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Core Concepts of Human Rights and Inclusion of Vulnerable Groups in the Disability and Rehabilitation Policies of Malawi, Namibia, Sudan, and South Africa

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Abstract

In recent decades, there has been a push to incorporate the World Health Organization "Health for All" principles in national, regional, and local health policy documents. However, there is still no methodology guiding the appraisal of such policies with regard to the extent that they address social inclusion. In this article, the authors report on the development of *EquiFrame,* a novel policy analysis framework that was used to evaluate the disability and rehabilitation policies of Malawi, Namibia, Sudan, and South Africa. The policies were assessed in terms of their commitment to 21 predefined core concepts of human rights and inclusion of 12 vulnerable groups. Substantial variability was identified in the degree to which the core concepts and vulnerable groups were featured in these policy documents. The overall summary rankings for the disability policies of the countries studied were as follows: Namibia–High, Malawi–Low, and Sudan–Low. The rehabilitation policy of South Africa was ranked as Low. The results support the idea that adequate disability and rehabilitation policies remain mostly undefined. *EquiFrame* may offer a useful methodology for evaluating and comparing human rights and social inclusion across policy documents.

Keywords
human rights, vulnerable groups, health policy analysis, equity

In 1978, the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) convened for a historical international conference in Alma-Ata (at that time, the capital of Kazakhstan) on the importance of primary health care. From this conference, the Alma-Ata Declaration (WHO, 1978) was adopted, in which primary health care was indicated as central to realizing the goal of "Health for All" by the year 2000 (WHO, 2008a). It anticipated that progressive policies would advance the level of health in deprived populations and therefore boost overall development; fair access to care and efficiency in service delivery were the principal objectives (Chan, 2008).

In recent decades, the Health for All principles have theoretically been central in the development of national, regional, and local health policy documents (Peiro et al., 2002). Yet, there is still a gap in the literature with regards to how to appraise or compare the development of policies and their effects on social inclusion, and this gap undermines the social accountability process and, by extension, the political credibility of the adopted strategies. As a result, researchers have called for the use of appraisal methodologies in analyzing, comparing, and following up on policies (Peiro et al., 2002). This gap is further exacerbated by disability studies that preserve a near exclusive focus on persons with disabilities in the Western (high-income) country context, although the majority of persons with disabilities are situated in low- and middle-income countries (Grech, 2008). As emphasized by Quinn (2009), disability law and policy research needs to become a great deal more international and comparative; international and comparative research reveals not only what "ought to be" but also what "can be" by revealing innovative solutions adopted elsewhere. Persons with disabilities experience a variety of severe physical and programmatic barriers to receiving

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health care services (Iezzoni, 2009; Wilson, 2009; Wiman, Helander, & Westland, 2002; Yee & Breslin, 2010). Although the number of persons with disabilities is increasing globally, adequate disability policies, in conjunction with their implementation and enforcement, remain for the most part undefined (Wiman et al., 2002). Equalization of opportunities for persons with disabilities is therefore yet to be realized (Michailakis, 1997).

Social activists and advocates for persons with disabilities have conceptualized disability as a political topic and an issue of basic civil rights (Bickenbach, Chatterji, Badley, & Ustun, 1999), an ideology underpinning the United Nations Convention on the Rights of Persons With Disabilities (UN CRPD; United Nations, 2006). The UN CRPD was adopted by the UN General Assembly in 2006 and entered into force on May 3, 2008. The UN CRPD is the first legally binding instrument with comprehensive protection of the rights of persons with disabilities, and it sets out the legal obligations on states to promote and protect the rights of persons with disabilities worldwide (United Nations Enable, 2008–2011a). Notwithstanding the fact that the moral case for the inclusion of persons with disabilities in every facet of life has been made, it is still evident that numerous governments, including some who have signed and ratified the UN CRPD, have yet to be convinced of the necessity of resolutely enacting legitimately inclusive public policy and practice (Lang, 2009). Although policies and programs may serve to protect human rights, they may also violate human rights; thus, establishing the manner in which policies and programs violate or protect disability rights and how relevant policies and programs are implemented, enforced, and regulated will point to ways to work toward legislative and government reform (Disability Rights Promotion International, 2007).

This article reports on a new analytical and peer-reviewed framework that identifies the strengths and weaknesses in current health policy according to the degree to which a policy protects core concepts of human rights in health care, particularly among vulnerable groups. *EquiFrame* evaluates the degree of stated commitment of an existing policy to 21 core concepts of human rights and to 12 vulnerable groups, guided by the ethos of universal, equitable, and accessible health services. The hope is that health policies instituted on the values and importance of equity are more likely to result in health services that are more justly distributed within the population. This means, in accordance with the WHO (2008b), that priority is given to vulnerable groups because health care founded on equity contributes to the empowerment and social inclusion of such groups. We believe it is important to establish not only whether health policies include commitments to core concepts of human rights for all but also whether these are promoted for vulnerable groups in a way that takes account of their "vulnerabilities." In other words, it is important to know whether human rights are promoted in health policies and, if so, whether they are promoted in a socially inclusive way. In its current form, *EquiFrame* is directed toward health policy-oriented researchers and policy makers. The hope is that this framework can be used to generate a systematic evaluative and comparative analysis of health policies on technical content and design as well as to promote equity, human rights, and social inclusion in the development of new policies.

We sought to assess the extent to which disability and rehabilitation (DAR) policy documents in Malawi, Namibia, Sudan, and South Africa promoted human rights and inclusion of vulnerable groups and, by extension, equitable access to health services. Our goal was to identify, at the policy level, the degree to which existing DAR policies in these four African countries address the health-related human rights of vulnerable groups and, by so doing, distinguish best-practice DAR policies and identify policies that may necessitate urgent revision.

