must evolve beyond compliance checklists. It requires thoughtful adaptation, inclusive design, and respectful engagement with children’s unique ways of knowing and communicating. Research becomes more than a technical exercise—it becomes a relational process grounded in equity and mutual learning.

“Ethical research doesn’t begin and end with consent forms—it unfolds through dialogue, responsiveness, and respect for children’s diverse ways of engaging with the world.”

Reflected sentiment across the panel

Recommendations

Figure 13: Recommendations for Webinar 5: Ethical involvement of children with disabilities in research

Addressing knowledge gaps

- Evaluate and share the effectiveness of participatory and non-verbal methods, including drawing, games, behavioral observation, and caregiver-supported communication, to build an evidence base around what works across diverse impairment types.
- Examine the role of ethics review processes in enabling or constraining disability-inclusive research, particularly in relation to assent, ongoing consent, and adaptations for children with complex support needs.
- Identify and address biases in who gets included, with attention to how age, impairment type, communication mode, and service access influence representation in current research.
- Develop indicators for ethical participation to move beyond procedural consent and toward more meaningful metrics—such as child agency, ongoing feedback, and shared decision-making.
- Build a shared evidence base on ethical practice by systematically documenting reflections, challenges, and adaptations from inclusive research efforts—particularly in low-resource and emergency contexts—to support learning, transparency, and continuous improvement.

Improving methodology and data systems

- Design research tools that are adaptable and accessible, using visual formats, simplified language, and alternative communication methods where needed.
- Embed flexible and ongoing assent processes, including non-verbal cues, paraphrasing, and revisiting consent and assent throughout the study.
- Ensure safe and enabling research environments that minimize discomfort, respect children's pace, and accommodate sensory or cognitive differences.

Increasing inclusion

- Engage children with disabilities, caregivers, and OPDs as co-creators in research design, tool development, and interpretation of findings.
- Strengthen partnerships with local researchers and disability organizations to ensure relevance, trust, and sustainability.
- Build the capacity of OPDs, caregivers, and community stakeholders to support inclusive research practices, including ethical facilitation, communication strategies, and safeguarding.
- Address gatekeeping dynamics by educating and equipping adults to enable, not restrict, children's participation.

Policy and programming

- Translate inclusive research findings into operational guidance, safeguarding protocols, and program design across sectors.
- Require and fund disability-inclusive research as part of program monitoring and evaluation frameworks.
- Equip ethics review boards and funding agencies with disability expertise and clear guidance to support inclusive research from inception.

Enablers and future research

- Evaluate the effectiveness and long-term impact of inclusive research approaches across different sectors and geographies.
- Examine mechanisms for ensuring accountability in ethical research practices, including how findings are shared, acted upon, and used to build long-term trust with participating communities.
- Explore child-led research models, including how children with disabilities can be involved not only as participants but as co-investigators or peer researchers.
- Investigate the role of digital and assistive technologies in enabling inclusive, remote, or hybrid research formats that extend reach and accessibility.

“The key takeaway is: disability inclusion is not a technical challenge. It is a political and moral one. It requires rethinking assumptions, reworking systems, and listening to those whose voices have been excluded for too long. We can build societies where all children, including those with disabilities, are seen, heard, and valued. Inclusion is not a favour; it is a right—and it is achievable. Research without us is not about us. And research with children, not just on them. True inclusion transforms research from observation into empowerment.”

Dr. Shefali Gulati
(06 May 2025, Webinar)

Annex F. Speaker and moderator list

Figure 14: Speaker and moderator list. All sessions were opened and closed by Dr. Gavin Wood

