Analyzing Eswatini's National Disability Policy Reforms: Access to Health Care Implications for Citizens With Disabilities

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Abstract

In 2012, Eswatini ratified the United Nation's Convention on the Rights of Persons with Disabilities (CRPD), and in 2013 developed the national disability policy reform documents to implement the CRPD across different domains, including health care. The current study aimed to analyze these policy reform documents for the actors, context, and processes involved in the development and implementation of the national disability policy reform documents. It also examined the provisions made for access to health care for persons with disabilities by utilizing a novel disability policy analysis framework. In-depth interviews with key informants were conducted to substantiate the findings obtained from document reviews. Focus group discussions were then conducted with persons with disabilities, caregivers of persons with disabilities, and health care professionals as the end users of the policy documents. The goal was to establish their knowledge of these documents and to ascertain how effective they perceived these documents to be. Findings indicated that while the content of the policy documents mirror most of the CRPD's principles, certain aspects related to geographical and financial accessibility should be reconsidered. There is evidence to suggest a gap in policy implementation, owing to the lack of disability conscientization in general and among policymakers in particular, and manifested through political, financial, and attitudinal factors. This implies a need for disability sensitivity programs, as well as clearer implementation guidelines and government's commitment to disability rights and the process of implementing the national disability policy reform documents.

Keywords: access, conscientization, disability, Eswatini, health care policy

Persons with disabilities account for about 16.8% of Eswatini's population (Swaziland Deputy Prime Minister's Office, 2013), which is slightly higher than the global prevalence rate of 15% (World Health Organization, 2011). In Eswatini, formerly known as Swaziland, persons with disabilities also form a significant part of the poor majority. Most of them (86%) live in the rural areas of the country (Eide & Jele, 2011). However, access to health care and health information continues to be a challenge for all Eswatini citizens with disabilities, regardless of whether they live in urban or in rural areas (Eide & Jele, 2011; Mavundla, 2015). The health care system in Eswatini comprises both private and public health care, with the vast majority of the population (including most persons with disabilities) utilizing public health care (Magagula, 2017).

The public health care system in Eswatini, which is fully funded by the government, is arranged according to four levels: (a) community-based care, which encompasses rural health initiatives; (b) faith-based health care, which includes volunteers and traditional practitioners; (c) primary health care facilities, which include health centers, public health units, rural clinics and outreach sites; and (d) secondary health care facilities, which include regional hospitals and national referral hospitals (Magagula, 2017).

Access to health care, specifically defined in relation to consumer satisfaction, refers to the "degree of fit between the patient and the healthcare system" (Penchasky & Thomas, 1981, p. 127). Penchasky and Thomas (1981) argued that access to health care is influenced by factors such as availability (i.e., an adequate number of health care professionals, facilities, resources, and programs in relation to the number of consumers and their health care needs); accessibility (i.e., the proximity of services to consumers in terms of distance, traveling time and transportation resources); accommodation (i.e., services that are structured to accommodate consumer needs as confirmed by themselves); affordability (i.e., the pricing of services relative to the consumers' ability to pay); and acceptability (i.e., the attitudes of the health care provider and the consumers toward one another, based on their perceptions and prejudice) of appropriate personal, physical and practice characteristics. This framework, which had been developed by Penchasky and Thomas already in 1981, was used by Peters et al. (2008) as a foundation to define access—specifically in the context of low- to middle-income countries (LMICs) such as Eswatini. According to Peters et al. (2008), access to health care in LMICs may materialize when availability, acceptability, geographical accessibility, and financial accessibility have been accounted for. Geographical and financial accessibility are of particular importance in LMICs, as many persons with disabilities live in poverty-stricken conditions. LMICs are severely under-resourced in terms of infrastructure and finances, which affect access to health care negatively (World Health Organization, 2011). Access to health care is further compounded by the social determinants of health in these countries, such as high rates of both communicable and noncommunicable diseases, severe malnutrition, unclean water, poor sanitation and shelter, gender inequity, low education levels, high unemployment, and poor income (Orach, 2009; United Nations Development Programme, 1998).

