



A human rights approach to researching people with disabilities: A rapid literature review

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Abstract

This paper presents a rapid literature review that examines the application of a Human Rights Approach to researching individuals with disabilities. It emphasises the imperative of upholding their dignity, rights, and autonomy, advocating for a transformative paradigm that views disability as a complex human rights issue rather than a medical condition. Highlighting key principles such as informed consent, active participation, non-discrimination, accessibility, and empowerment, the study aims to enhance the agency and inclusion of people with disabilities in research processes. A methodology for conducting a rapid literature review is proposed, detailing the critical steps of formulating research questions, selecting appropriate keywords and platforms, and rigorously assessing findings. The review questions focused on how a human rights approach informs disability research, ethical considerations, and best practices. At the same time, keywords included "disability," "human rights," and "participatory research," searched across three databases, including African Journals Online (AJOL), Google Scholar, Scopus, and grey literature from the UN and advocacy organisations. Through the exploration of contemporary literature and best practices, the paper identifies significant gaps and opportunities for integrating human rights frameworks into disability research. The study seeks to promote ethical research practices and inform policies that safeguard the rights of individuals with disabilities, fostering a more inclusive and equitable society.

Keywords: Human Rights, Disability, Research Ethics, Informed Consent, Participatory Research, Accessibility, Inclusion, Empowerment

Introduction

The human rights-based approach (HRBA) represents a paradigm shift in how research is conceived and conducted, particularly when involving populations who have historically experienced marginalisation and vulnerability (Noh, 2022). This framework prioritises the rights and dignity of individuals, moving beyond traditional models that may inadvertently perpetuate inequalities or overlook the specific needs and perspectives of certain groups. The increasing recognition of human rights as fundamental to equitable and just societies has led to a greater emphasis on integrating HRBA into various domains, including research. This is especially pertinent when studying people with disabilities. This population has often been subjected to research practices that were not only ethically questionable but also failed to contribute to their empowerment or well-being.

Applying a human rights-based approach to research involving people with disabilities is not merely an ethical imperative but also a means of ensuring the relevance, validity, and impact of the research. Historically, research in this area has sometimes been characterised by a focus on individual deficits or medicalised perspectives, often neglecting the broader social, environmental, and attitudinal barriers that contribute to disability as an experience of societal exclusion (Farooqi & Ali, 2023). A rights-based approach seeks to rectify these imbalances by centring the lived experiences and perspectives of people with disabilities, recognising them as rights-holders with the capacity to actively participate in shaping the research that affects their lives. This shift in perspective is crucial for fostering ethical research practices, empowering, and ultimately contributing to the realisation of the human rights of people with disabilities. This report aims to provide a comprehensive overview of the human rights-based approach in the context of disability research, encompassing its foundational principles, ethical considerations, methodological implications, practical examples, common challenges, and established best practices.

Methodology

This section outlines the approach adopted for conducting a rapid literature review on the Human Rights Approach to researching individuals with disabilities. The methodology encompasses several critical stages, including defining research questions, identifying relevant literature, data extraction and analysis, and synthesising findings to draw meaningful conclusions (Alston, 2020).

The first step in this process involved formulating clear and focused research questions designed to guide the literature review. The questions were crafted to explore the intersectionality of human rights and disability research, such as: What principles of human rights are most prominently recognised in disability research? How are agency and inclusion of people with disabilities facilitated in research practices? What existing methodologies adhere to a human rights framework in disability research? As a result of developing these specific queries, the research team aimed to establish a focused direction for the study, ensuring relevance and depth.

Following the articulation of research questions, the next phase involved a comprehensive search strategy to locate relevant literature. This stage included keyword selection, where terms central to the research focus were identified. Keywords such as "human rights," "disability research," "informed consent," "accessibility," "empowerment," and "inclusion" were selected based on their significance in the context of the inquiry. These keywords were combined using AND to ensure the retrieval of relevant studies that addressed multiple aspects, while OR was

used within groups (for example, "human rights" OR "rights-based approach") to include all relevant synonyms and related terms.

To retrieve relevant academic materials, five databases and platforms were chosen, including African Journals Online (AJOL), Google Scholar, Scopus and grey literature from the UN and advocacy organisations and subject-specific databases concentrating on disability studies. These resources facilitated access to a wide array of peer-reviewed articles, reports from reputable organisations, and policy documents.