Development of *EquiFrame*

There is paucity of literature that outlines and uses analytical frameworks for the content of policies "on the books" (Stowe & Turnbull, 2001); however, a body of research on the process of health policy development (Gilson, Buse, Murray, & Dickinson, 2008) does exist. A number of frameworks have been devised to address this process, including the "Stages" Models (Exworthy, 2008), Policy Triangle Framework by Walt and Gilson (cited in Walt et al., 2008), Network Frameworks (Tantivess & Walt, 2008), Policy Space Analysis (Crichton, 2008), Multiple Streams Theory (Kingdon, 1984), Punctuated Equilibrium Theory (Exworthy, 2008), Implementation Theory (Walt et al., 2008), and Critical Theory Approach (Duncan & Reutter, 2006). Although these approaches focus on the critical importance of how policy is made, they offer very little guidance on evaluating existing policy (i.e., how, once formulated, policy should then be evaluated). These "process theories" do not adequately address the actual content of policies, that is, what results from the process of policy formation. Developing and applying a method for analyzing the content of policies was the focus of the present research, which was undertaken from the perspective of African low- and middle-income countries. *EquiFrame* has been developed as part of a work package by Ahfad University for Women, Sudan, within a larger EU FP7-funded project, EquitAble, which is led by the Centre for Global Health at Trinity College Dublin, with a consortium of international partners (see www.equitableproject.org).

The authors of the report *Working Together for Health* (WHO, 2006) noted that Africa has the greatest disease burden of any continent but has the poorest health services. The four African countries that are the focus of this policy analysis framework each represent distinct challenges in terms of equitable access to health care. These four countries allow us to address how access to health care systems for vulnerable groups can best be promoted in contexts where (a) a large proportion of the population has been displaced (Sudan), (b) the population is highly dispersed (Namibia), (c) chronic poverty and high disease burden compete for meager resources (Malawi), and (d) despite relative wealth, universal and equitable access to health care has yet to be attained (South Africa). With the intention of developing a health policy analysis framework that would be of particular relevance in low-income countries in general, and in Africa in particular, we started with a literature review to identify potential frameworks that could address the motivating principles around which our research is focused: universal, equitable, and accessible health services. These searches and discussions assisted in identifying key themes related to human rights, the right to health, and vulnerability, which were of relevance across a variety of health delivery contexts and particular health equity challenges.

The draft framework was presented at consultation workshops conducted in Sudan, Malawi, Namibia, and South Africa that were attended by more than 100 participants, including relevant clinicians and practitioners, civil servants, elected government representatives, nongovernmental organizations, independent consultants, researchers, and academics. Feedback was incorporated into a revised Framework, which was then used to assess more than 70 health policies drawn from the four African country partners, as well as African regional and international documents. The results of this analysis were then presented at feedback workshops in each country.

The framework presented here also benefited significantly from a workshop conducted for the Ministry of Health in Malawi, for the purpose of revising the Malawian National Health Policy (Munthali, Mannan, & MacLachlan, 2011). Novice users of the framework provided feedback suggesting, for instance, simpler labels for the core concepts and simpler definitions of those concepts, to enhance user friendliness. Feedback from conference presentations and high-level meetings where the ethos, approach, or results have been presented have assisted in shaping *EquiFrame* (e.g., Dube, MacLachlan, Amin, & Mannan, 2010 [African Union Social Welfare Ministers Annual Meeting, Khartoum, Sudan]; MacLachlan et al., 2008 [Global Ministerial Forum on Research for Health, Bamako, Mali]; and Mannan, Amin, MacLachlan, & El Tayeb, 2010 [Health System Strengthening Conference, Montreux, Switzerland]). Finally, advisory groups to Project EquitAble include disability studies scholars, who have reviewed the mapping of the core concepts and vulnerable groups incorporated in *EquiFrame* as well as the finalized version of the framework. Feedback and expert advice beyond our own project team, from a variety of sources, have therefore facilitated in shaping and adding authority and representativeness to the version of *EquiFrame* presented below.

EquiFrame sought to fill a gap in the literature and to look for available research tools to address this gap. Although we were not able to identify an ideal instrument, we drew on several existing approaches in the area. These included the *core concepts of disability policy* as developed by Turnbull and colleagues (Reichard, Sacco, & Turnbull, 2004; Stowe & Turnbull, 2001; Turnbull, Beegle, & Stowe, 2001; Turnbull & Stowe, 2001), the *right to health* (United Nations Economic and Social Council, 2000), *equity in health care* (Stevens, 2003), the *principles of universal design* (Connell et al., 1997), the *need to address health inequalities* (Braveman, 2006; Oliver, Healey, & Le Grand, 2002), and current thinking in health policy analysis more broadly (Gilson et al., 2008; Russell & Gilson, 2006). The Stowe and Turnbull approach, although specific to persons with disabilities and developed for use in North America, had many features relevant to our own interests. We therefore used some of the concepts they had identified, revised others, and developed more concepts from the literature outlined above.

Core Concepts

Core concepts for each of the three principles (universal, equitable, and accessible) were identified, and the available definitions were extracted from the above literature, resulting in the initial identification of 37 core concepts. Through group discussion and e-mail consultation with the project team and stakeholders meetings, these concepts were refined and integrated, resulting in the final 21 core concepts used in the current framework. These stakeholder meetings, held between April and July of 2009, were conducted in Sudan, Namibia, Malawi, and South Africa, and were established to deliberate on the process and rationale for the inclusion of each core concept in *EquiFrame*. The meeting participants consisted of policy analysts and researchers from relevant ministries, including health and social affairs, and civil society organizations, including organizations of persons with disabilities.

The reduction from 37 to 21 core concepts was necessary to make subsequent policy analysis manageable and to have categories that were sufficiently discrete. Specifically, the core concept of *access*, used in the current framework, was derived from the consolidation of 8 preliminary core concepts corresponding to accessibility derived from the literature (Connell et al., 1997; Stevens, 2003; United Nations Economic and Social Council, 2000); the core concept of *nondiscrimination* was derived from the synthesis of a further 6 concepts (Connell et al., 1997; Stowe & Turnbull, 2001; United Nations Economic and Social Council, 2000); *capacity building* was derived from the merging of 2 concepts (Stevens, 2003; Stowe & Turnbull, 2001); *cultural responsiveness* was derived from the consolidation of 2 concepts (Stowe & Turnbull, 2001; United Nations Economic and

Social Council, 2000); *protection from harm* was derived from the synthesis of 2 concepts (Connell et al., 1997; Turnbull et al., 2001); and *individualized services* was derived from the amalgamation of a further 2 concepts (Connell et al., 1997; Turnbull & Stowe, 2001).