Basic health care as a human right is confirmed by the United Nations Convention of the Rights of Persons with Disabilities (CRPD; United Nations [UN], 2006), a piece of international human rights legislature. Eswatini is a signatory to the CRPD, and the country ratified both the CRPD and its optional protocol in 2012 (Mavundla, 2015). As such, Eswatini is mandated to develop and implement policy reforms that guard against the violation of the rights of persons with disabilities, while the country must also ensure that persons with disabilities have access to adequate services. Eswatini honored its mandate to the CRPD by developing the National Disability Policy of Swaziland in 2013 (Swaziland Deputy Prime Minister's Office, 2013). Subsequently, the national disability plan of action (Swaziland Deputy Prime Minister's Office, 2015) and the national disability bill of rights (Swaziland Deputy Prime Minister's Office, 2016) were developed in 2015 and 2016, respectively (Mavundla, 2015).

Despite the development of these policy reform documents evidence seems to suggest that persons with disabilities in Eswatini continue to struggle to access health care services (Masuku, 2020; Matter & Eide, 2018). Although the national disability policy of Eswatini has been ratified, the national disability bill of rights is yet to be passed as law as it is currently awaiting the conclusion of parliamentary processes. Potential gaps in policy development and/or implementation processes may thus be implied. Alant et al. (2007) suggested that, globally, governments develop policies as a tick box exercise, rather than with the intention of

using them as change agents. This observation is supported by the evident gaps in the implementation of disability policies. Duncan et al. (2011) and Shumba and Moodley (2018) concurred with Alant et al. (2007), who believed that the implementation of policies may be unsuccessful due to the fragmentation of and poor coordination among intersectoral stakeholders responsible for policy implementation; the limited or sometimes complete lack of human and financial resource allocation; and the clear division between the processes of policy development and implementation.

For persons with disability who live in LMICs, the implementation of international human rights-based policies such as the CRPD is imperative to encourage advocacy, social mobilization, and the development of legal structures to support human rights and address human rights violations (Broberg & Sano, 2018; Hussey et al., 2017). International human rights-based approaches are also particularly relevant in LMICs because, regardless of context, persons with disabilities are vulnerable members of society who share similar global challenges, even though the degree might be compounded in LMICs. The implementation of policy documents based on international human rights approaches in LMICs—without proper considerations for contextual, cultural, and political factors—has been interrogated, as these factors may influence how a human rights-based approach is perceived and ultimately implemented (Broberg & Sano, 2018; Hussey et al., 2017).
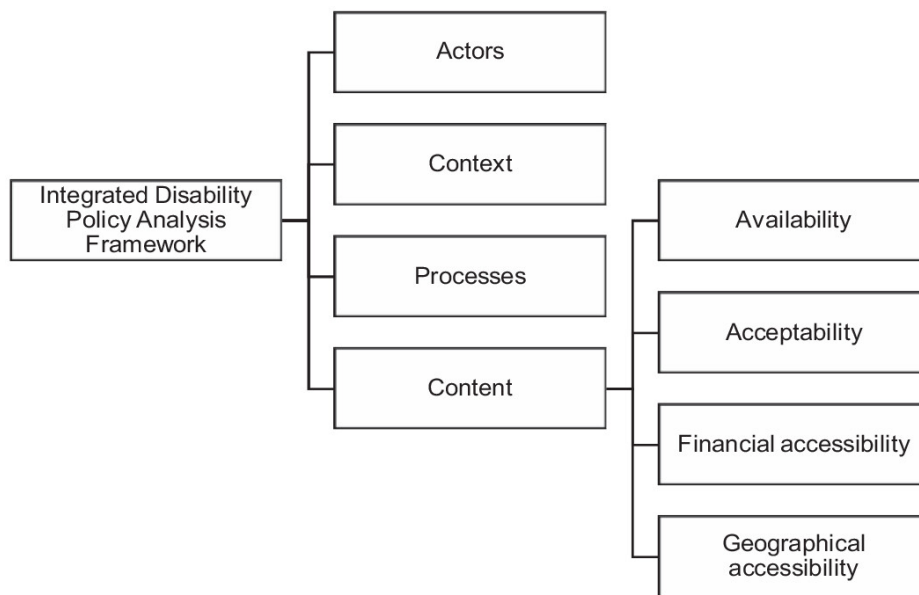

Figure 1. The Integrated Disability Policy Analysis Framework (Masuku, 2020) Combining the Frameworks of Walt and Gilson (1994) and Peters et al. (2008).

