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Rethinking Disability Assessment in Kenya: Towards a Participatory Model for Parents and Caregivers

Rethinking Disability Assessment in Kenya: Towards a Participatory Model for Parents and Caregivers

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Abstract
Disability assessment in Kenya remains largely grounded in a reductionist medical model that prioritises diagnosis over the functional abilities of persons with disabilities. Although Kenya has progressive legislation promoting inclusive assessment practices, meaningful participation of parents and caregivers remains limited due to inadequate legal enforcement, professional gatekeeping, bureaucratic inefficiencies, inconsistent assessment procedures, and weak accountability. These systemic barriers restrict equitable access to disability certification, educational placement, rehabilitation services, and social protection programmes, particularly for vulnerable children and their families. Consequently, parents and caregivers, despite possessing essential knowledge of a child's daily functioning, are excluded from assessment processes, reducing the accuracy and comprehensiveness of assessment outcomes and limiting the delivery of sound interventions. This study employed a mixed-methods design, drawing on a qualitative phenomenological approach using semi-structured in-depth interviews and open-ended survey responses. Purposive sampling identified institutional stakeholders, while snowball sampling expanded participation to parents, caregivers, special needs educators, allied health professionals, and social workers across Nairobi, Kisumu and Meru counties. Data were analysed thematically to explore participants' experiences and perceptions of disability assessment. The findings identified four major categories of challenges: information gaps, unequal professional–caregiver power relations, socio-cultural stigma and institutional deficiencies. Despite these barriers, participants across stakeholder groups consistently agreed that active caregiver participation enhances early identification, improves service coordination, strengthens educational planning, and promotes inclusive assessment practices. The study proposes the Informed Participatory Model (IPM), a collaborative framework designed to bridge the policy implementation gap by institutionalising meaningful caregiver participation, promoting transparent, equitable and family-centred disability assessment.

Introduction

Disability assessment provides the foundation for identifying the rights, services, and accommodations required by persons with disabilities. Globally, assessment has evolved from a medical model focused on diagnosis and impairment to rights-based frameworks that recognise disability as the interaction between impairments and environmental barriers (WHO, 2011). In Kenya, disability assessment has traditionally been impairment-oriented, but constitutional and policy reforms have promoted a more holistic approach. Guided by the Constitution of Kenya (2010), the Persons with Disabilities Act (2003), and the UNCRPD, current approaches emphasise participation,

inclusion, and the removal of environmental, attitudinal, and institutional barriers. Despite significant policy and conceptual advances, disability assessment in Kenya continues to face major challenges. These include shortages of qualified assessment personnel, inadequate locally appropriate assessment tools, disparities in service provision between urban and rural areas, and limited family and caregiver involvement. Assessment practices remain largely clinician-centred, with insufficient consideration of environmental factors that influence the functioning and participation of persons with disabilities.

Contemporary disability assessment frameworks advocate a biopsychosocial approach that integrates medical, educational, psychological, and social dimensions of disability. Guided by the International Classification of Functioning, Disability and Health (ICF) and the *World Report on Disability* (WHO, 2011), these frameworks emphasise functional ability, environmental influences, and the active participation of individuals with disabilities and their families. However, implementation in Kenya remains inconsistent. Assessment systems continue to reflect traditional medical paradigms that privilege professional expertise over the experiential knowledge of parents and caregivers (Singal, 2016). Although Kenya has progressive legal and policy frameworks supporting inclusion and participation, gaps persist between policy and practice. Institutional fragmentation, resource constraints, county-level disparities, and socio-cultural stigma continue to hinder meaningful caregiver engagement and shared decision-making. These challenges underscore the need for contextually responsive, participatory assessment approaches that promote inclusive education and support the achievement of Sustainable Development Goal 4 on equitable and quality education.

A significant gap exists between Kenya's legislative and policy provisions on disability inclusion and their implementation in practice. This study addresses this implementation gap by examining how disability assessment practices can be strengthened through the meaningful participation and empowerment of primary caregivers within assessment and decision-making processes. Through the use of qualitative primary data gathered through interviews and questionnaires in three important counties in Kenya, this paper presents the Informed Participatory Model (IPM). The IPM provides a robust operational framework for strengthening participatory disability assessment by integrating caregiver engagement, interdisciplinary collaboration, and rights-based decision-making that is designed for the Kenyan socio-cultural and institutional context and that draws on two important theoretical models: the Social Model of Disability (Oliver, 1990) and the Human Rights Model of Disability (Degener, 2016).