The definitions of the resulting 21 core concepts cover a broad range of human rights issues in the context of equity in health as well as health care (Braveman & Gruskin, 2003; Oliver et al., 2002) and enable delivery of health services as a basic human right (Gilson et al., 2008; Russell & Gilson, 2006). The core concepts were not positioned in terms of equivalent importance within the framework but rather were included with a view to representing a broad range of salient concerns in striving for equitable, accessible, and universal health care (see Table 1 for the core concepts, with key questions and key language on which the concepts are based).

Vulnerable Groups

Although the term *vulnerable groups* is one of the most frequently used terms in social science research, difficulties arise when it comes to applying this concept as a measure in policy analysis. Quantifying vulnerability is challenging as is identifying just who is to be considered "vulnerable." This concept needed to be clarified to reinforce its heuristic capacity, as well as political and practical relevance. Literature identifying vulnerable groups from international and national perspectives was consulted to draw up a comprehensive list of these groups, and this list was refined and integrated to produce relevant groups across the four project countries, as well as regional and international health policies. Hence, through literature review and stakeholders consultation, we developed operational definitions for 12 vulnerable groups: *limited resources* (WHO, 2007), *increased relative risk for morbidity* (Office of the United Nations High Commissioner for Human Rights & WHO, 2008), *mother/child mortality* (United Nations Economic and Social Council, 2000), *women-headed households* (WHO, 2002), *children* (*with special needs*) (Pan American Health Organization, 2008), *aged* (Hunt & Backman, 2008; La Rosa-Salas & Tricas-Sauras, 2008), *youth* (United Nations Economic and Social Council, 2000), *ethnic minorities* (WHO, 2007), *displaced populations* (Office of the United Nations High Commissioner for Human Rights & WHO, 2008), *living away from services* (Ensor & Cooper, 2004; La Rosa-Salas & Tricas-Sauras, 2008), *suffering from chronic illness* (Goudge, Gilson, Russell, Gumede, & Mills, 2009), and *disabled* (United Nations Economic and Social Council, 2000). These definitions are outlined in Table 2. It has been argued that although the number of persons with disabilities is increasing globally, this is not reflected by the coverage of this group in relevant policies (Wiman et al., 2002). Accordingly, a particular interest of the research team was to assess the degree to which persons with disabilities (identified by *EquiFrame* as a vulnerable group) were incorporated in policy documents for the purpose of promoting more accessible health care. For further details specific to *EquiFrame* and the process of its formulation, including a more detailed discussion of literature sources for core concepts and vulnerable groups, readers are referred to the *EquiFrame* manual (Mannan, Amin, MacLachlan, & the EquitAble Consortium, 2011; see also Amin et al., 2011; Mannan, Amin, MacLachlan, and the EquitAble Consortium, in press; MacLachlan et al., in press).

Selection of Policies

The term *health policies* was defined as "courses of action (and inaction) that affect the set of institutions, organizations, services and funding arrangements of the health system" (Buse, Mays, & Walt, 2005, p. 6). Health policies were included if they met the following criteria:

1. health policy documents produced by the Ministry of Health,
2. policies addressing health issues outside of the Ministry of Health,
3. strategies that address health policies, and
4. policies related to the top 10 health conditions identified by WHO.[1]

A search was carried out to locate available health policies. The relevant ministries, agencies, and libraries were contacted and asked to identify policy documents falling within the scope of our research. The number of policy documents meeting the inclusion criteria in the four countries were as follows: Malawi = 14, Namibia = 10, South Africa = 11, and Sudan = 16. We sought to assess the extent to which these health policy documents in the four countries promoted equitable, accessible, and inclusive health services.

The Framework

EquiFrame evaluates the degree of stated commitment of an existing policy to 21 core concepts of human rights and to 12 vulnerable groups, guided by the ethos of universal, equitable, and accessible health service provision. The Framework has been devised with the aim of generating a systematic evaluative and comparative analysis of health policies on technical content and design. The Framework has been presented at a workshop conducted for the Ministry of Health in Malawi, consisting of senior policy makers (Munthali et al., 2011), and provided guidance toward the redrafting of the Malawian National Health Policy. We therefore hope that the utility of *EquiFrame* will extend beyond a tool for evaluation of policies to the promotion of equity, human rights, and social inclusion in

