

Editorial

The Inclusion and Welfare of Children and Young People with Disabilities

by

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Special issue on The Inclusion and Welfare of Children and Young People with Disabilities

Article 7 of the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) states that all children and young people with disabilities have the right to a full life, and that states parties shall take all necessary measures to ensure their full enjoyment of all human rights and fundamental freedoms on an equal basis with other children. Taken together, the CRPD and the Convention on the Rights of the Child (UN, 1989) mean that governments, professionals, institutions and communities are held accountable for their commitment to remove barriers that prevent children and young people with disabilities from living independently and participating fully in their societies.

However, nearly three decades after the Convention on the Rights of the Child and two decades after the CRPD's adoption, the gap between what has been legislated and what is lived in reality remains. The vast majority of children and young people with disabilities, particularly in the Global South, face limited inclusion in terms of access to education (Kamenopoulou & Karisa' 2023), health care (Singal & Muthukrishna, 2014), protection from violence and exploitation (Adugna, Ghahari, Merkley, & Rentz, 2022), and employment (Hanass-Hancock & Mitra, 2016). This Special Issue took that gap as its point of departure and has brought together empirical, conceptual and practice-based contributions, capturing both Global South and Global North perspectives, and that have interrogated how and why inclusion for this specific category remains limited, and what might be done differently for the commitment above to be achieved.

From Education and Social Work disciplinary perspectives, it is important to understand conceptually what is understood by inclusion and exclusion. At the policy level of discourse, inclusion is often framed in terms of technical issues of access, such as installing a ramp, appointing a classroom assistant, or signing a policy. However, more critically, inclusion does not only mean access, but also that a child with disability is physically present in a classroom to begin with and if they are, that they have the same possibility to learn in this environment as any other child. Inclusion is about the knowledge systems, pedagogies, and welfare structures that

recognise the child with disabilities as a full, valued participant who participates fully alongside his or her able-bodied counterparts. Conversely, exclusion is not about mere absence. It is the sum and outcome of negative everyday practices, professional assumptions, and resource allocations that were never designed to accommodate disabled children and often treat their inclusion as an afterthought rather than a core priority (Hayes & Bulat, 2017; Walton, 2018).

Foregrounding the distinction between inclusion and exclusion in this Special Issue is important because it shifts the focus from merely documenting the well-known extent of exclusion (Makuyana, 2022; Sæbjørnsen, Makuu, & Ødegård, 2023). The contributions from the respective authors have also explored what social innovation, professional education, and interprofessional collaborations should look like if disabled children and young people, their families, and communities are viewed as active collaborators and participants in knowledge production, rather than merely recipients of policies designed by people without disabilities. In that respect, the Special Issue does not aim to standardise inclusion within a single global model but to enable various professional and geographic perspectives to challenge each other's assumptions. In essence, this special issue does not provide a definitive method for the inclusion of children and young people with disabilities. It challenges the taken-for-granted categories that underpin how inclusion is planned, measured, and implemented worldwide.

A common challenge, well-known among disability scholars but often overlooked by policymakers, is that inclusive education policies are typically written by individuals without personal experience with disability (Hayes & Bulat, 2017). Those implementing these policies in rural schools, underfunded clinics, and township welfare offices must reconcile top-down directives with the actual lived experiences of the children and young people with disabilities they serve. Further, the pandemic intensified and revealed existing inequalities, children and young people with disabilities who were often most affected by this event, highlighting these policy gaps and resource shortages (Chirowamhangu et al., 2024; Makuyana, 2022). These challenges were a common point of contention in Disability Studies globally but were especially pronounced in African and other Global South contexts. However, solutions to address these challenges often originate in the Global North, bringing

with them assumptions about childhood, disability, and professional practice that may not align with local realities (Donohue & Bornman, 2014). This happens because of the limited existence of genuine international, comparative, and interprofessional research between the two regions, which mirrors how disciplinary and regional boundaries influence which knowledge about disability is considered authoritative (Roy, 2024). Addressing this comparative gap is a particular focus of this Special Issue. It has brought together papers from various disciplines and professions, including social workers, educators, health experts, psychologists and philosophers, their perspectives developed from their respective fields and through engagement with each other in collaboration between the Global North and South. This mix is reflected in the composition of the Editorial Team for this Issue who themselves represent a collaboration spanning Global South (Ndlovu, Molapisi) and North (Sjåfjell, Sæbjørnsen, Hean) regions and disciplinary perspectives (Education: Ndlovu, Molapisi, Hean) and Social Work (Sjåfjell, Sæbjørnsen).