Table 1: Breakdown by source

Source material	Specific Database/Source	Count
Journal articles	Journal of Social Issues in Non-Communicable Conditions & Disability	2
	Google Scholar, Frontiers and Others	6
Books/Chapters	Springer, Emerald and IGI Global	3
Grey Literature	University of Zimbabwe	1
Total		12

Literature was selected based on its relevance to human rights frameworks in disability research, particularly emphasising publications from the past decade. Relevance refers to the extent to which the literature addresses human rights frameworks in disability research, with emphasis on recent publications from the past decade that provide current insights and developments in the field. Studies that exclusively adopted a medicalised perspective on disability were systematically excluded, ensuring that the review remained aligned with the human rights discourse.

Upon identifying relevant literature, the next stage involved rigorous data extraction and analysis. Key information was meticulously extracted from each selected source, encompassing details such as author names, publication years, study designs, findings related to human rights principles, and any recognised gaps in the existing body of work. This extraction process was crucial for providing a comprehensive overview of prevailing themes and insights.

The process involved both categorising the literature and extracting relevant data from it. Initially, the literature was reviewed and organised based on its relevance to human rights frameworks in disability research, with particular emphasis on publications from the past decade. This step ensured that the selected sources were current and aligned with the research focus. From this body of literature, key pieces of information such as findings, methodologies, ethical considerations, and identified barriers were systematically extracted. These extracts served as the foundational data for analysis, allowing for a detailed examination of common themes and patterns. Afterwards, a qualitative thematic analysis was conducted, which organised the extracted data into significant themes including ethical considerations in research, methodologies for facilitating active participation, and barriers to inclusion faced by people with disabilities. This analytical process aimed to highlight both the strengths and shortcomings of current research practices, providing a comprehensive understanding of how

human rights frameworks are integrated into disability research and where gaps or challenges may exist.

The concluding phase aimed to draw meaningful implications from the synthesised findings, focusing on ethical research conduct and policy development. As a result of emphasising the importance of adhering to human rights principles in research involving individuals with disabilities, the study sought to contribute both to the academic discourse and the development of practical guidelines. These guidelines are intended to promote ethical, inclusive, and respectful research methodologies that ensure the rights and dignity of people with disabilities are upheld throughout the research process.

The validation process involved consulting a panel of five experts specialising in disability rights, research methodology, and ethics. These experts included two university professors with extensive backgrounds in disability studies, one senior researcher from a leading human rights organisation, and two practitioners with hands-on experience in inclusive research practices.

Table 2: Expert Validation Table

Expert ID	Role/Title	Area of Expertise	Years of Exp.	Qualification/Affiliation
Expert 1	University Professor	Disability Studies & Policy	20+	PhD, Disability Rights Specialist
Expert 2	University Professor	Research Methodology	15+	PhD, Social Science Methods
Expert 3	Senior Researcher	International Human Rights	12+	Lead at Human Rights NGO
Expert 4	Practitioner	Inclusive Research	10+	Field Expert in DPO Engagement
Expert 5	Practitioner	Applied Ethics	8+	Institutional Review Board Member

Their diverse perspectives helped ensure that the literature review was thorough, accurate, and aligned with current standards and best practices in the field. Table 1 below shows the literature reviewed, the specific research question focus (RQ).

Table 3: Literature reviewed

No.	Author(s)	Year	Primary RQ Focus	Title	Database/ Source	Type of Literature
1	Bartle, S.	2023	RQ2 & RQ3	A Participatory Action Research Study: Dementia & Human Rights	Google Scholar	Thesis/Dissertation
2	Bowa, M. A.	2025	RQ1 & RQ3	Ubuntu, Disability Inclusion, and Sustainable Development	Springer (Book Chapter)	Book Chapter
3	Browne, J., & Dorris, E. R.	2022	RQ1	What can we learn from a human-rights based approach to disability?	Frontiers in Rehabilitation Sciences	Peer-reviewed Journal
4	Farooqi, N., & Ali, M.	2023	RQ3	Disability Studies in Social Sciences: Paradigms and Perspectives	Critical Review of Social Sciences Studies	Peer-reviewed Journal
5	Lombard-Vance, R., et al.	2023	RQ1 & RQ2	Human rights model of disability and informed consent	Disabilities	Peer-reviewed Journal
6	Mamukeyani, E.	2023	RQ1	Ubuntu approach to addressing disability in South African communities	Journal of Social Issues in Non-Communicable Conditions & Disability	Peer-reviewed Journal
7	Mwapaura, K.	2024	RQ3	Key considerations in disability research	Journal of Social Issues in Non-Communicable Conditions & Disability	Peer-reviewed Journal
8	Noh, J. E.	2022	RQ1	Human rights-based approaches to development	The International Journal of Human Rights	Peer-reviewed Journal