Table 1. *EquiFrame* Key Questions and Key Language of Core Concepts

Key question	Key language	Core concept	No.
Does the policy support the rights of members of vulnerable groups to equal opportunity in receiving health care?	Vulnerable groups are not discriminated against on the basis of their distinguishing characteristics (i.e., living away from services; persons with disabilities; ethnic minority or aged).	*Nondiscrimination*	1
Does the policy support the rights of vulnerable groups through individually tailored services to meet their needs and choices?	Vulnerable groups receive appropriate, effective, and understandable services.	Individualized services	2
Does the policy indicate how vulnerable groups may qualify for specific benefits relevant to them?	People with limited resources are entitled to some services free of charge, or persons with disabilities may be entitled to respite grant.	Entitlement	3
Does the policy recognize the capabilities existing within vulnerable groups?	For instance, peer-to-peer support among women-headed households or shared cultural values among ethnic minorities.	Capability-based services	4
Does the policy support the right of members of vulnerable groups to participate in the decisions that affect their lives and enhance their empowerment?	Members of vulnerable groups can exercise choices and influence decisions affecting their lives. Such consultation may include planning, development, implementation, and evaluation.	Participation	5
Does the policy support assistance of vulnerable groups in accessing services from within a single provider system (interagency) or more than one provider system (intra-agency) or more than one sector (intersectoral)?	Vulnerable groups know how services should interact where interagency, intra-agency, and intersectoral collaboration is required.	Coordination of services	6
Are vulnerable groups protected from harm during their interaction with health and related systems?	Vulnerable groups are protected from harm during their interaction with health and related systems.	Protection from harm	7
Does the policy support the right of vulnerable groups to be free from unwarranted physical or other confinement?	Vulnerable groups are protected from unwarranted physical or other confinement while in the custody of the service system/provider.	Liberty	8
Does the policy support the right of a member of a vulnerable group to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?	Vulnerable groups can express "independence" or "self-determination." For instance, a person with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice.	Autonomy	9
Does the policy address the need for information regarding vulnerable groups to be kept private and confidential?	Information regarding vulnerable groups need not be shared among others.	Privacy	10
Does the policy promote the use of mainstream services by vulnerable groups?	Vulnerable groups are not barred from participation in services that are provided for the general population.	Integration	11
Does the policy recognize that vulnerable groups can be productive contributors to society?	Vulnerable groups make a meaningful contribution to society.	Contribution	12
Does the policy recognize the value of the family members of vulnerable groups in addressing health needs?	The policy recognizes the value of family members of vulnerable groups as a resource for addressing health needs.	Family resource	13
Does the policy recognize individual members of vulnerable groups may have an impact on the family members, thus requiring additional support from health services?	Persons with chronic illness may have mental health effects on other family members, such that these family members themselves require support.	Family support	14
Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic aspects of the person?	(i) Vulnerable groups are consulted on the acceptability of the service provided. (ii) Persons at health facilities, or who provide goods and services, must be respectful of ethical principles and culturally appropriate (i.e., respectful of the culture of vulnerable groups).	Cultural responsiveness	15

(continued)

Table 1. (continued)

Key question	Key language	Core concept	No.
Does the policy specify to whom, and for what, service providers are accountable?	Vulnerable groups have access to internal and independent professional evaluation or procedural safeguard.	Accountability	16
Does the policy support vulnerable groups in seeking primary, secondary, and tertiary prevention of health conditions?		Prevention	17
Does the policy support the capacity building of health workers and of the system in which they work when addressing health needs of vulnerable groups?		Capacity building	18
Does the policy support vulnerable groups—physical, economic—and information access to health services?	Vulnerable groups have accessible health facilities (i.e., transportation; physical structure of the facilities; affordability and understandable information in appropriate format).	Access	19
Does the policy support quality services to vulnerable groups through highlighting the need for evidence-based and professionally skilled practice?	Vulnerable groups are assured of the quality of the clinically appropriate services.	Quality	20
Does the policy support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of vulnerable groups?		Efficiency	21

Table 2. *EquiFrame* Vulnerable Groups Definitions

Attributes or definitions	Vulnerable group	No.
Referring to poor people or people living in poverty	Limited resources	1
Referring to people with one of the top 10 illnesses, identified by WHO, as occurring within the relevant country	Increased relative risk for morbidity	2
Referring to factors affecting maternal and child health (birth–5 years)	Mother/child mortality	3
Referring to households headed by a woman	Woman-headed household	4
Referring to children marginalized by special contexts, such as orphans or street children	Children (with special needs)	5
Referring to older age	Aged	6
Referring to younger age without identifying gender	Youth	7
Referring to nonmajority groups in terms of culture, race, or ethnic identity	Ethnic minorities	8
Referring to people who, because of civil unrest or unsustainable livelihoods, have been displaced from their previous residence	Displaced populations	9
Referring to people living far from health services, either in time or distance	Living away from services	10
Referring to people who have an illness that requires continuing need for care	Suffering from chronic illness	11
Referring to persons with disabilities, including physical, sensory, intellectual or mental health conditions, and also to synonyms of disability	Disabled	12

Note: WHO = World Health Organization.

the revision of existing policies and development of new policies.

Summary Indices

The four summary indices of *EquiFrame* are outlined in this section.

Core concept coverage. A policy was examined with respect to the number of core concepts . . . mentioned of the 21 core concepts identified; . . . and this ratio was expressed as a rounded-up percentage. In addition, the actual terminologies used to explain the core concepts within each document were extracted to allow for future qualitative analysis and cross-checking between raters (see Mannan, Amin, MacLachlan, & the EquitAble Consortium, 2011; Amin et al., 2011; Mannan, Amin, MacLachlan, and the EquitAble Consortium, in press; MacLachlan et al., in press).

Vulnerable group coverage. A policy was examined with respect to the number of vulnerable groups mentioned that . . . mentioned of the 12 Vulnerable Groups identified; . . .

Table 3. Summary Indices for the Disability and Rehabilitation Policies of Malawi, Sudan, Namibia, and South Africa

DAR policy	Vulnerable groups (%)	Core concepts (%)	% of core concept quality between 3 and 4	Overall summary ranking
Malawi	16	57	42	Low
Namibia	58	95	57	High
Sudan	42	62	24	Low
South Africa	41	47	19	Low

Note: DAR = disability and rehabilitation.

and this ratio was expressed as a rounded-up percentage. In addition, the actual terminologies used to describe the vulnerable groups were extracted to allow for qualitative analysis and cross-checking between raters (see Mannan, Amin, MacLachlan, & the EquitAble Consortium, 2011; Amin et al., 2011; Mannan, Amin, MacLachlan, and the EquitAble Consortium, in press; MacLachlan et al., in press).

Core concept quality. A policy was examined with respect to the number of core concepts within it that were rated as 3 or 4 (as either stating a specific policy action to address a concept or an intention to monitor a concept) out of the 21 core concepts identified; and this ratio was expressed as a rounded-up percentage. When several references to a core concept were found to be present, the top quality score received was recorded as the final quality scoring for the respective concept.