Masuku (2020) developed the integrated disability policy analysis framework for LMICs by supplementing the Walt and Gilson (1994) policy analysis framework with the access-to-health care framework of Peters et al. (2008) (see Figure 1). Walt and Gilson (1994) theorized that if policymakers and researchers use a simple model that integrates actors, context, content, and processes, they may better understand the process of policy improvement. This could enable them to plan for policy implementation more effectively. Although the Walt and Gilson (1994) policy analysis framework has been successfully used to analyze the implementation of health policies, it was insufficient as a stand-alone framework to evaluate the content component, that is, access to health care. The integrated disability policy analysis framework (Masuku, 2020)

appears to be better suited for the analysis of Eswatini's national disability policy reform (NDPR) documents, as it considers not only the above-mentioned aspects, but also the relevant contextual, political, and cultural factors (Broberg & Sano, 2018).
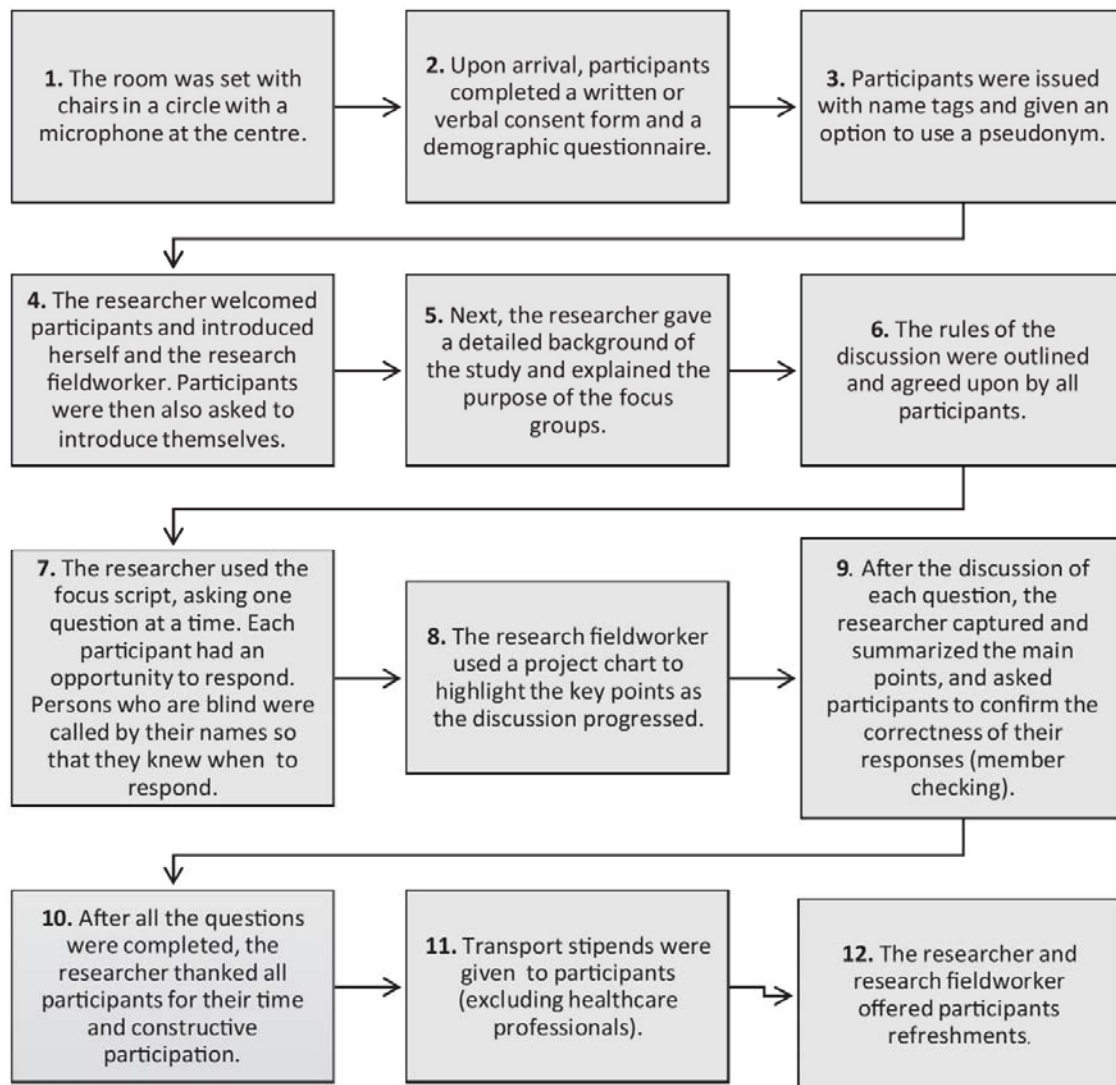