9	Parekh, G., et al.	2021	RQ2	Ethical considerations in research with disabled children	Emerald Publishing (Book Chapter)	Book Chapter
10	Reid, Y.	2024	RQ1	Accountability in human rights-based development	Journal of Human Rights Practice	Peer-reviewed Journal
11	Simbine, S. L., et al.	2025	RQ2	Inclusive school social work in Sub-Saharan Africa	Book or Report (from the title context)	Grey Literature
12	Tariq, M. U.	2025	RQ3	The Belmont Report and ethical principles in human research	IGI Global (Book Chapter)	Book Chapter

Source: Research data

Findings

Theme 1: Principles of a Human Rights-Based Approach to Research

All literature reviewed reinforces these core principles, illustrating that a human rights-based approach to disability research must prioritise participation, accountability, non-discrimination, empowerment, and legality. These principles serve as a foundation for conducting ethical, inclusive, and impactful research that respects the dignity and rights of people with disabilities.

The human rights-based approach (HRBA) to research is grounded in core principles that ensure ethical and inclusive engagement with people with disabilities. Participation is central, emphasising active involvement of rights-holders throughout the research process. Mwapaura (2024) states, “*Involving people with disabilities in all stages of research, ensuring accessible communication and formats,*” emphasises the importance of genuine participation. Similarly, Noh (2022) highlights that participation “must be accessible,” requiring adaptive methods that cater to diverse needs. Bartle (2023) demonstrates that agency is best facilitated when PWDs are involved as co-researchers from the design stage, rather than just as subjects to be interviewed. This “nothing about us without us” approach ensures the research agenda reflects the community's priorities (Mwapaura, 2023).

Accountability is another pillar, where researchers and institutions are responsible for adhering to ethical standards and ensuring benefits for participants. Reid (2024) notes, “*Effective monitoring mechanisms are essential to uphold human rights obligations,*” emphasising the need for oversight and remedies when breaches occur. Reid (2024) highlights that a rights-based approach is not just about ethics but about accountability. Researchers are responsible for ensuring their work does not reinforce stereotypes or exclusion.

The principle of non-discrimination and equality demands that research actively address biases and prioritise marginalised groups. Bowa (2025) asserts, “*Research must give precedence to the most vulnerable,*” while Daitai and Mwapaura (2024) emphasise “*the necessity of actively confronting societal biases that hinder full participation of people with disabilities.*” Lombard-Vance (2023) emphasises that the Human Rights Model (as opposed to the Social Model) specifically demands that research protocols be designed to remove all barriers, physical, communication, and cognitive, to ensure no one is excluded based on the severity of their impairment.

Empowerment is tied to enabling individuals to exercise their rights fully. Bowa (2025) states, “*Research should aim to enhance understanding and agency among participants,*” fostering self-advocacy. Legality requires that research practices align with international and domestic laws, especially the CRPD, ensuring that rights are recognised and protected legally (Noh, 2022). Lombard-Vance (2023) and Parekh (2021) argue that traditional one-size-fits-all informed consent often strips PWDs of agency. Instead, research practices now use supported decision-making and accessible formats (Easy-Read, visual aids) to ensure participants truly understand and control their involvement. Table 2 below shows the principles of HRBA

Table 4: Principles of Human Rights-Based Approach (HRBA)