Overall summary ranking. Each document was given an overall summary ranking in terms of it being of *high, moderate,* or *low* standing according to the following criteria:

- *High* = if the policy achieved ≥50% on all of the three scores above.
- *Moderate* = if the policy achieved ≥50% on two of the three scores above.
- *Low* = if the policy achieved <50% on two or three of the three scores above.

Scoring

Each core concept received a score on a continuum from 1 to 4. This was a rating of the quality of commitment to the core concept within the policy document: 1 = *concept only mentioned*, 2 = *concept mentioned and explained*, 3 = *specific policy actions identified to address the concept*, and 4 = *intention to monitor concept was expressed*. If a core concept was not relevant to the document context, it was stated as not applicable.

Each policy document was assessed by two independent raters. For each document, the presence of core concepts was assessed for each vulnerable group that was identified in the policy. If no vulnerable group was mentioned but a core concept addressed the total population (e.g., "all people"), the core concept was scored as "universal." The total numbers and scores for mentioned core concepts and vulnerable groups were calculated for each document across the four countries. Interrater reliability was established through the comparison of evaluations by raters subsequent to separately analyzing a relevant policy document.

To illustrate, the application of *EquiFrame* to the UN CRPD (United Nations, 2006) revealed that in terms of interrater reliability, there was 100% agreement with regard to the scores assigned to the *Core concept quality* for the document (Level 1 = *concept mentioned*, Level 2 = *concept mentioned and explained*, Level 3 = *specific policy actions identified to address the concept*, Level 4 = *intention to monitor expressed*). In terms of *Core concept coverage,* however, there was a 1 in 10 instance of a dissimilar identification of core concepts by raters for a particular segment of the UN CRPD. For example, in Article 22(2) of the UN CRPD relating to "Respect for Privacy," it is stipulated that "States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others." For this segment, the core concept of *privacy* was identified by both raters, while one rater also identified the core concept of *nondiscrimination*. The dissimilar identification of core concepts for a given segment of the UN CRPD was resolved on discussion between raters subsequent to analyzing the document, and the agreement to identify two or more core concepts to a particular segment of the UN CRPD was not found to alter the overall scorings for this document on *EquiFrame*'s summary indices.

Results

Human Rights and Vulnerable Groups in DAR Policies

Illustrated in Table 3 are the summary indices for the DAR policies of Malawi, Namibia, Sudan, and South Africa. The vulnerable groups of mother/child mortality and ethnic minorities were not mentioned in any policy, while increased relative risk for morbidity, women-headed households, displaced populations, living away from services, and suffering from chronic illness were each mentioned in only one policy document. All of the core concepts of human rights, except for privacy, were mentioned in at least one policy document. Having considered more general findings from the application of the framework to the DAR policies across the four countries, we now discuss the output of *EquiFrame* in relation to more detailed findings from individual country DAR policies.

Malawi: National Policy on Equalization of Opportunities for Persons With Disabilities (2006)

There are more than 500,000 persons with disabilities in Malawi, and a great deal of progress has been made in terms of recognizing persons with disabilities as equal citizens. Hence, they are afforded the same rights and obligations as every other citizen as stipulated in the Constitution of the Republic of Malawi. Nonetheless, challenges still remain because the majority of persons with disabilities continue to have difficulties in accessing education, health services, and employment. This policy, adopted in June 2006, promotes the rights of persons with disabilities to enable them to play a full and participatory role in society and consequently have access to the same rights and responsibilities as every other Malawian citizen. Although the government of Malawi has established the ministry responsible for persons with disabilities, the policy recognizes that the ministry cannot accomplish a great deal in isolation and that disability is a cross-cutting development issue. The policy further defines the roles of different stakeholders.

Vulnerable group coverage. For this policy, vulnerable group coverage was 16% (see Figure 1). Two vulnerable groups were mentioned: children (with special needs) and disabled persons. The remaining vulnerable groups—limited resources, increased relative risk for morbidity, mother/child mortality, women-headed households, aged, youth, ethnic minorities, displaced populations, living away from services, and suffering from chronic illness—were not mentioned. The vulnerable group of disabled persons was mentioned 141 times, whereas children with special needs was mentioned only thrice. Disabled persons was predominantly mentioned with reference to four core concepts, namely, participation, nondiscrimination, capacity building, and access.

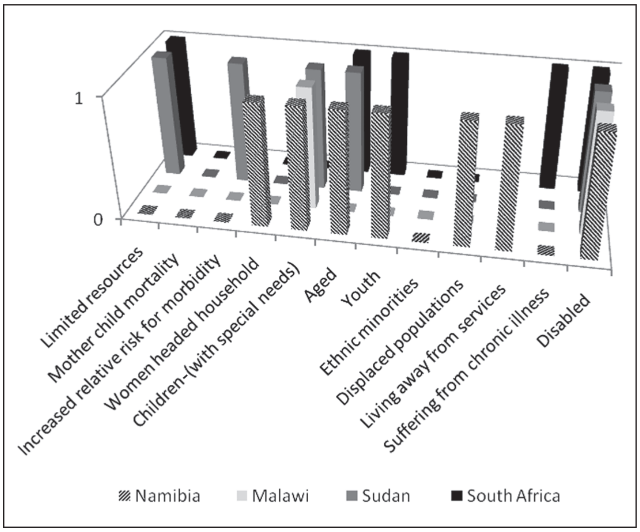

Figure 1. Inclusion of vulnerable groups for disability and rehabilitation policies of Malawi, Namibia, Sudan, and South Africa
Note: 0 = *not mentioned*, 1 = *mentioned*.

Core concept coverage. This was assessed as 57% for Malawi's policy (see Figure 2). A number of concepts were therefore not mentioned, namely, privacy, liberty, cultural responsiveness, family resource, family support, integration, entitlement, accountability, and quality. The concept of capacity building was most frequently mentioned (51 times), followed by participation (40 times), nondiscrimination (38 times), and access (31 times). Although mentioned only 4 times, it is important to highlight the concept of contribution because the policy promotes access to loans and credit facilities for income-generating activities for persons with disabilities.