Webinar 1: Early identification and intervention for children with disabilities	
Speaker	Dr. Hollie Hix-Small
Speaker	Dr. Toby Long
Speaker	Dr. Mijna Hadders-Algra
Facilitator	Dr. Aleksandra Karovska
Webinar 2: Preventing and protecting children with disabilities from all forms of violence and abuse	
Speaker	Ms. Emily Eldred
Speaker	Dr. Claudia Arisi
Speaker	Dr. Cecilie K. Moesby-Jensen
Speaker	Ms. Maryam Ehsani
Facilitator	Ms. Lucy Marie Richardson
Webinar 3: Access to assistive technology in low-resource settings	
Speaker	Mr. Fernando Botelho
Speaker	Dr. Israel Balogun
Speaker	Dr. Paul Lynch
Facilitator	Dr. Deborah Taub
Webinar 4: Children with Disabilities in Emergencies	
Speaker	Ms. Brigitte Rohwerder
Speaker	Prof. Maria Kett
Speaker	Dr. Israel Balogun
Facilitator	Dr. Gavin Wood
Webinar 5: Ethical involvement of children with disabilities in research	
Speaker	Dr. Mary Wickenden
Speaker	Dr. Sheffali Gulati
Speaker	Dr. Tracey Smythe
Facilitator	Prof. Bronagh Byrne

Annex G. Full poll results (all themes)

1. Early Identification and Intervention for Children with Disabilities

Poll 1: How familiar are you with the concept of early identification and intervention for children with disabilities?

- Very familiar: 61%
- Somewhat familiar: 21%
- Not familiar: 18%

Poll 2: What do you believe is the most significant barrier to early identification and intervention research?

- Lack of Funding: 44%
- Access to families and caregivers: 41%
- Lack of consensus on definitions: 15%

Poll 3: What is the most effective way to involve families and caregivers in early intervention research?

- Co-designing research studies with families: 59%
- Conducting interviews and focus groups with caregivers: 24%
- Including family voices in data interpretation: 17%

Poll 4: Which approach holds the greatest potential for strengthening research in early identification and intervention? (Open-Ended)

- Asking children and parents what they think from the start!
- Participatory research with families, ECI organisations and government officials involved. This will help promote maximum use of research results
- Parents/caregiver -researcher partnership
- Inclusive approach.
- Whole Government, whole society approach
- listening to families before conducting the research
- participatory approach where families and multidisciplinary professionals contribute.
- Creativity and participatory in nature.

Poll 5: What is one thing you will take from this webinar that you are going to implement? (Open-Ended)

- Talk to families and caregivers
- Research on ECI should be undertaken with the full participation of all countries. Thank you
- being innovative and creative in designing research in LMIC with more family involvement
- Investigate SINDA
- Involving caregivers in research design
- Developmental monitoring and screening must go hand in hand - not as isolated checkboxes, but as a routine part of early childhood systems. Universal screening at key intervals (9, 12, 24, 48 months...) must become the norm.
- Consider the voice of affected families
- SINDA tool
- SINDA to explore more and to understand better what and how
- Embracing creativity!

2. Preventing and protecting children with disabilities from all forms of violence and abuse

Poll 1: What do you see as the biggest barrier to preventing violence against children with disabilities?

- Stigma: 46%
- Lack of data:25%
- Policy gaps:17%
- Insufficient funding:12%

Poll 2: In your experience, which sector plays the most critical role in safeguarding children with disabilities?

- All equally: 63%
- Education: 19%
- Social Services: 13%
- Justice: 5%

Poll 3: How do stigma and negative societal attitudes most impact research outcomes?

- Lead to underreporting: 8%
- Influence research design and sampling: 4 %
- Skew interpretation of findings: Nil
- All the above: 88 %

Poll 4: Which of the following is the biggest challenge in conducting participatory research with children with disabilities?

- Difficulty accessing participants: 48%
- Limited research capacity:29%
- Ethical concerns:14%
- Lack of funding:9%

3. Access to assistive technology in low-resource settings

Poll 1: What are the most pressing evidence gaps in AT research that need urgent attention?

- User-centred studies on AT usability, relevance, and adoption by children and caregivers:80%
- Research on equitable access to AT in low-resource and humanitarian settings:10%
- Evidence on AT effectiveness in improving learning outcomes for children with disabilities:10%

Poll 2: Which of the following areas presents the greatest challenge in AT provision in low-resource or humanitarian contexts?