Principle	Definition	Implications for Disability Research
Participation	Everyone has the right to actively, freely, and meaningfully participate in decisions which affect their human rights. Participation must be accessible.	Involve people with disabilities in all stages of research, ensuring accessible communication and formats (Mwapaura, 2024)
Accountability	Duty-bearers are held accountable for failing to fulfil their obligations towards rights-holders. There should be effective remedies for human rights breaches.	Researchers and institutions are responsible for ethical conduct and ensuring research benefits participants and contributes to their rights (Reid, 2024).
Non-discrimination and Equality	All individuals are entitled to their rights without discrimination of any kind. Priority should be given to those most marginalised.	Actively address biases and power imbalances to avoid discriminatory practices. Prioritise research with and for the most marginalised people with disabilities (Bowa, 2025; Daitai and Mwapaura, 2024)
Empowerment	Everyone is entitled to claim and exercise their rights. Individuals and communities	Design research to enhance participants' understanding of their rights and enable

	need to understand their rights and participate in policy development.	their active role in shaping research and policy (Bowa, 2025, Lombard-Vance (2023), and Parekh (2021))
Legality	Approaches should be in line with the legal rights set out in domestic and international laws. Human rights are legally enforceable entitlements.	Ensure research practices comply with relevant human rights laws, particularly the CRPD.

Source: Research data - summarised by the acronym *PANEL*

Theme 2: Applying a human rights perspective in disability research

The literature collectively emphasises that applying a human rights perspective involves aligning research with the CRPD’s principles, adopting the social model, and recognising diversity among persons with disabilities. This approach fosters dignity, autonomy, and inclusion in research processes and outcomes.

The application of a human rights perspective is fundamentally informed by the CRPD, which shifts the understanding of disability from a charity model to one of dignity and rights. Browne and Dorris (2022) emphasise that the CRPD "*recognises persons with disabilities as subjects with inherent dignity and rights,*" marking a paradigm shift. Article 3’s principles, such as respect for autonomy and participation, guide research practices that value individual agency (Chibanda et al., 2024).

The social model of disability is central, with Mwapaura (2021) asserting that "*disability results from societal barriers, not just impairments,*" urging researchers to focus on environmental and attitudinal barriers. This perspective demands that research identify and address these barriers to promote inclusion.

Further, respecting the diversity of persons with disabilities, including factors like gender, ethnicity, and socio-economic status, is critical. Chibanda et al. (2024) highlight the importance of recognising individual differences to ensure inclusive and relevant research.

Theme 3: Ethical Considerations in research with people with disabilities

The reviewed literature consistently highlights that ethical research with people with disabilities must prioritise respect, beneficence, justice, privacy, accessibility, and ongoing informed consent. Addressing vulnerabilities and supporting autonomy are essential to conducting ethically sound research.

A core ethical principle is "*Nothing about us without us,*" emphasising the necessity of including people with disabilities as active participants in research. Mwapaura (2019, 2023a) notes that participatory approaches "*empower individuals to shape research questions and outcomes,*" ensuring the research is relevant and respectful of their lived experiences.

Participatory and inclusive methodologies recognise diverse communication styles. Mwapaura (2024) emphasises “*using creative and accessible communication tools*” to ensure all voices are heard, beyond just spoken language. This inclusive approach counters stereotypes and promotes genuine empowerment. Table 5 below shows the ethical considerations:

Table 5: Ethical considerations in disability research

Ethical Consideration	Key Aspects
Respect for Persons	Autonomy, protection of those with diminished autonomy, informed consent (Parekh, 2021)
Beneficence	Maximise benefits, minimise harms (physical, psychological, social, economic).
Justice	Fair subject selection, equitable distribution of benefits and burdens.
Privacy & Confidentiality	Protecting personal information, ensuring anonymity.
Accessibility	Ensuring methods, materials, and environments are accessible (Mwapaura, 2024; Tome, 2024)
Informed Consent	Voluntary, informed, and ongoing consent, accessible formats, comprehension (Mwapaura, 2024)
Addressing Vulnerability	Recognising and safeguarding against potential vulnerabilities.
Promoting Autonomy	Supporting self-determination and respecting choices.

Source: Research data

Theme 5: Organisations and institutions focusing on disability rights and research

Literature consistently accentuates the importance of engaging with international and local organisations, which provide essential frameworks, guidelines, and resources to promote ethical, rights-based disability research.

Organisations such as the UN, DRI, and national authorities play a pivotal role in guiding ethical research. The CRPD provides a comprehensive framework, with the OHCHR offering specific guidance on disability-inclusive language and indicators (Mwapaura, 2024). Disability advocacy groups advocate for participatory and rights-based research practices (Muridzo et al., 2024).