The editorial team and the papers presented in this Special Issue aim to echo and strengthen current debates in cognate decolonial scholarship. However, we are aware that by producing a body of work using the analytic vocabulary of an internationally circulating disability rights framework, as well as applying the rigorous criteria and norms required of peer reviewed international research literature, that we risk reproducing the very epistemic hierarchies this special issue sets out to question. It cannot be said that this tension has been resolved. However, we can report, in the spirit of editorial honesty, about the conditions of knowledge production is in the Special Issue itself. This special issue is hosted by a journal based in Norway, edited by a team spanning South Africa and Norway, and is open access to a global readership. It had the explicit aim of providing opportunity for global south and especially African-authored and Africa-focused research on disability for their work and voice to reach audiences and policy circles it might not otherwise reach. In doing so, the need to provide voice to these perspectives, often conflicts with meets the rigid review requirements and what is considered academic quality in published works, whose requirements remain concentrated in the Global North. This Issue does not claim to have resolved the tensions. Instead, the editorial team and reviewers have encouraged genuine inclusion by asking authors to examine the inclusion of children with disability from multiple national settings, especially those in in the global

South, and at all levels. This ranges from the constitutional and policy commitments made by states, through the professional training of teachers, social workers and health workers, to the lived experience of children, young people and families navigating systems that were not designed with them in mind. Several contributions draw on qualitative, quantitative and participatory methods that center the voices of disabled children and young people directly, a methodological choice that is itself a modest corrective to a field long dominated by adult, professional and often Northern perspectives (Bannink Mbazzi, Hameed, Ganle, Shakespeare, & Polack, 2024). Second, the editorial team have encouraged reviewers to favour providing voice to a variety of national settings and perspectives rather than adhering to strict, often western notions of what constitutes scientific quality. This inclusive approach has led to a more multidisciplinary, multinational and multi theoretical presentation of perspectives on the inclusion of children with disability than may otherwise have been possible.

The articles in this Special Issue

This special issue features articles that together move across levels of analysis and across regions, from macro-level comparative disability governance, through conceptual accounts of social work's own institutional and legal role, through the everyday workings of schools and universities, to the intimate terrain of families and caregiving, and finally to forms of vulnerability that continue to fall outside mainstream disability and social work agendas.

Some articles focus on a policy angle: Beullah Matinhira, for instance, in *Addressing Drug Abuse Among Youth with Disabilities in Zimbabwe: An Inclusive Care Ethics Perspective*, examines the near-total absence of young people with disabilities from Zimbabwe's national response to a growing drug and substance abuse crisis, despite their particular vulnerability in this context. Drawing on an Inclusive Care Ethics framework (Tronto), read together with Ubuntu, the article argues that policymakers carry a care responsibility toward young people with disabilities in drug prevention policy that is currently unmet, and calls for policy reform, practice improvement and a research agenda that treats this population as neither an afterthought nor invisible.

Other articles take a policy angle but include a comparative view that account for country-specific perspectives. For instance, the article by Saharuddin Daming, Prihatini Purwaningsih, Mufidatul Husna and Denisa Aulia, *A comparative study of disability welfare policies in Nordic countries and Indonesia*, compares disability governance and welfare arrangements across the Nordic countries (Norway, Sweden, Finland) and Indonesia, drawing on welfare state theory to interpret anti-discrimination legislation, social security systems, accessibility policy and monitoring mechanisms. Daming's comparison makes the point that runs through the Special Issue as a whole: that formal legal recognition of disability rights is a necessary but insufficient condition for inclusion. It must be accompanied by institutional design and sustained political commitment if it is to be felt in the lives of children and young people with disabilities. The article concludes that Nordic disability governance is characterised by long-term institutional consolidation, integrated monitoring and enforcement mechanisms embedded within comparatively generous welfare systems, whereas Indonesia demonstrates strong formal and legislative convergence with international disability norms, but that implementation is uneven across a decentralised administrative structure with differentiated subnational capacity.

Christopher Romanowski-Kirchner in *Social Work's Role in Promoting Participation for Children and Youth with Mental Health-Related Disabilities in the German Child and Youth Welfare System*, also considers policy regulations, offering a theory and legally informed conceptual analysis of interprofessional collaboration between youth welfare and child and adolescent psychiatry in Germany and focusing on the legal construct of "seelische Behinderung" (mental health-related disability) under Section 35a of the German Social Code (SGB VIII). Combining the World Health Organisation's concept of disability with the social work theory of Integration and Life Conduct, the article concludes that integration assistance under Section 35a can only realise its participation-oriented mandate if interprofessional contributions, especially that of social work's distinct contribution, is consistently articulated and enacted; It emphasizes that legal frameworks should acknowledge that providing assistance to children with disability occurs at the interface between youth welfare and child and adolescent psychiatry and that clinical diagnosis should be linked consistently to the assessment of the youth welfare and participation restrictions.