Figure 2. Steps Followed During the In-Depth Interviews and Focus Groups.

The current study concedes that when appraising disability policies for access to health care, it is imperative to report on the actors, context, content, and processes of the policy documents. The study goes on to propose that an integrated theoretical framework is necessary to further demarcate the content component of policy documents. This process not only increases the rigor of the policy analysis but also creates a structure for reporting—with the clear purpose to identify content gaps in specific components of access. Figure 1 presents the novel integrated disability policy analysis framework (Masuku, 2020) that was applied in the analysis of Eswatini's NDPR documents (Figure 2). Three questions guided this research:

Research Question 1 (RQ1): Who were the actors in and the context and processes surrounding the development and implementation of the NDPR documents of Eswatini?

Research Question 2 (RQ2): How did the NDPR documents provide for the health care of persons with disabilities in Eswatini?

Research Question 3 (RQ3): What are the perceptions of persons with disabilities, caregivers of persons with disabilities and health care professionals about the success of the NDPR documents in facilitating access to health care for persons with disabilities?

Method

Data were collected sequentially from three data sources: a step-by-step document review of the NDPR documents, in-depth interviews with key informants, and focus group discussions with end users.

Document Review

An online search was conducted to establish what NDPR documents exist in Eswatini. The national disability unit was also consulted to confirm information obtained online. The NDPR documents (i.e., the National Disability Policy of Swaziland and the national disability plan) were downloaded from the Eswatini website for analysis. The first author and two independent coders (with experience in policy analysis) then systematically read the NDPR documents, line by line, to identify any policy segments within the documents that related to access to health care (content, actors, context, and processes). They used collaborative coding as proposed by Saldana (2009) to ensure a robust discussion involving multiple minds and to ensure the rigor of the data analysis (Richards & Hemphill, 2018).

In-Depth Interviews

Additional interviews were conducted with key informants (stakeholders who were involved in the development and implementation of the NDPR documents). Potential participants were identified via the national disability unit of Eswatini and then contacted telephonically to invite them to participate in the interviews. A follow-up email with information detailing the purpose of the study and the expected role of participants in the study was sent to all who initially expressed interest during the telephonic contact. Interview dates and venues were confirmed with consenting participants. All interviews were conducted at a time and place (i.e., the participants' office) convenient for the participants, and the first author adhered to an interview guide and recorded the conversations.

Focus Group Discussions With End Users

Three focus group discussions were held with end users, namely persons with disabilities, caregivers of persons with disabilities, and health care professionals. Participants for Focus Groups 1 and 2 were recruited via the database of a disability organization in Eswatini, with the permission of the president of the federation. Permission and informed consent letters explaining the aims and details of the study, participant requirements and the contact details of the researcher, were sent via email to all prospective participants. Interested individuals contacted the first author who then arranged focus groups based on the availability of participants. A room at the local library was used to conduct these two focus group discussions.

Health care professionals were recruited for Focus Group 3 via a government hospital, following permission from its director of health and the hospital superintendent. The resident

speech-language therapist liaised with researchers to invite potential participants to participate in the study. Once their informed consent had been obtained in writing, a focus group discussion was conducted in a boardroom of the hospital during the lunch hour. This ensured that participation was convenient for all health care professionals in terms of time and location.