Historical Trajectories of Disability Assessment

Disability assessment has undergone significant ideological transformation, shifting from a predominantly medical model to a rights-based and participatory approach. Historically, the medical model viewed disability as an individual impairment requiring diagnosis and correction by medical professionals (Finkelstein, 1980). Within this framework, professionals exercised considerable authority over decisions concerning education, employment, rehabilitation, and access to social services, while individuals with disabilities and their families had minimal involvement. Critics argue that this approach reinforced discrimination by emphasising deficits rather than individual strengths and capabilities (Barnes & Mercer, 2010).

Following Kenya's independence, disability assessment largely reflected the medical model. Access to education, rehabilitation, and government support depended primarily on clinical evaluations conducted by medical experts, with limited consideration of environmental factors, family perspectives, or community participation. Assessments focused on categorising impairments rather than evaluating functional abilities and support needs, contributing to delayed identification,

exclusion from education, and unequal access to services, particularly among children and adults in rural and underserved communities.

International and national policy developments have gradually shifted disability assessment towards a rights-based paradigm. The adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Constitution of Kenya (2010), the Persons with Disabilities Act, and inclusive education policies has promoted participation, accessibility, and individualised support. This transition was further strengthened by the World Health Organization's International Classification of Functioning, Disability and Health (ICF), which conceptualises disability as the interaction between health conditions and environmental and personal factors (WHO, 2001; Bickenbach et al., 2012). The ICF emphasises functioning, participation, and the removal of environmental barriers, aligning closely with inclusive education and human rights principles.

Despite these advances, implementation of participatory, context-sensitive assessment remains inconsistent in many developing countries, including Kenya. Assessment systems continue to rely heavily on Western-developed tools that often fail to reflect local cultural, linguistic, and socio-economic realities (Singal, 2016). Persistent challenges include shortages of multidisciplinary assessment teams, inadequate locally adapted assessment tools, limited parental involvement, and disparities between urban and rural services. Consequently, empirical studies continue to report the dominance of clinical and deficit-oriented assessment practices that marginalise families (Mwangi & Orodho, 2015; Ngugi, 2019). These challenges highlight the need for an informed participatory assessment model that actively engages caregivers, educators, and persons with disabilities to ensure culturally responsive, equitable, and family-centred disability assessment in Kenya.

Parental and Caregiver Roles in Disability Assessment

Empirical evidence shows that caregivers possess valuable knowledge about a child's development, behaviour, functional abilities, and home environment, making family-centred assessment more accurate, culturally responsive, and effective in supporting sustainable interventions (Turnbull et al., 2015; Epstein, 2011). However, caregiver participation is often limited by professional hierarchies, technical language, and tokenistic engagement (Kalyanpur & Harry, 2012). In Kenya, these barriers are compounded by low institutional literacy, long distances to assessment centres, poor communication, cultural stigma, and gendered caregiving roles, with women disproportionately affected by poverty and limited opportunities to participate in assessment processes.

Interdisciplinary Collaboration and Culturally Responsive Assessment

It should be noted that the modern standards imply an integration of specialists from such spheres as special education, medicine, psychology, social work, and parents in the diagnosis process (Friend & Cook, 2017). In Kenya, such practice is not applicable due to the fragmentation of health, educational, and social protection services (Ndurumo, 2019). It should be noted that cultural issues are often ignored in the application of psychometric and functional tests, which may lead to diagnostic errors. Indeed, the application of Western standardised tests in Africa can reduce the validity of diagnostic procedures. Culturally appropriate assessment needs adjustments of methods according to the environment, knowledge frameworks, and language used in the region (Hwa-Froelich & Westby, 2003).

Theoretical Foundations

The Informed Participatory Model (IPM) is theoretically grounded in the integration of two complementary frameworks: the Social Model of Disability and the Human Rights Model of Disability. The Social Model of Disability, developed by disability activists and scholars, distinguishes an individual's impairment from the social, environmental, and institutional barriers that produce

disability (Oliver, 1990). By shifting attention from individual deficits to societal barriers, the model advocates for disability assessment systems that identify and address institutional, architectural, communicative, and attitudinal barriers that restrict meaningful participation and equitable access to services (Barnes, 2012). Within disability assessment, this perspective emphasises collaborative processes that recognise parents, caregivers and persons with disabilities as active contributors to the welfare of persons with disabilities rather than passive recipients of professional decisions.

Complementing this perspective, the Human Rights Model of Disability incorporates the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by recognising persons with disabilities as rights holders entitled to dignity, autonomy, equality, and full participation in decisions affecting their lives (Degener, 2016). This model places a legal and ethical obligation on governments and public institutions to establish transparent, inclusive, and participatory assessment processes that respect the voices of persons with disabilities and their caregivers.