- Affordability issues:31%
- Lack of effective screening methods for AT needs:31%
- Lack of service integration (health, education, rehabilitation):31%
- Supply and demand mismatch:7%

Poll 3: How can research methods avoid reinforcing inequities in AT provision?

- By co-designing studies with underrepresented communities and AT users:80%
- By addressing structural barriers—such as regulatory, funding, and market constraints—in research design:20%
- By ensuring inclusion of diverse, low-resource, and humanitarian contexts in research samples: Nil

Poll 4: What is the most urgent AT research priority?

- Embedding AT research within broader disability inclusion studies:25%
- Innovative methodologies for assessing AT access and needs:13%
- Moving from charity-based to rights-based AT provision: Nil
- All the above:62%

4. Children with disabilities in emergencies

Poll 1: What do you see as the biggest barrier to disability-inclusive humanitarian research?

- Weak integration of disability inclusion in humanitarian response:59%
- Short-term research priorities:29%
- Limited funding:14%
- Lack of data collection methods suited for crisis settings: Nil
- Ethical challenges of conducting research in emergencies: Nil

Poll 2: In your view, what are most promising ways to strengthen research on children with disabilities in emergency and humanitarian settings?

- Partner with local researchers and communities on field research:33%
- Co-create research outputs and share authorship:19%
- Strengthen local research capacity and leadership:33%
- Make research findings, including grey literature, widely accessible:11%
- Don't know (no experience):4%
- Recognize and integrate high-quality grey literature: Nil

Poll 3: What type of participatory methods ensures meaningful engagement of children with disabilities in research?

- Use of accessible, creative tools (e.g., drawing, storytelling, digital media) to support expression:46%
- Child-led or co-designed research approaches adapted to local contexts:36%
- Partnerships with OPDs and community facilitators to ensure ethical, inclusive engagement:18%

Poll 4: What type of research is most needed to assess the long-term impact of inclusive humanitarian interventions?

- Innovative mixed-methods research:34%
- Longitudinal studies:22%
- Participatory evaluations:22%
- Comparative cross-country studies:22%

5. Ethical involvement of children with disabilities in research

Poll 1: In your experience, which of the following is the most challenging ethical issue when conducting research with children with disabilities?

- Avoiding tokenism and ensuring meaningful participation:53%
- Ensuring truly informed consent and assent:17%
- Balancing inclusion with logistical and financial constraints:12%
- Protecting privacy and confidentiality, especially with communication barriers:12%
- Minimizing emotional and physical burdens of participation:6%

Poll 2: Which group do you find most critical in supporting ethical research with children with disabilities?

- Child participants themselves:37%
- Ethics review boards:25%
- Parents or caregivers:19%
- Organizations of Persons with Disabilities (OPDs):13%
- Educators or service providers:6%

Poll 3: What kind of support would most strengthen your ability to conduct ethical, inclusive research with children with disabilities?

- Practical tools for inclusive data collection:38%
- Partnerships with OPDs or disability advocates:25%
- Training on consent and assent with communication barriers:13%
- Guidance on navigating gatekeeper dynamics:12%
- Case studies or examples of ethical accommodation:12%

Annex H. Reference List

This reference list serves to identify all specific research papers or reports that speakers referred to in their presentations.

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Annex I. Links to YouTube Videos

In addition to the insights captured in the final report, UNICEF Beyond Barriers: Advancing Research for Children with Disabilities webinar series is available on YouTube. These webinars feature speaker presentations, expert panel discussions, and interactive Q&A sessions that delve deeper into the challenges and opportunities of inclusive research practices. Links to the individual webinar recordings can be found below for easy reference.

Table 2: YouTube Video Links

Webinar #	Date	Theme	Link to the YouTube video
1	22Apr2025	Early identification and intervention for children with disabilities	Linked here
2	24Apr2025	Preventing and protecting children with disabilities from all forms of violence and abuse	Linked here
3	30Apr2025	Access to assistive technology in low-resource settings	Linked here
4	02May2025	Children with disabilities in emergencies	Linked here
5	06May2025	Ethical involvement of children with disabilities in research	Linked here

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