Instrumentation

Coding Book for Document Review: With the input from two independent coders, the first author developed a coding book based on the concepts of the integrated disability policy analysis framework (see Figure 1). As mentioned before, these concepts included actors, context, processes, and content (which comprised availability, acceptability, financial accessibility, and geographical accessibility). Operational concept definitions were jointly developed and approved, after which the first author and the same two coders jointly perused the NDPR documents. They subsequently agreed on the policy extracts related to access to health care that should be imported into the coding book (Nili et al., 2017). The coding book was developed based on a procedure similar to that followed by Ramaahlo et al. (2018) and described in detail in Masuku (2020).

Interview Script: A self-developed interview script encompassing four sections was used. Section A contained eight demographic items (age, gender, educational level, job title, institution of employment, department where participants were employed during the development of the NDPR documents, participants' involvement in the development of the NDPR documents, participants' involvement in the implementation of the NDPR documents). Sections B to D consisted of open-ended questions where key informants presented their perspectives on the actors and the contextual factors that influenced the initiation, development, and implementation of the NDPR documents.

Focus Group Guide: A self-developed focus group script consisting of four sections was also used. Section A contained varied biographic items that were specific to each group of participants. For instance, persons with disabilities were asked to give information on their gender, age, languages spoken, place of residence, type of disability, how long they had lived with a disability, and the frequency of accessing health care services. Caregivers of persons with disabilities were also asked about their gender, age, where they reside, the type of disability that the person they were caring for presented with, and how often they accompanied them to a health care facility. Apart from their age and gender, health care professionals were asked about their current place of employment, their profession, their highest level of education, the number of years that they had been practicing their profession, and the number of years they had been working with persons with disabilities.

The questions for focus group discussions included what participants knew about the NDPR documents, what improvements had they seen in the provision of health care since the inception of the NDPR documents, and their current perceptions and experiences of access to health care for persons with disabilities in Eswatini.

Participants

Purposive, non-probability sampling was used to select the final sample of 32 participants (20 females, 12 males with an age range of 30–63 years and an average age of 42 years), for the in-depth interviews ($n = 7$) and to engage in focus groups ($n = 25$). Purposive sampling ensured that participants had the necessary insight into and knowledge of the NDPR documents

(Elmusharaf, 2012), based on their involvement in the development and implementation of the NDPR documents or from their role as beneficiaries of this reform. The participants involved in the in-depth interviews included national government employees ($n = 3$), as well as members of non-governmental organizations ($n = 2$) and disability organizations ($n = 2$). Focus group participants were persons with disabilities ($n = 5$), caregivers of persons with disabilities ($n = 6$), and health care professionals ($n = 14$).

Data Analysis

For the document analysis, a total of 44 individual segments that address access to health care in the NDPR documents as identified and agreed upon by the first author and two independent coders were used as a basis for the coding book (Ramaahlo et al., 2018). The first author and two independent coders further collaboratively categorized the policy segments to constitute the pillars of the integrated disability policy analysis framework, namely, actors, context, processes, and content. The latter consisted of availability, acceptability, and accessibility (financial and geographical).

All interviews and focus group discussions were conducted by the first author in either Siswati or English, Eswatini's two official languages. Audio recordings that were made of all discussions were transcribed verbatim by the first author. Siswati transcripts were translated into English by the first author and back-translated into Siswati by a research fieldworker who is a first language Siswati speaker. This was done to ensure that no meaning was lost.
For the in-depth interviews and focus group data, a framework analysis approach that used deductive thematic analysis (Srivastava & Thomson, 2009) was adopted to analyze all transcribed data. Data from the three focus group discussions with end users were collapsed into a single data set, as they all responded to the same question pertaining to their knowledge of and perceptions about the policy reform documents.

During the thematic analysis process, the first and second authors used a strategy of collaborative coding (Saldana, 2009). They followed the six steps proposed by Braun and Clarke (2013) to address the first research aim. The themes obtained from thematic analysis were then mapped onto the predetermined components of the integrated disability policy analysis framework (Masuku, 2020). Two overarching themes that are relevant to the second research aim emerged from the focus group data, namely, the participants' perceptions of the success (or failure) of the NDPR documents and factors that influenced this.