In the Kenyan context, these theoretical principles are interpreted within a devolved governance system where disability assessment and support services are implemented across counties with varying institutional capacities and resource availability. The realisation of rights-based and participatory assessment is therefore influenced by disparities in county and sub-county funding, uneven distribution of specialised personnel and assessment services, and persistent cultural beliefs and stigma surrounding disability. Consequently, the IPM adapts these theoretical foundations by advocating context-responsive participatory mechanisms that promote equitable stakeholder engagement while acknowledging the operational realities of Kenya's decentralised service delivery system. Collectively, the Social Model and the Human Rights Model position caregiver participation not as professional goodwill or charity but as a fundamental right and an essential component of equitable, inclusive, and accountable disability assessment.

Methodology

Research Design

The current study adopted a Mixed-Methods design based on Interpretive (Hermeneutic) Phenomenology and guided by an interpretivist epistemology. Interpretivist epistemology is premised on the view that reality is socially constructed through individuals' interactions, experiences, and interpretations of their social world (Creswell & Poth, 2018). Within the context of disability assessment, this perspective acknowledges that assessment is not merely an objective medical determination of impairment but a socially constructed process in which meanings are negotiated through interactions among clinicians, educators, social workers, institutional systems, and families. Consequently, caregivers' experiences of disability assessment are shaped not only by clinical findings but also by institutional procedures, professional practices, communication processes, and broader socio-cultural contexts.

Interpretive (Hermeneutic) Phenomenology was adopted because the study sought to understand and interpret the meanings caregivers and other stakeholders attach to their experiences of disability assessment while examining the systemic and institutional factors that influence those experiences. Rather than simply describing participants' lived experiences, this approach enabled the researcher to interpret how institutional practices, power dynamics, fragmented service delivery, and opportunities for caregiver participation shape disability assessment processes in Kenya. The qualitative design therefore provided a context-sensitive framework which explored participants' lived experiences and the underlying structural conditions that informed the development of an informed participatory model for disability assessment.

Participants and Sampling

The study included a purposive sample of 54 participants, selected through purposive and snowball sampling to obtain information-rich cases capable of providing in-depth insights into disability assessment practices in Kenya. The sample size was determined based on the principle of thematic saturation, whereby data collection continued until no substantially new themes emerged within and across stakeholder groups. Including participants from Nairobi, Kisumu, and Meru counties facilitated cross-county comparison of disability assessment experiences across diverse service contexts, encompassing urban, peri-urban, and rural settings with varying levels of institutional infrastructure and service accessibility. The multi-site design strengthened the study by capturing contextual variations in assessment practices while allowing for the identification of common patterns across different environments. The study further employed multi-stakeholder triangulation by incorporating the perspectives of parents of children with disabilities (n = 24), primary caregivers (n = 12), special needs teachers (n = 8), healthcare specialists (n = 6), and social workers (n = 4). This diversity of participants enabled the corroboration and comparison of experiences across families, education professionals, healthcare providers, and social service practitioners, thereby enhancing the credibility and depth of the findings. To ensure participants had relevant and current experiences, parents and caregivers were required to have undergone a formal disability assessment process for their child within the preceding five years.

Considering the make-up of this particular sample, there is an analytical distinction made between two participant groups within this research, rather than considering all 54 participants to belong to one homogenous phenomenological group. First of all, parents and caregivers (n = 36) were considered the primary phenomenological group in this study because only they had firsthand experience of the disability assessment process for their kids; the interpretations and experiences of these participants were the main subject matter of the hermeneutic phenomenological analysis. Second, special needs educators, healthcare professionals, and social workers (n = 18) were not considered to have first-hand experience in this matter and hence did not represent the primary phenomenological group; however, they were used as an institutional triangulation group whose accounts could verify, provide context to, or in certain cases challenge the accounts provided by caregivers. Their professional accounts served to corroborate, contextualise, and, where relevant, challenge caregivers' testimonies regarding the systemic and institutional barriers encountered during assessment, without being interpreted as equivalent first-person experiential data. The differentiation continued throughout all stages of data analysis, whereby the caregiver interviews were first coded independently to develop themes from the parents' own experiences, before analysing the data from the professionals for stakeholder triangulation regarding institutional context and the credibility of the results (Denzin & Lincoln, 2018). The differentiation helped ensure the preservation of the research's phenomenological approach even while incorporating the benefits of stakeholder views.