Core concept quality. With regards to core concept quality, approximately 42% of concepts scored 3 or 4. The following concepts were mentioned with an intention to monitor: *Protection from harm, Prevention, Participation, Non-discrimination, Coordination of services, Capacity building, Individualized services, Access,* and *Efficiency*. The concepts of *Contribution* and *Capability based services* were mentioned and explained, while Autonomy was only mentioned in the policy.

Summary. The Malawian disability policy scored above 50% on *EquiFrame's* summary index of Core Concept Coverage. However, this policy scored below 50% on the indices of Vulnerable Group Coverage and Core Concept Quality. The Malawian National Policy on Equalization of Opportunities for Persons with Disabilities therefore received an Overall Summary Ranking of *Low* quality.

Namibia: National Policy on Disability (1997)

The government of the Republic of Namibia, as stated in the vision underpinning its disability policy, dedicates itself to strive for the creation of a "society for all" based on the principles of the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" (United Nations, 1994). The mission of the government, as outlined

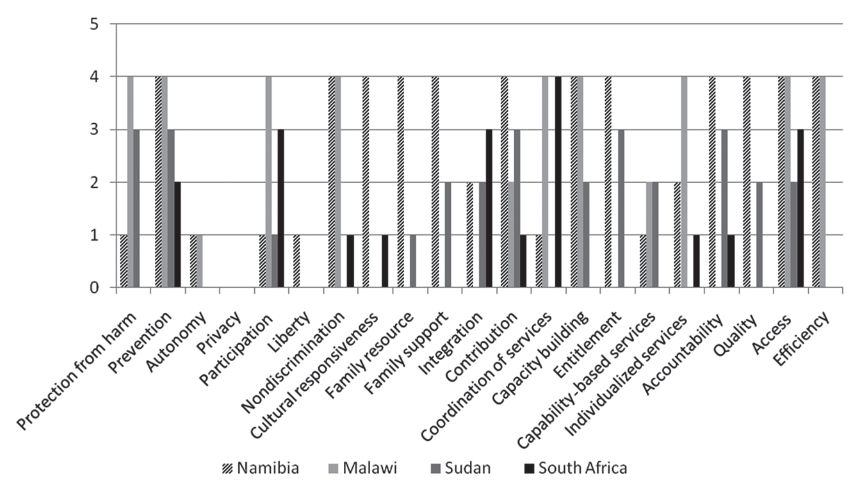

Figure 2. Core concept coverage and quality for disability and rehabilitation policies of Malawi, Namibia, Sudan, and South Africa
Note: 0 = *concept not mentioned*, 1 = *concept only mentioned*, 2 = *concept mentioned and explained*, 3 = *specific policy actions identified to address concept*, 4 = *intention to monitor concept expressed***.**

in this policy, is to improve quality of life through enhancing the dignity, well-being, and empowerment of persons with disabilities. The policy defines its development objective as the achievement of full social integration for persons with disabilities in society, to be achieved by, inter alia, providing and making accessible the following areas: rehabilitation services, education, training, and employment, as well as making changes in the environment to enable persons with disabilities to lead more independent and meaningful lives. At the core of this policy is access, which specifies that all persons with disabilities shall have full access to rehabilitation, therapeutic aids, and orthopedic technical services within their communities as part of a community-based rehabilitation program.

Vulnerable group coverage. For this policy, vulnerable group coverage was 58%. The vulnerable groups of limited resources, increased relative risk for morbidity, mother/child mortality, ethnic minorities, and suffering from chronic illness were not mentioned. The vulnerable group of disabled persons was mentioned 24 times, whereas children with special needs was mentioned 7 times, aged 4 times, both women-headed households and youth mentioned twice, and both displaced populations and living away from services mentioned once.

Core concept coverage. For this policy, core concept coverage was 95%. The core concept of privacy was not mentioned. Access was mentioned 52 times, integration 21 times, nondiscrimination 20 times, participation 16 times, coordination of services 12 times, prevention 11 times, quality 9 times, and capability-based services 5 times. Cultural responsiveness, family resource, and efficiency were mentioned 4 times, and protection from harm, autonomy, family support, and capacity building were mentioned twice in the policy. Liberty, contribution, entitlement, individualized services, and accountability were each mentioned once.

Core concept quality. With respect to this item, 57% of Concepts scored 3 or 4. *Prevention, Non-discrimination, Cultural responsiveness, Family resource, Family support, Contribution, Capacity building, Entitlement, Accountability, Quality, Access,* and *Efficiency* were each mentioned with an intention to monitor. The concepts of *Integration* and *Individualized services* were mentioned and explained. *Protection from harm, Autonomy, Participation, Liberty, Coordination of services,* and *Capability based services* were each only mentioned.

Summary. The overall summary ranking for Namibian disability policy was *high* quality.

Sudan: National Policy for Disability, 2003

According to the 1993 Sudan National Census, the prevalence rate of disability was 1.5%, with a higher rural than urban ratio, and the prevalence rates were 53% for males and 47% for females. The Sudanese National Policy for Disability defines *disability* as “individuals who are affected by functional disability being motor, sensory or mentally, occurring from birth or as a result of an accident which permanently or partially affected individual’s natural/normal life pattern.” The document consists of five sections, including a situational analysis followed by policy objectives. The third and fourth parts encompass the policy statement, including its principles and action areas, while the concluding section defines the proposed 5-year national strategy for disability. Overall, the document is of a generalized nature, addressing various issues and core concepts, with limited emphasis, however, on action areas or monitoring mechanisms. Furthermore, the document uses the term *disabled* as one unit and therefore does not distinguish among the various types, targets, and needs of persons with disabilities.

Vulnerable group coverage. The policy mentioned 42% of vulnerable groups. Five vulnerable groups, namely, limited resources, increased relative risk for morbidity, children (with special needs), aged, and disabled persons were explicitly mentioned in the document. The most frequently mentioned vulnerable group was disabled persons (21 times), followed by increased relative risk for morbidity and children with special needs (each mentioned twice), and limited resources, and aged (each mentioned once).