Trustworthiness

To ensure rigor, the study employed multiple data sources. The integrated disability analysis framework (Masuku, 2020) was used to map data from all data sources. Various trustworthiness strategies were employed. For example, conformability was ensured by audit trails and collaborative coding (Shenton, 2004), while credibility was ensured through data triangulation, member checking, peer scrutiny of the research, and keeping a procedural checklist. Transferability was ensured through providing in-depth descriptions of the methodology, the representativeness of participants, and the piloting of the interview and focus group script.

Ethical Considerations

Prior to the commencement of the study, ethics approval was obtained from the Research Ethics Committee in the Faculty of Humanities at the University of Pretoria (Project number GW20160721HS). Permission was also granted by the Eswatini Medical Research Committee and the Eswatini Ministry of Health. Before the in-depth interviews and focus groups were embarked on, written or oral consent was obtained from participants. They were also assured of confidentiality and that they could withdraw from the study at any time without any negative consequences.

Results

The findings are presented according to the three RQs examined by the study. First is a discussion of the actors in, the context of, and the processes followed during the development and implementation of the NDPR documents, in response to RQ1. Second, to answer RQ2, results pertaining to the content (including four subcomponents: availability, acceptability, financial accessibility, and geographical accessibility) are presented. Last, to address RQ3, the perceptions of persons with disabilities, caregivers, and health care professionals about the NDPR documents and the subsequent success of these documents in facilitating access to health care for persons with disabilities are described.

Actors and Context/Processes Surrounding Development and Implementation of the NDPR Documents

Actors: The document review stipulated the involvement of the deputy prime minister's office, the respective government ministries, nongovernmental organizations, organizations of persons with disabilities, and a Commonwealth officer who was visiting Eswatini during the period of conceptualization of the policies aimed at developing the National Disability Policy of Swaziland (Eswatini). In-depth interviews with key informants further clarified the respective roles of these actors in the policy processes. For example, all the government ministries, including the Deputy Prime Minister's office, were regarded as custodians of social welfare—including disability. Government ministries initiated and facilitated the process of developing and implementing the NDPR documents. They not only read and edited drafts but also funded the roll-out of the plan of action in the different ministries. In liaison with the Department of Justice, the policy documents were drafted in acceptable policy language. In essence, the National Disability Unit was responsible for the co-ordination of all activities pertaining to the development and implementation of the NDPR documents. The Unit also had to collate all the ideas that had been contributed to inform the content of the NDPR documents.

Disability organizations, the Council of Churches, as well as UN organizations in Eswatini were involved as actors in the development stage of the NDPR documents. They all had the responsibility to make recommendations on the content of these documents, based on disability rights issues in Eswatini, and they were expected to follow the progress of policy implementation. In addition, a Commonwealth officer who was knowledgeable on policy development and implementation played an advisory role during the development of the NDPR documents, as he happened to be paying the Ministry of Justice a once-off visit during that time. Follow-up consultation with this officer was unfortunately not possible when the current study was conducted.

Table 1. Context of the National Disability Reform Documents of Eswatini.