Stakeholder Category	Nairobi (Urban)	Kisumu (Semi-Urban)	Meru (Rural)	Total Cohort	Primary Data Method
Parents of Children with Disabilities	8	8	8	24	Interviews / Questionnaires
Primary Caregivers	4	4	4	12	Interviews / Questionnaires
Special Education Teachers	3	3	2	8	Semi-Structured Interviews
Healthcare Professionals	2	2	2	6	Semi-Structured Interviews
Social Workers	2	1	1	4	Semi-Structured Interviews
Total Representation	19	18	17	54	Triangulated Sample

Data Collection and Triangulation

Data were collected using complementary qualitative methods to generate rich, contextually grounded insights. Semi-structured interviews lasting 60–90 minutes were conducted with participants experienced in disability assessment, using a pilot-tested interview guide developed from the literature and study objectives. To enhance geographic inclusivity, a qualitative survey with open-ended questions was administered to parents and caregivers, particularly in rural areas of Meru and Kisumu, reducing barriers to participation. Interviews explored diagnostic experiences, professional–family interactions, and participation barriers. Participants with location or availability constraints completed structured questionnaires containing open- and closed-ended questions, which were translated into Kiswahili.

Analytical Protocols

All audio recordings from the semi-structured interviews were transcribed word-for-word and translated into English where necessary. The texts were analysed following the inductive thematic analysis framework established by Braun and Clarke (2006). This process included six structured phases: intensive data familiarisation, initial code generation, searching for broader themes, reviewing and mapping themes against raw data, defining and naming final thematic codes, and assembling the analytic report. The coding process was entirely inductive, allowing categories to emerge directly from stakeholder statements rather than forcing data into pre-existing theoretical brackets. To ensure qualitative reliability, member-checking was completed with eight participants, and an independent peer reviewer monitored the analytical trail to minimise researcher bias (Lincoln & Guba, 1985).

Findings

Theme 1: Institutionalised Marginalisation of Caregivers

The findings consistently demonstrated the systematic exclusion of parents and caregivers from active participation in disability assessments. Quantitative results showed that family perspectives were frequently overshadowed by professional expertise, while qualitative evidence reinforced this pattern. One mother in Nairobi remarked, *"I was summoned in order to tell me what was wrong with my child and not to assist in finding out,"* illustrating the passive role assigned to caregivers. Social workers similarly observed that institutional cultures often position parents as recipients rather than partners in the assessment process.

These findings are consistent with previous Kenyan studies. Bonjo (2017) reported low parental involvement in Educational Assessment and Resource Centres (EARCs), despite policies advocating family-centred assessment, with professionals dominating decision-making. Similarly, studies on autism diagnosis pathways in Nairobi found that families experienced lengthy, fragmented assessment journeys involving multiple professionals before receiving a diagnosis. Kamau (2020) further reported that parents in Garissa County were dissatisfied with assessment services, felt their concerns were initially dismissed, and struggled to understand the diagnostic process because of poor communication and unclear referral pathways. Collectively, these findings support the arguments of Kalyanpur and Harry (2012) on tokenistic participation and Mutua and Dimitrov (2001) on the dominance of professional knowledge over family knowledge. Although disability assessment has increasingly embraced inclusive principles, meaningful caregiver participation remains limited in practice, highlighting the need for genuinely collaborative and family-centred assessment approaches.

Theme 2: Multidimensional Barriers to Meaningful Involvement

The findings revealed that caregiver participation in disability assessment is hindered by interconnected barriers at the individual, institutional, and socio-cultural levels. At the individual level, inadequate knowledge of assessment rights and procedures emerged as the most significant barrier, reported by 81% of caregivers. Many parents were unaware of their rights to initiate assessments, question professional decisions, or provide comprehensive developmental information during clinical reviews. In rural Meru County, caregivers indicated that they learned about disability assessment services mainly through informal community networks rather than formal institutional channels.

Institutional challenges also constrained meaningful participation. Shortages of qualified clinical assessors, understaffing, and weak referral systems limited collaboration between healthcare providers and special needs education professionals. A physical therapist explained, "*With too many patients, there is hardly any time left to discuss things in detail with the family,*" highlighting how resource limitations reduce opportunities for family engagement.

At the socio-cultural level, disability-related stigma discouraged many families from seeking professional assessment. Caregivers in Kisumu County reported that extended family members often opposed disability assessment because of fears of social discrimination and community exclusion. One caregiver explained, "*My relatives kept telling me not to take my child for assessment because once people know there is a disability in the family, they will start talking about us and treating us differently.*" A physical therapist similarly noted that "*Many families postpone assessment because they are worried about how the community will perceive them.*" One mother also admitted delaying assessment because she feared rejection from her relatives. Overall, the findings demonstrate that caregiver participation is influenced by inadequate knowledge, institutional capacity constraints, and persistent cultural stigma, underscoring the need for integrated strategies that strengthen caregiver empowerment, improve service delivery, and reduce disability-related stigma.