Core concept coverage. The policy addressed 13 core concepts (62%). The core concepts of autonomy, privacy, liberty, nondiscrimination, cultural responsiveness, coordination of services, individualized services, and efficiency were not mentioned in the policy. Protection from harm was mentioned most frequently at 5 times, followed by integration, mentioned 4 times. The core concepts of prevention, contribution, accountability, and quality were each mentioned thrice, while entitlement and capability-based services were both mentioned twice. Participation, family resource, family support, capacity building, and access were mentioned once in the policy.

Core concept quality. 24% of concepts were scored as 3. No concepts were mentioned with an intention to monitor. Specific policy actions were identified to address the concepts of *Protection from harm, Prevention, Contribution, Entitlement,* and *Accountability*. The core concepts of *Family support, Integration, Capacity building, Capability-based services, Quality*, and *Access* were mentioned and explained in the policy. The concepts of *Participation* and *Family resource* were only mentioned in the policy.

Summary. The Sudanese National Policy for Disability received an overall summary ranking of *low* quality.

South Africa: National Rehabilitation Policy (2000)

Throughout recent years, there has been concern about the lack of policies and guidelines in the area of rehabilitation in South Africa. This dearth of policy making has resulted in services that are either absent or underdeveloped for the most part in South Africa. The National Rehabilitation Policy forms part of the strategy to improve the quality of life of persons with disabilities. The primary goal of this policy is to improve accessibility to all rehabilitation services to facilitate the realization of every citizen's constitutional right to have equitable access to health care services. The objectives outlined in this policy are as follows:

1. improve accessibility of rehabilitation services for persons suffering from conditions that can lead to disability as well as those living with disabilities;
2. establish mechanisms for intersectoral collaboration to implement a comprehensive rehabilitation program;
3. facilitate human resource development that takes into account the needs of both the service providers and the consumers;
4. encourage the development and implementation of monitoring and evaluation strategies for rehabilitation programs;
5. ensure participation of persons with disabilities in planning, implementation, and monitoring of rehabilitation programs; and
6. encourage research initiatives in rehabilitation and related areas.

Vulnerable group coverage. For this policy, coverage was 41%. The vulnerable groups of increased relative risk for morbidity, mother/child mortality, women-headed households, children (with special needs), ethnic minorities, displaced populations, and living away from services were not mentioned in the policy. Disabled persons were mentioned 10 times, youth 4 times, aged thrice, suffering from chronic illness twice, and limited resources once.

Core concept coverage. Coverage was 47%. The core concepts of protection from harm, autonomy, privacy, liberty, family resource, family support, capacity building, entitlement, capability-based services, quality, and efficiency were not mentioned in the policy. Access was mentioned 5 times, both integration and individualized services were mentioned thrice, and prevention and nondiscrimination once each.

Core concept quality. 19% of concepts were scored 3 or 4. The core concept of *Coordination of services* was mentioned with an intention to monitor. Specific policy actions were identified to address the concepts of *Participation, Integration* and *Access*. The concept of *Prevention* was mentioned and explained with reference to *Disabled* persons. The concepts of *Non-discrimination, Cultural responsiveness, Contribution, Individualized services* and *Accountability* were only mentioned.

Summary. The overall summary ranking of South African rehabilitation policy was *low* quality.

Discussion

Substantial variability was identified in the degree to which inclusion of vulnerable groups and core concepts of human rights, as well as commitment to core concepts, were featured across these policy documents. Only the vulnerable group of disabled persons was assessed to be common across all policy documents. Across all four countries, however, the vulnerable groups of mother/child mortality and ethnic minorities were not explicitly mentioned. Core concept coverage and core concept quality were also variable across the four countries. Only the core concepts of prevention, participation, contribution, and access were mentioned across all four countries; the core concept of privacy was not explicitly mentioned in any of the four policy documents. Notwithstanding country-specific patterns, our analysis has highlighted a number of serious shortcomings, particularly with respect to the DAR policy documents of Malawi, Sudan, and South Africa, in terms of the overall summary ranking.

In our analysis, less than 50% of core concepts in the DAR policies of Malawi, Sudan and South Africa were mentioned in conjunction with specific policy actions to address the concept or an expression of an intention to monitor the concept. DAR policies must demonstrate not solely an incorporation of but also a high quality of *commitment to* core concepts of human rights, to strengthen the social accountability as well as political credibility of policies.

We argue that legitimate commitment to the WHO Health for All principles will not be realized by WHO member states without recognition in DAR policies of a variety of prevalent contexts in which persons with disabilities may be subject to multiple forms of discrimination. Although persons with disabilities may present similar challenges regarding their equitable access to health care, various subpopulations of persons with disabilities may present distinctive challenges. Findings from our analysis indicating that less than 50% of vulnerable groups outlined by *EquiFrame* were included in the DAR policies of Malawi, Sudan, and South Africa is alarming. Until specific mechanisms of exclusion and detailed needs of subgroups of persons with disabilities are explicitly addressed, the DAR policies of these three countries will fall short of their objectives.