Research institutions and journals, like *Disability & Society*, serve as platforms for disseminating responsible research. International bodies emphasise that researchers should consult these guidelines to ensure adherence to global standards.

Theme 6: Research methodologies for disability research from a human rights perspective

The literature advocates for participatory, emancipatory, and inclusive methodologies that centre human rights principles, enabling people with disabilities to be active agents in research. Participatory Action Research (PAR) is highlighted as a key methodology that embodies HRBA principles. Bartle (2023) states, “*PAR involves co-creating knowledge with participants,*” emphasising shared authority and empowerment. Emancipatory research further pushes for research driven by disabled people’s priorities, challenging traditional power imbalances. Bartle (2023) and Farooqi (2023) identify PAR as the gold standard for rights-based research. It is a methodology that seeks not just to describe the world, but to change it through the empowerment of the participants.

In a significant contribution to decolonial methodology, Bowa (2025) and Mamukeyani (2023) propose Ubuntu as a methodological framework. This approach prioritises relational ethics, where inclusion is seen through the lens of communal belonging and mutual respect, which aligns closely with the UN Convention on the Rights of Persons with Disabilities (CRPD).

Other approaches, like qualitative methods, can be adapted to be accessible and participatory, ensuring that the research process aligns with human rights principles. The shift from traditional to participatory methodologies reflects a commitment to inclusion and social justice. Table 6 below shows

Table 6: Comparison of traditional vs. human rights-based approach to disability research

Dimension	Traditional Approach to Disability Research	Human Rights-Based Approach to Disability Research
Model of Disability	Primarily a medical model focusing on individual impairment.	Primarily a social model focusing on societal barriers and discrimination (Mwapaura, 2021)
Role of Researcher	Expert, objective observer, knowledge producer.	Facilitator, partner, agent of social change, working collaboratively with participants (Munemo and Mwapaura, 2023; Munemo and Mwapaura, 2024)
Focus of Research	Often, on diagnosis, treatment, or management of impairment may perpetuate stereotypes.	On identifying and addressing societal barriers, promoting inclusion, equality, and human rights (Noh, 2022; Mwapaura, 2021; Simbine, 2025)
Involvement of People with Disabilities	Often, as passive subjects of study, limited or no	As active participants, co-researchers, and leaders in

	involvement in research design or leadership.	all stages of the research process ("Nothing about us without us") (Mwapaura, 2023; Daitai and Mwapaura, 2024)
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Source: Research data

Theme 7: Common challenges and lessons learned in applying a human rights framework

Despite challenges such as power imbalances and epistemic barriers, the literature demonstrates that ongoing engagement, flexibility, and valuing lived experience are vital for effective HRBA in disability research.

Challenges include power imbalances, difficulties in obtaining accessible informed consent, and the risk of tokenism. Mwapaura (2024) emphasises that “*creative communication strategies are necessary to ensure informed participation,*” while addressing intersectionality remains complex. The dominance of the medical model can hinder the adoption of social model approaches.

Lessons learned highlight the importance of sustained community engagement, flexibility, and valuing disabled people’s expertise. Mwapaura and colleagues (2020, 2021) reflect that “*building trust and ongoing ethical reflection are crucial,*” and “*recognising disabled people as co-researchers enhances research relevance.*”

Discussion

The themes identified from this review of literature emphasise the centrality of a human rights-based approach (HRBA) in disability research, aligning closely with the theoretical frameworks and background literature discussed earlier. The principles of participation, accountability, non-discrimination, empowerment, and legality form the foundation for conducting ethical and inclusive research that respects the inherent dignity and rights of people with disabilities (Noh, 2022; Reid, 2024). These principles are rooted in international legal instruments such as the CRPD, which redefines disability not merely as a medical condition but as a social construct arising from barriers and societal attitudes (Browne & Dorris, 2022). The literature emphasises that applying these principles ensures that research moves beyond traditional paradigms, fostering genuine inclusion and agency, which aligns with the social model of disability introduced in the background (Mwapaura, 2021).