Ecological Level	Identified Barrier Vector	Empirical / Weight Indicator	Illustrative Proof-Point
Microsystemic (Individual)	Exaggerated information gap about rights; internalized socio-cultural stigma.	81% of caregivers had a total deficit in procedural literacy.	Caregivers dissuaded by extended families because of social isolation (Kisumu)
Mesosystemic (Interaction)	Imbalanced power equations; dominance of clinical language; tokenism in feedback mechanisms.	79% of caregivers felt totally unconsented during assessments.	"I was summoned to be told what was wrong with my child, not to assist in finding out." (Nairobi)
Exosystemic (Institutional)	Resource constraints in the workforce; weak multi-sectoral referral systems.	64% of caregivers had reports that used unintelligible jargon.	"Due to the load of work, family consultations could not be lengthy." (Physio).
Macrosystemic (Socio-Cultural)	Rejection of indigenous or spiritual discourses of distress; isolation.	Prevalence of fatalistic/spiritual etiologies of impairment in rural nodes.	Relying on community pathways rather than formal institutional routes for early services identification.

These findings indicate that the barriers to participation by parents and caregivers in disability assessments in Kenya manifest at different ecological levels. According to Bronfenbrenner's Ecological Systems Theory, isolation does not only stem from personal problems but from interactions between various factors at the individual, interpersonal, institutional, and sociocultural levels. It turns out that even though inclusive policies have been introduced, disability assessment in Kenya is still expert-oriented.

Microsystemic Level: Information Deficits and Internalised Stigma

Individual-level findings showed significant information asymmetry concerning rights, assessment process, and service provision for children with disabilities. The fact that 81% of the caregivers lacked procedural literacy shows that many families embark on the assessment process with limited knowledge necessary for advocating for their children. This is consistent with other Kenyan studies, according to which parents do not have sufficient information on disability assessment processes and interventions (Bonjo, 2017; Muthiga et al., 2025).

The stigma also adds to this problem. It has been reported from the region of Kisumu and other rural regions that some caregivers felt discouraged by the extended families because of fear of social rejection and stigma. Such results have also been reported in Kenya, where disability was seen as a sign of misfortune, witchcraft, curse, or divine punishment, and families tend to hide the children with disabilities and avoid getting help from any kind of formal institution (Gona et al., 2011; Kamau, 2020).

Mesosystemic Level: Unequal Professional–Family Relationships

The findings revealed significant interpersonal power imbalances between caregivers and professionals during disability assessment. A majority (79%) of caregivers reported that they were not consulted about decisions concerning their children, reflecting limited family involvement. One caregiver remarked, *"I was called to be told what was wrong with my child and not to help in finding out,"* illustrating the continued dominance of the medical model in assessment practices. These findings are

consistent with research by Bonjo (2017), which found minimal parental involvement in Educational Assessment and Resource Centres (EARCs) in Kenya despite policies promoting family-centred interventions. Additionally, the use of technical language further hindered effective communication and caregiver participation.

Exosystemic Level: Institutional Capacity Constraints

In terms of institutions, shortage of staff and poor referral processes were found to be major hindrances to participation in assessment. In this regard, the fact that 64% of caregivers were given jargon-filled reports that they did not understand speaks volumes about some of the systemic issues in the Kenyan health, education, and social welfare sectors. Practitioners have observed that due to large caseloads, there is little room left for family participation. The comment by the physiotherapist on how family discussions could not continue due to workload pressures is a testament to the same.

There is still a shortage of paediatricians, developmental psychologists, occupational therapists, speech therapists, and assessment officers with regard to special needs in Kenya, especially in non-urban areas. Families have to go through several organisations in order to get their child diagnosed. This makes the process of diagnosis harder since families are not taken into consideration in such fragmented assessments.

Macrosystemic Level: Cultural Beliefs and Knowledge Systems

The findings showed that caregiver participation in disability assessment is hindered by interconnected individual, institutional, and socio-cultural barriers. At the individual level, 81% of caregivers lacked knowledge of assessment rights and procedures, limiting their involvement. Institutionally, shortages of qualified assessors, understaffing, and weak referral systems reduced opportunities for meaningful family engagement, with one therapist noting insufficient time to discuss assessment outcomes with families. Socio-cultural stigma further delayed assessment, as many caregivers feared discrimination and social exclusion. These findings highlight the need for integrated strategies that improve caregiver awareness, strengthen institutional capacity, and address disability-related stigma**.**

Synthesis of Findings

The results combined show that the process of excluding parents from disability assessments in Kenya is a complex phenomenon that results from the interaction of various ecological influences. Deficiencies in information at the individual level, power imbalances between professionals and families at the interactional level, limitations of institutional resources, and socio-cultural belief systems work together to marginalise caregivers. The research results affirm the recent disability literature on the need for a shift from the current expert-led model of assessment towards a participatory, family-based model.