Takudzwa Leonard Mathende, Tatenda Goodman Nhapi and Noel Garikai Muridzo in *Institutionalized Exclusion of Children with Disabilities and the Role of Social Work Perspectives from Zimbabwe and South Africa*, drawing on secondary literature from Zimbabwe and South Africa and a Social Model of Disability reinforced by a human rights perspective, examine the intractable challenge of the institutionalised exclusion of children with disabilities, and concludes that social workers, through advocacy, service provision and support, are integral to the transformative empowerment of children with disabilities and their families, including in contexts further strained by climatic shocks and socio-economic turbulence.

The latter two articles by Romanowski-Kirchner and Mathende, Nhapi and Muridzo although grounded in a Global North (Germany) and Global South (South Africa, Zimbabwe) legal-welfare system, share the claim that disability is best understood not as an individual condition to be treated, but as an environmental and institutional imperative, one that requires social work as a profession to actively modify the environments in which children with disabilities live.

The next four articles turn to education systems themselves, moving from the inclusion of children with disability into secondary schooling, vocational and higher education, and across South Africa, Botswana, Sri Lanka and Tanzania.

Gaone Molapisi in *The Role of Phonological Awareness in Enhancing Reading Proficiency among Learners with Mild Hearing Impairment in South African Mainstream Classrooms*, for instance, examines reading instruction for learners with hearing impairment in South African secondary schooling, drawing on Young's (1996) concept of communicative democracy, and concludes that phonological awareness should be central to reading activities designed to support these learners' literacy development at this level of education.

Macedelyn Mosalagae and Leslie S. Nthoi in *Rethinking Practical Methodologies: The Capability Approach in Conversation with Botho and Inclusive Education for Students with Disabilities in Vocational Education in Botswana* turn to technical and vocational education in Botswana, applying Sen Nussbaum Capability Approach (Gasper, 1997), alongside the Botho philosophy of interdependence and belonging. They find

that physical access alone does not secure inclusion: without teacher agency, collaborative practice, training grounded in Botho principles, and more flexible curricula and assessment, learners with disabilities remain excluded in practice even where policy exists.

At a higher education level, Hirosha Kalupe in *Structural Barriers to Inclusive Education: Students' Perspectives and Institutional Policy Analysis of Physical and Digital Infrastructure in a Sri Lankan State University*, examines the translation of disability-inclusion policy into physical and digital infrastructure at rural higher education institutions in Sri Lanka, using the Social Model of Disability, which locates exclusion in institutional, environmental, and attitudinal barriers rather than in impairment itself. The article shows that accessibility infrastructure tends to be selectively retrofitted rather than embedded by design, that digital systems are technically present but not pedagogically integrated, that teaching remains organised around a hearing, speaking "standard" learner with no provision for sign language, and that students with disabilities are consequently left dependent on peers and family to navigate campus life.

Asia Rubeba and Eugen Philip in *Including the Excluded: Lived Learning Experiences of Students with Disabilities in Higher Learning Institutions in Tanzania*, also examining higher education in Tanzania through a Critical Disability Theory lens, also find that peer support was the most commonly received form of psychosocial support among students with disabilities, indicating that informal, relational forms of support fill gaps left by formal institutional provision. Across these four articles, a common thread emerges: that access policies tend to outpace the pedagogical, attitudinal, and infrastructural changes needed for genuine participation and belonging.

Two articles, both grounded in Tanzania, shift the focus away from institutions to families, asking how caregivers and parents of children with disabilities are supported and, in turn, how they support their children's inclusion.

Solfrid Raknes, Carolyn Yamala, Faudhia Kitenge, Brittany Schuler and Mariana Makuu in *Impact of a Caregiver Collective*, examine the Uhuru Mama Collective, a

school-based initiative that combines income generation, peer support and collective empowerment for caregivers of children with disabilities, many of whom have intellectual disabilities. Using a community-based participatory, mixed-methods longitudinal design follows thirty-three female caregivers over sixteen months, they draw theoretically on Freirean empowerment, Kabeer's resources-agency-achievements framework, Bronfenbrenner's ecological theory, Ungar's social-ecological resilience and Ubuntu. The study concludes that a school-based, caregiver-led collective can generate sustained economic, social and mental health benefits for caregivers while also supporting child development, strengthening school-family relationships and reducing stigma. The authors point to the necessity to integrate caregiver support into disability, education and social protection policy in low-resource settings.