In several contexts, the experience of disability interplays with other factors that may generate susceptibility to double discrimination and multiple disadvantage (women with disabilities [Barnes, 2001; Council of Europe, 2005; Quinn & Bruce, 2003; United Nations, 2006; United Nations Economic and Social Council, 2003; United Nations Enable, 2011; World Bank, 2004, World Bank, 2010; WHO & UNFPA, 2009], children with disabilities [Barnes, 2001; Council of Europe, 2005; Kilkelly, 2002; Lansdowne, 2009; Maulik & Darmstadt, 2007; Pan American Health Organization, 2008; United Nations, 2006; United Nations Economic and Social Council, 2003; WHO, 2010], ethnic minorities with disabilities [Castellino, 2002; Council of Europe, 2005; Elliott, Utyasheva, & Zack, 2009], aged populations with disabilities [United Nations Economic and Social Council, 2003)], persons with disabilities with limited resources [Mercer & MacDonald, 2007; United Nations Economic and Social Council, 2003; World Bank, 2004], persons with disabilities living away from services [United Nations Enable, 2008–2011b; WHO & World Bank, 2011], persons with disabilities suffering from chronic illness [DeJong & Basnett, 2001], mother/child mortality for persons with disabilities [United Nations Children's Fund (UNICEF), 2008; World Bank, 2010; WHO & UNFPA, 2009], persons with disabilities at increased relative risk for morbidity, in particular HIV/AIDS [Dube, 2009; Dutch Coalition on Disability and Development, 2008; Elliott et al., 2009; Grant, Strode, & Hannass-Hancock, 2009; Groce, 2003; Rohleder, Swartz, & Philander, 2009; The Africa Campaign, 2008; United Nations Enable, 2011; United Nations Human Rights, WHO, & UNAIDS, 2009; World Bank, 2004; World Bank, 2010; Yousafzi & Edwards, 2004], and displaced populations with disabilities [United Nations High Commissioner for Refugees, 2001–2011; Women's Commission for Refugee Women and Children, 2008; WHO & UNFPA, 2009]).

Both through the process of undertaking this policy analysis initiative and by providing feedback of results to stakeholder workshops in the four countries, we have observed several factors that are important to consider when interpreting the results of our analysis. For instance, the core concept of privacy was not mentioned in the DAR policies across the four countries. Aldersey and Turnbull (2011), in their policy analysis of the United Republic of Tanzania's National Policy on Disability, stated that cultural relativists would caution against automatically translating Western values of rights, such as privacy, to a non-Western context without exploring the suitability of doing so within the specific cultural context. We recognize that the experience and expression of disability are likely to vary across different contexts and cultures, as do interpretations of human rights (MacLachlan, 2006). One value of *EquiFrame* may be to help us understand the pattern of such variations and to establish whether "omissions" are by design or through oversight.

In the various feedback workshops, some stakeholders argued that some documents use the term *all,* as in "all people," to be fully inclusive; therefore, reference to specific vulnerable groups is not necessary. Indeed, subsidiary analysis of the use of *all,* or its synonyms, indicates that documents using such "all-inclusive" terms also specify certain vulnerable groups but not others. Accordingly, we feel it is important to establish which vulnerable groups are included, and which are not, as the use of inclusive terminology does not necessarily address the concerns of specific vulnerable groups.

The indices we have used—scores of 50% or greater for each of our ratings—could be altered to reflect different weighting or sensitivity with regard to human rights, vulnerability, or specific actions to address a concept or intention to monitor a concept being expressed. Indeed, these latter two categories could be treated separately rather than combined, as we did here. Ultimately *EquiFrame* is a methodology for descriptive analysis, providing several indices that can be fine-tuned for the required purpose.

Although *EquiFrame* has been developed for the purposes of policy analysis, we believe that its form of analysis can also be usefully applied to other types of planning and guiding documents, and that the coverage of core concepts of human rights and the inclusion of vulnerable groups is pertinent to a range of diverse documents. Fuller understanding of the content of any such documents can and should always be strengthened by understanding of the context in which the document was developed, the process of its development, and the implementation actions that must accompany it for it to take effect. However, describing policy "on the books" is not only a legitimate but also vital practice if we are to recognize and develop documents that are most likely to support human rights and promote greater inclusion in health service provision. If we fail to do this, we risk privileging some groups over others, perhaps addressing the concerns of dominant groups, particularly in the context of services provided through international aid support (MacLachlan, Carr, & McAuliffe, 2010).

As emphasized by Walt et al. (2008), health policy analysis may be beneficial both retrospectively and prospectively in the understanding of past policy failures and successes and the development of future policy implementation. Accordingly, we hope that the utility of *EquiFrame*, as a policy analysis tool will extend beyond its application as a framework for evaluation to the development of new policy documents and to the revision of existing documents. By highlighting some high-quality documents, *EquiFrame* can point countries toward some best practice examples of human rights coverage and vulnerable group inclusion. It can also provide a checklist of factors for consideration, as well as indicate specific terms and phrasing for use in a policy.

Social activists and advocates for persons with disabilities conceptualize disability as a political topic and an issue of basic civil rights (Bickenbach et al., 1999), an ideology underpinning the UN CRPD (United Nations, 2006). Yet some governments have failed to endorse policies that are legitimately committed to human rights and are inclusive of vulnerable groups. Adequate DAR policies remain on many occasions undefined (Wiman et al., 2002). Although, as emphasized by Lang (2009), some governments assert that they are without sufficient financial resources to implement such policies when weighted against other competing developmental challenges, such contentions are unfounded when taking into consideration that the design and execution of legitimately inclusive policies can benefit the population at large and not exclusively persons with disabilities. Through its discernment of policy commitment to core concepts of human rights and inclusion of vulnerable groups, we hope that *EquiFrame* may provide a novel and valuable tool for policy appraisal, providing a window for states to strengthen the social accountability and political credibility of their DAR policies, and to ultimately narrow the gap between declaration and delivery with regards to equitable and accessible health services for all.

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Note

1. The top 10 health conditions identified by WHO:
    - Malawi: HIV/AIDS, lower respiratory infections, malaria, diarrheal diseases, perinatal conditions, cerebrovascular disease, ischemic heart disease, tuberculosis, road traffic accidents, and protein energy malnutrition
    - Namibia: HIV/AIDS, perinatal conditions, cerebrovascular disease, tuberculosis, ischemic heart disease, diarrheal disease, malaria, violence, lower respiratory infections, and road traffic accidents
    - South Africa: HIV/AIDS, cerebrovascular disease, ischemic heart disease, violence, tuberculosis, diarrheal diseases, road traffic accidents, diabetes mellitus, and chronic obstructive pulmonary disease
    - Sudan: Ischemic heart disease, malaria, HIV/AIDS, diarrheal diseases, measles, tuberculosis, cerebrovascular disease, perinatal conditions, war, and road traffic accidents

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