Theme 3: Epistemic Value of Caregiver Insights

There was clear agreement among all professionals about the high diagnostic value of the caregiver's insight in making the diagnosis. Special education teachers pointed out that short-term assessments do not usually do justice to a child's ability, which is completely opposite to what the child does at home. A special education teacher in Nairobi confirmed that parents consistently give important developmental information that cannot be captured by professionals through clinical interviews, reinforcing the partnership frameworks of Turnbull et al. (2015). Healthcare professionals also agreed that information provided by caregivers about developmental stages, eating, social, and emotional behaviours provides important clinical insight that cannot be captured by standard tests alone. This

was substantiated with quantitative data, where 83% of the professionals said that parental feedback was 'somewhat' or 'greatly' useful in increasing the accuracy of the diagnosis.

Theme 4: Existing Facilitators and Community Strengths

The research identified several successful approaches employed by community-based networks that help in achieving harmony between families and professionals. It is possible to build a solid ground for scalable models on the basis of understanding such natural systems of operation.

Community Facilitator / Strength	Operational Mechanism	Institutional / Long-Term Impact
Community Health Volunteers (CHVs)	Implement early localized screening, ensure that parents are prepared for diagnostics, and translate clinical language into local languages.	Crosses the geographic and linguistic barriers separating rural families from the regional testing centers.
Organized Parent Support Groups	Act as platforms for capacity-building, legal knowledge dissemination, and strategy formulation by peers.	Makes caregivers more confident, functional, and able to advocate on behalf of their children during consultations.
Multi-Professional Planning Meetings	Form case review committees where families work alongside multidisciplinary professionals.	Harmonizes clinical and educational objectives into a single track, though not fully explored yet.

Structured support group for parents was highly effective in helping to develop the confidence, literacy, and advocacy of the caregiver as well. The caregivers in such groups were able to articulate the needs of the child in professional settings and understand bureaucratic processes, thus aligning with the community models described by Epstein (2011). Meetings between multiple professionals, including families, were very successful, although it was pointed out that such integrative reviews are uncommon in modern institutions.

Theme 5: Early Identification and Diagnostic Delays

A notable issue that emerged in discussions with all groups is that there was no emphasis on the tracking of early childhood, ages 0-5, in Kenya. It was brought to the stakeholders' attention that children aged six to eight were referred for assessment only because of academic underachievement. This procedure proved to be very cumbersome for the parents trying to get their kids tested. Eventually, it came out that the reason for this was the poor referral process from local health centres to regional diagnostic centres, poor training of the general practitioners about developmental signs, and a lack of community screening programs.

Discussion

The results reveal that assessment of disabilities in Kenya takes place in a rather complicated setting of structural discrimination, insufficient resources, cultural complexity, and the neglect of the experience of the carers. Such tendencies coincide with more general scientific findings about diagnostic issues for sub-Saharan Africa (Singal, 2016; Ngugi, 2019). Marginalisation of parents is a direct violation of the commitments made by Kenya through its national and international laws. As per Article 7 of the UNCRPD, the state should take any necessary actions to ensure that children with disabilities exercise their rights fully, and this includes the provision of information and decision-making to families (United Nations, 2006).

As per Bronfenbrenner's (1979) Ecological Systems theory, the above-mentioned barriers can be viewed as a multilevel system that requires integration and coordinated interventions. The first barrier is building the capability of care providers at home within the microsystem level, while the second involves improving communication and power relationships between families and clinicians within the mesosystem level, and updating institutional policies within the macrosystem level. Moreover, taking into consideration the importance of culture is important. As noted by Articles and Kozleski (2007), the use of standardised instruments for diagnosis based on Western standards may undermine diagnostic reliability.

The Informed Participatory Model (IPM)

Description

To bridge the policy-implementation gap and move away from outdated medical models, this paper proposes the Informed Participatory Model (IPM) as a systematic blueprint for reform in Kenya. The IPM is structured around five core, interconnected pillars designed to operate within Kenya's decentralised governance system.