Mariana Makuu in *Parental Involvement in the Education of Children with Intellectual Disabilities in Inclusive Primary Schools in Tanzania: A Case of Uhuru Mchanganyiko Primary School, Dar es Salaam*, also examines parental involvement in the education of children with intellectual disabilities in an inclusive government primary school in Tanzania but drawing on Epstein's framework of six types of parental involvement. The article finds that parents generally hold positive attitudes toward involvement in their children's education, but that time constraints, limited awareness and financial instability continue to constrain sustained engagement. Read alongside one another, the articles by Raknes et al and Makuu suggest that the inclusion of children with disabilities cannot be secured within the school gate alone; it depends on whether families, and particularly mothers and caregivers, are themselves adequately supported, recognised and resourced.

Lastly, two articles by Ndlovu and Kimani further illuminate the gap between inclusive intentions and their realisation in practice, approaching this challenge from different levels and perspectives. In her article *An Inclusive Policy within an Exclusionary System: Learners with Mild Intellectual Disabilities and Inclusion in South African Mainstream Schools*, Ndlovu examines why South Africa's inclusive education policy has not resulted in meaningful inclusion of learners with mild intellectual disabilities in mainstream schools. Drawing on a literature review and Bronfenbrenner's ecological theory, she identifies systemic and institutional barriers and argues that meaningful

inclusion requires changes in educational structures, resources, professional competence and practice.

Kimani's article *Professional Learning Communities for Inclusive Pedagogy: How Teachers and Learning Support Professionals Develop a Coherent Community in an Inclusive School in South Africa* presents an empirical qualitative case study of professional learning communities in a South African school. Drawing on an integrated theoretical framework, the study shows how professional collaboration and learning can support more inclusive practices, while also demonstrating how their transformative potential is constrained by structural and institutional conditions.

Taken together, these two contributions demonstrate how inclusion is negotiated across interconnected levels, from policy and educational systems, through professional practice and collaboration, to families and community-based support.

The papers included in this Special Issue draw from a wide range of theoretical perspectives, such as the welfare state theory, the WHO concept of disability and the social work theory of Integration and Life Conduct, the Capability Approach, Inclusive Care Ethics, the Social Model of Disability, Critical Disability Theory, Freirean empowerment, ecological and resilience theory, Epstein's model of parental involvement, and communicative democracy, alongside African relational philosophies articulated as Ubuntu and Botho. Several contributors put Global North and Global South theoretical traditions deliberately into conversation with one another, for instance, combining the Capability Approach with Botho, or care ethics with Ubuntu, or a German legal-welfare framework with a Southern African, human-rights-reinforced Social Model, and an American model of parental involvement with a Tanzanian schooling context and its implicit Ubuntu undertones. Rather than treating these traditions as competing, the articles suggest these theoretical/philosophical stances are often complementary, each asking a related but distinct question of the following underlying concerns: can young people with disabilities live they have reason to value (Capability Approach); who cares, how, and under what conditions (care ethics); how must institutions, laws and environments change to secure their rights and participation (Social Model, Critical Disability Theory, Integration and Life Conduct); and how do communities live well

together so that people with disabilities are a full and valued part of the said community (Ubuntu, Botho). This theoretical plurality can be viewed as a modest act of inclusion, refusing to let any single tradition, Northern or Southern, monopolise the field's understanding of disability.

Inclusion as a dimension of academic knowledge production

Inclusion when working with children with disability is not only a question of the subject matter of the articles of this Special Issue. It is also a challenge in the conditions of knowledge production. First, inclusion issues are relevant when *reporting* on studies children with disability; when peer reviewing and critiquing academic articles on these research studies for instance. Judgements about what constitutes rigorous research and academic writing continue to be largely set by criteria, journals, and editorial boards based in the Global North which can marginalise scholars, methods, and forms of dissemination originating in the Global South that either have different criteria or levels of experience in Global North traditions. Further, reporting in a language that is not your mother tongue is a further form inclusion. Second, inclusion becomes an issue in *data collection* phases of the research process being reported. For instance, some research reported in this issue refers to online data collection (e.g. Kalupe) , but this points then also to the potential risk of people with disability being excluded then from the research process because of challenges in digital exclusion for this group of vulnerable people overall. Further, exclusion may occur *at ethical levels*, when ethics committees restrict access to children with disability, that whilst protecting the child, also exclude them from the research process.