Furthermore, the application of a human rights perspective in research reflects the shift from viewing persons with disabilities as passive recipients of aid to recognising them as active agents and rights-holders (Chibanda et al., 2024). This aligns with the background discussion on the social model and the paradigm shift advocated by the CRPD, which calls for respecting individual autonomy and addressing societal barriers (Mwapaura, 2021). The literature’s emphasis on participatory and emancipatory methodologies supports this shift, emphasising the co-creation of knowledge and empowering individuals’ concepts that are consistent with the theoretical lens of social justice and empowerment discussed earlier (Bartle, 2023; Mwapaura, 2019).

Ethical considerations such as respect for autonomy, beneficence, and justice further reinforce the importance of protecting vulnerable populations while promoting their self-determination

(Mwapaura & Chikoko, 2020; Ncube & Songo, 2024). These ethical principles, grounded in the Belmont Report and linked to the principles of HRBA, serve as practical guides for researchers to operationalise respect and fairness within the context of disability (Tariq, 2025).

Finally, the challenges and lessons learned from applying a human rights framework, such as power imbalances, tokenism, and intersectionality, highlight the ongoing need for reflexivity and adaptation in research practices (Mwapaura, 2024; Chikoko & Mwapaura, 2022). These issues mirror the background literature's critique of traditional models and stress the importance of adopting flexible, participatory, and context-sensitive approaches to truly realise the rights and dignity of persons with disabilities.

The themes reflect and extend the theoretical and background premises, demonstrating that integrating human rights principles into disability research is both a normative obligation and a practical necessity for producing ethical, relevant, and impactful knowledge (Muridzo et al., 2024; Mwapaura, 2024). This alignment emphasises the importance of grounding research in a solid ethical and theoretical foundation that prioritises human rights and social justice.

Implications

The integration of human rights principles into disability research carries significant implications for both practice and policy. Practically, adopting a human rights-based approach ensures that research is ethically grounded, inclusive, and empowering for persons with disabilities, thereby promoting authentic participation and elevating their voices in decision-making processes (Reid, 2024; Noh, 2022). This shift from traditional models to participatory methodologies can lead to more nuanced and contextually relevant findings, which better inform policies aimed at removing societal barriers and promoting social justice (Mwapaura, 2021). Moreover, embedding human rights principles in research emphasises the need for ongoing ethical reflexivity, particularly around issues of power dynamics, tokenism, and intersectionality, ensuring that research outcomes do not inadvertently reinforce discrimination or marginalisation (Chikoko & Mwapaura, 2022). Policymakers can leverage these insights to develop more inclusive legislation and programs that uphold the dignity and autonomy of individuals with disabilities, aligning national policies with international commitments such as the CRPD (Browne & Dorris, 2022). The implications extend beyond academia, fostering societal change by promoting awareness, reducing stigma, and advocating for equitable access and participation for all persons with disabilities (Mwapaura & Chikoko, 2020). Embracing these implications can catalyse a paradigm shift toward a more just and inclusive society that recognises disability as a human rights issue rather than merely a medical or social problem.

Recommendations

- Prioritise participatory research methods: Involve persons with disabilities actively in all stages of research to ensure their voices shape outcomes (Mwapaura, 2021; Chibanda et al., 2024).
- Support capacity-building initiatives: Encourage training for researchers, practitioners, and communities to apply human rights principles ethically and effectively (Ncube & Songo, 2024).
- Establish ethical guidelines: Develop and enforce policies that emphasise respect for autonomy, non-discrimination, and justice in disability research and practice (Mwapaura & Chikoko, 2020).

- Promote awareness and advocacy: Implement campaigns to challenge societal stigma and promote inclusive attitudes aligned with international human rights standards like the CRPD (Browne & Dorris, 2022).
- Address intersectionality: Focus future research on understanding diverse experiences of persons with disabilities to inform inclusive policies that recognise multiple identities (Mwapaura, 2024).
- Encourage policy integration: Advocate for the incorporation of human rights-based approaches into national disability policies and legislation to ensure lasting impact.

Conclusion

In summary, applying a human rights-based approach to disability research and practice is crucial for ensuring that persons with disabilities are treated with dignity, respect, and fairness. The key themes highlight the need for genuine participation, ethical conduct, and societal change to break down barriers and challenge stigma. Through embracing strategies like capacity-building, clear ethical standards, and advocacy, we can create a more inclusive environment where everyone's rights are recognised and protected. Moving forward, a steadfast commitment to these principles will be essential in making lasting progress toward social justice and meaningful inclusion for all.

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