IPM Core Pillar	Theoretical Grounding	Strategic Mechanism for Kenya	Accountable Stakeholders
1. Shared Decision-Making	Biopsychosocial Paradigm & Rights-Based Models	Mandatory multi-professional team conferences; translation of clinical data into accessible language.	Clinical Assessors, Special Needs Teachers, Social Workers.
2. Caregiver Capacity Building	Family-Centered Empowerment Framework	Systemic, community-based training on child development and legal rights via local networks.	Community Health Volunteers (CHVs), Parent Support Networks.
3. Culturally Responsive Practice	Epistemic Pluralism & Contextual Validity	Standardizing functional tools for local populations; incorporating caregiver narrative histories.	Sub-county Assessment Centers, Language Experts, and Researchers.
4. Intersectoral Collaboration	Integrated Care Architecture	Unified cross-ministry digital referral registries; institutionalizing regional case-review panels.	Ministries of Health, Education, and Social Protection.
5. Continuous Early Detection	Longitudinal Developmental Surveillance	Proactive early childhood screening programs (0-5 years) built into primary health networks.	Primary Care Nurses, CHVs, Early Childhood Educators.

7.2 IPM in Action

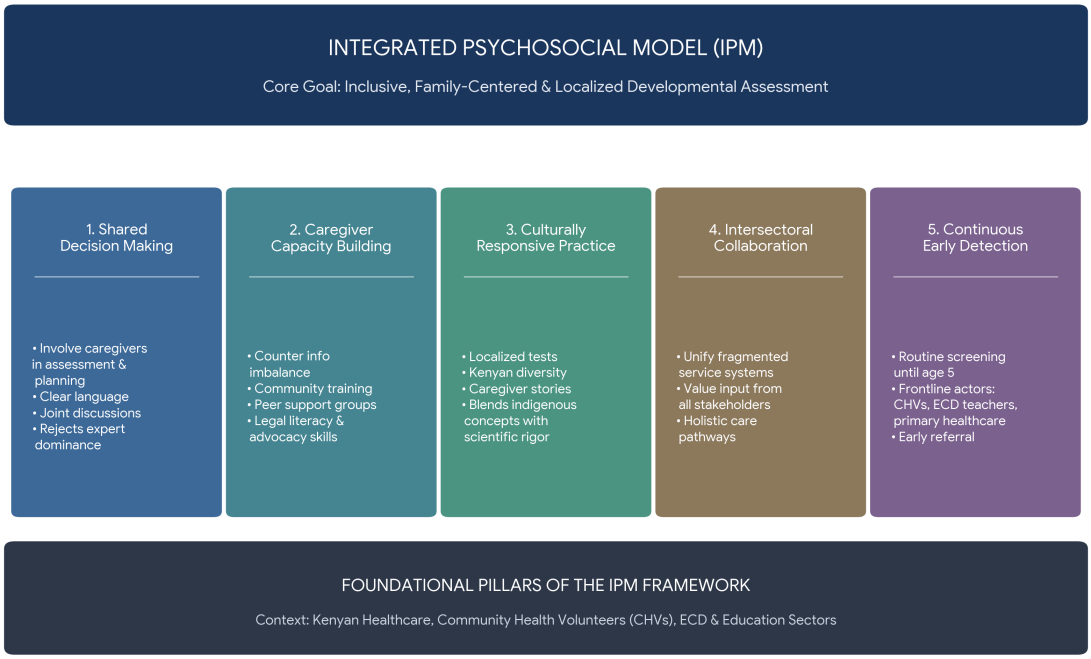

Figure 1: Informed Participatory Model (IPM) for Disability Assessment in Kenya

The Informed Participatory Model (IPM) is an evidence-based partnership framework that promotes collaborative decision-making by bringing together professionals, caregivers, and other key stakeholders (Samia et al., 2022). Rather than relying solely on professional expertise, the model encourages meaningful participation by those directly affected by assessment decisions.

The IPM comprises five interrelated pillars. Shared Decision-Making promotes active caregiver involvement in assessment, interpretation of results, and intervention planning through clear communication and joint discussions. Caregiver Capacity Building addresses knowledge gaps by providing community-based training, peer support, and legal literacy to empower caregivers to participate effectively. Culturally Responsive Practice advocates for locally adapted assessment tools that recognise Kenya's linguistic and cultural diversity while incorporating caregiver perspectives. Intersectoral Collaboration strengthens coordination among health, education, and social service providers to improve service delivery and reduce fragmentation. Finally, Continuous Early Detection emphasises routine developmental screening from birth to five years through community health volunteers, early childhood teachers, and primary healthcare providers to facilitate timely identification and referral.

Together, these five pillars create a participatory, culturally responsive, and coordinated assessment system that enhances caregiver engagement, improves assessment accuracy, supports early intervention, and promotes better educational and developmental outcomes for children with disabilities.

Conclusions

This research has proven that existing disability evaluation techniques in Kenya often do not involve the main caregiver, thereby hampering accuracy in the diagnosis process and negating the inclusive education policy. This paper has suggested an Informed Participatory Model (IPM). Future studies can evaluate the long-term effects of applying the IPM model in different regions using a combination of qualitative and quantitative methods in assessing the effects on socio-emotional progress and education.