The editorial team attempted to address some of these points of inclusions in some small way by choosing to privilege hearing the voice of authors writing from marginalised positions over strict conformity with dominant conventions of scientific presentation. We have been tolerant and have encouraged the use of generative AI tools, to manage language and structure, that can be a tool for inclusion by narrowing the gap between English and non-English speaking scholars. However, we have balanced this view against the danger of the tool being used uncritically, and hereby quietly eroding the research rigour and integrity of the work it is meant to support. We

wish to raise these editorial dilemmas here, recognizing these are not yet resolved in the academic community, but and that these issues must be explored if we are to decolonise and promote inclusion in the “the inclusion and welfare of children and young people with disabilities” field as a discipline.

The Special Issue concludes that children with disabilities are accounted for in policy internationally but still excluded from some areas of policy (e.g., substance use).

When policy is in place for this group, practice has some way to catch up with policy aspirations. Inclusion is an important issue at all phases of the child's education. The field is multi-theoretical and benefits from merging North and South theoretical stances and philosophies, and lastly, inclusion is not only the subject of the research presented in this issue but is also a knowledge production issue.

References

- Adujna, M., Ghahari, S., Merkley, S. & Rentz, K. (2022). Children with disabilities in Eastern Africa face significant barriers to access education: A scoping review. *International Journal of Inclusive Education*, 28(10). 2281-2297.
<https://doi.org/10.1080/13603116.2022.2092656>
- Bannink Mbazzi, F., Hameed, S., Ganle, J. K., Shakespeare, T. & Polack, S. (2024). Participatory research with youth with disabilities: Experiences from sub-Saharan Africa. *African Journal of Disability*, 13, a1491.
<https://doi.org/10.4102/ajod.v13i0.1491>
- Chirowamhangu, E., et al. (2024). Inclusive education pandemic: Learning barriers for children with disabilities in South Africa. *African Journal of Disability*, 13, 1462. <https://doi.org/10.4102/ajod.v13i0.1462>
- Donohue, D. & Bornman, J. (2014). The challenges of realising inclusive education in South Africa. *South African Journal of Education*, 32(2), 1–14.
<https://doi.org/10.15700/201412071114>
- Gasper, D. (1997). Sen's capability approach and Nussbaum's capabilities ethic. *Journal of International Development*, 9(2), 281-302.
[https://doi.org/10.1002/\(SICI\)1099-1328\(199703\)9:2<281::AID-JID438>3.0.CO;2-K](https://doi.org/10.1002/(SICI)1099-1328(199703)9:2<281::AID-JID438>3.0.CO;2-K)
- Hanass-Hancock, J. & Mitra, S. (2016). Livelihoods and disability: The complexities of work in the global south. In S. Grech & K. Soldatic (Eds.), *Disability in the global south: The critical handbook* (pp. 133-149). Springer International Publishing. https://doi.org/10.1007/978-3-319-42488-0_9
- Hayes, A. M. & Bulat, J. (2017). *Disabilities inclusive education systems and policies guide for low- and middle-income countries*. RTI Press.
<https://doi.org/10.3768/rtipress.2017.op.0043.1707>
- Kamenopoulou, L. & Karisa, A. (2023). Inclusive education in the Global South: can we turn promises into actions?. *Disability and the Global South*, 10(1), 2181-2188.
- Makuyana, T. (2022). Towards interventions on school dropouts for disabled learners amidst and post-COVID-19 pandemic. *African Journal of Disability*, 11, 1009.
<https://doi.org/10.4102/ajod.v11i0.1009>

- Roy, A. (2024). Decolonizing disability studies: Identities, epistemologies and Global South perspectives. *The Creative Launcher*, 9(6), 70–81.
<https://doi.org/10.53032/tcl.2024.9.6.07>
- Sæbjørnsen, S. E. N., Makuu, M. J. & Ødegård, A. (2023). Change agents – improving the situation of children with disabilities. In S. E. N. Sæbjørnsen, M. J. Makuu & A. Ødegård (Eds.), *Change agents: An interprofessional book about children with disabilities in Tanzania and Norway* (pp. 19–32).
<https://doi.org/10.18261/9788215057903-23-01>
- Singal, N. & Muthukrishna, N. (2014). Education, childhood and disability in countries of the South—Re-positioning the debates. *Childhood*, 21(3), 293-307.
<https://doi.org/10.1177/0907568214529600>
- United Nations. (1989). *Convention on the Rights of the Child*.
<https://www.refworld.org/legal/agreements/unga/1989/en/18815>
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities*.
<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Walton, E. (2018). Decolonising (through) inclusive education? *Educational Research for Social Change*, 7(Special issue), 31–45. <https://doi.org/10.17159/2221-4070/2018/v7i0a3>