References

Barnes, C. (2012). Understanding the social model of disability: Past, present and future. In N. Watson, A. Roulstone, & C. Thomas (Eds.), Routledge handbook of disability studies (pp. 12–29). Routledge.

Barnes, C., & Mercer, G. (2010). *Exploring disability (2nd ed.)*. Polity Press.

Basic Education Act, No. 14 of 2013 (Kenya). Government of Kenya.

Bickenbach, J. E., Cieza, A., Rauch, A., & Stucki, G. (Eds.). (2012). *ICF core sets: Manual for clinical practice*. Hogrefe Publishing.

Bonjo, P. N. (2017). Extent of involvement of parents in the identification of children with special needs in Kenya. *IRA International Journal of Education and Multidisciplinary Studies*, 8(2), 127–141.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Constitution of Kenya (2010). *Government of Kenya*. National Council for Law Reporting.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five Approaches (4th ed.)*. SAGE.

Degener, T. (2016). Disability in a human rights context. *Laws, 5*(3), 35.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2018). *The SAGE handbook of qualitative research (5th ed.)*. SAGE.

Epstein, J. L. (2011). *School, family, and community partnerships: Preparing educators and improving schools (2nd ed.)*. Westview Press.

Finkelstein, V. (1980). *Attitudes and disabled people: Issues for discussion*. World Rehabilitation Fund.

Friend, M., & Cook, L. (2017). Interactions: Collaboration skills for school professionals (8th ed.). Pearson.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2016). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child: Care, Health and Development, 37*(2), 175–183. https://doi.org/10.1111/j.1365-2214.2010.01124.x

Hwa-Froelich, D. A., & Westby, C. E. (2003). Considerations when working with interpreters. *Communication Disorders Quarterly*, *24*(2), 78–85. https://doi.org/10.1177/152574010302400203

Samia, P., Wamithi, S., Kassam, A., Tirkha, M., Kija, E., Moges, A., ... & Armstrong, R. (2022). Child disability and family-centred care in East Africa: Perspectives from a workshop with stakeholders and health practitioners. *African Journal of Disability*, *11*, 931.

Kalyanpur, M., & Harry, B. (2012). *Cultural reciprocity in special education: Building family-professional relationships*. Brookes.

Kamau, L. Z. (2020). Autism spectrum disorders (ASD) in Kenya: The diagnostic experience of parents of persons with autism in Garissa County and its policy implications. *Quest Journals Journal of Research in Pharmaceutical Science, 6*(1), 1–7.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Mutua, N. K., & Dimitrov, D. M. (2001). Parents' expectations about future outcomes of children with intellectual disability in Kenya: Differential effects of disability types and gender. *The Journal of Special Education, 35*(3), 172–180. https://doi.org/10.1177/002246690103500305

Mwangi, E. N., & Orodho, J. A. (2015). Implementation of inclusive education policy in public primary schools: Challenges in Nyeri Town sub-county, Nyeri County, Kenya. *Journal of Education and Practice, 6*(18), 124–132.

Ndurumo, M. M. (2019). *Exceptional children: Developmental consequences and intervention*. Longman Kenya.

Ngugi, C. W. (2019). Assessment of learners with special needs in Kenya: Challenges and prospects. *African Journal of Special Needs Education, 4*(1), 13–27.

Oliver, M. (1990). *The politics of disablement*. Macmillan.

Persons with Disabilities Act, No. 14 of 2003 (Kenya). Government of Kenya.

Republic of Kenya. (2018). *National survey on children with disabilities and special needs in education*. Ministry of Education.

Singal, N. (2016). Education of children with disabilities in developing countries. In M. A. Peters (Ed.), Encyclopedia of educational philosophy and theory (pp. 1–6). Springer. https://doi.org/10.1007/978-981-287-532-7_171-1

Singal, N. (2016). Preparing teachers to work with children with disabilities in developing countries: Are we asking the right questions? ALTER – *European Journal of Disability Research, 10*(2), 1–11. https://doi.org/10.1016/j.alter.2016.02.003

Turnbull, A. P., Turnbull, H. R., Erwin, E. J., Soodak, L. C., & Shogren, K. A. (2015). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust (7th ed.)*. Pearson.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United Nations. (2015). Transforming our world: The 2030 agenda for sustainable development. https://sdgs.un.org/2030agenda

World Health Organisation. (2001). *International classification of functioning, disability and health (ICF)*. WHO.

World Health Organisation. (2011). *World report on disability*. WHO.