Themes	Subthemes	Verbatim excerpts from participants
National Disability Law	Need for laws to protect persons w/disabilities	• "What was happening was that … persons with disabilities had no law protecting them and holding people who treat them inappropriately accountable. So, we knew that after the policy we would come up with the Bill which is the law" (P9).
	Need for laws to operationalize the national disability policy reform documents	• "We did the policy, when I left, we had already drafted the act that supports the policy because you can have your policy, what does it matter nothing. So, we need to have the law that is going to then operationalise that policy because policy is just talk, oh" (P4).
International Disability Law: UN role and mandate	Mandate for the CRPD	• "So, the CRPD is what was ratified in 2012. The ratification had to be domesticated into what we could do as a country for persons with disabilities. That is why we started by developing the disability policy and then from the disability policy we developed the National Disability Plan of Action and the Bill" (P12).
	Pressure from UN	• "So, I think that the government felt the pressure to explain why we did not have a policy. It pointed to everyone. So, we had to stand up and make the policy happen. It was from the UN that by this time, you should have done this and that in place what is your problem?" (P3).
Financial support for persons with disabilities	Need for grant support for persons w/disabilities	• "Especially for us, persons with disabilities, we are poor, it is common that in most cases persons with disabilities come from poor families. So, we thought that a lot of things would change after the policy and that social support would be given to persons with disabilities to access things like healthcare" (P14).
	Need for consistency in grant allocation	• "If you had a child with a disability and you talked a lot, you would get a grant and if you were that parent that did not talk a lot and knew nobody, you wouldn't get a grant. So, we had to formalise grants for persons with disabilities" (P14).
Accessibility for persons with disabilities	Need for accommodation of persons w/disabilities across all entities	• "We needed and still need to be able to go to school, we need infrastructure that is conducive for us, we need to be able to go to hospitals everything as we have learnt from other countries that maybe if there were certain things that could be financially subsidised so that persons with disabilities can access things that they need" (P3).
Disability mainstreaming	Need for bringing disability into mainstream thinking	• "Mainstreaming was important. Mainstreaming is making sure that we don't treat disability activities separately and that they are inculcated in different parts with other stakeholders of government and civil society" (P1).

Note. CRPD = Convention on the Rights of Persons with Disabilities.

Context: The document review indicated that the NDPR documents were conceived by the government as a way of fulfilling its obligation toward the CRPD. The Eswatini NDPR documents, therefore, built on the principles of the CRPD. Additional information related to the context of the documents was obtained from interviews conducted with key informants. Table 1 presents the themes related to the context of the policy with supporting verbatim excerpts from these interviews.

Processes

Findings from the document review indicate that the development of the NDPR documents was a collaborative and consultative effort from various actors who represented different sectors. Key informants elaborated on the process. Table 2 presents the themes and subthemes related to the processes of the policy, as well as supporting verbatim excerpts from participants.

Table 2. Process in the Development of the Context of the National Disability Reform Documents of Eswatini.

Themes	Subthemes	Extracts from participants
Procedures of implementation	Development of the National Disability Plan of Action	• "We were also responsible for the development of the National Disability Plan of Action, which is the 'how to' of implementing the policy" (P4). • "The National Disability Plan of Action was developed by different government ministries as the blueprint of implementing the National Disability Policy of Swaziland" (P24).
	Development of the National Disability Bill of Rights	• "The National Disability Bill was actually one of the pillars of the programme of implementing the national disability policy of Swaziland" (P4). • "To operationalise the policy, we developed the National Disability Bill as a way of implementing the national disability policy of Swaziland as law" (P6).
	Lack of commitment from policy implementers	• "Let us say that with such things to be successful you need commitment at all levels. I am not going to say that you need commitment from junior staff, politicians and senior management. Once we have agreed on the implementation, we should all commit to it" (P9). • "I think that the kind of personnel that is to drive implementation requires time, understanding of disability and commitment" (P12).
Progress of implementation	National Disability Bill of Rights has not been legalized	• "But in terms of implementation, the current government is leaving office and Bill has not been signed and passed as law" (P5). • "So, I believe that we also still have a long way. I am personally concerned that this law that I left as a draft Bill when I left office still has not seen the light of day" (P4).
Financial resources for policy implementation	Prioritize funding for policy implementation	• "During the implementation, I can look at an idea and how to implement it, but the government looks at what funding they have available and what they can prioritise at that time with the finances available" (P12). • "Policy implementation requires a level of funding. Effective implementation requires funding that needs to from the state, and I am not certain that that is happening" (P6).
Knowledge and skill resources	Lack of knowledge and skills of implementers	• "Part of the reason that implementation is slow is because people who are tasked with implementation do not have an understanding of disability" (P13). • "The success of policies also lies in having personnel who are trained in disability and who have knowledge on implementation" (P6).

Content of the NDPR Documents

The content component comprises four subcomponents as shown in Figure 1. Each one is described in detail below.

Availability: The NDPR documents promised the provision of medical intervention to all persons with disabilities who required it. They would be helped by trained health care professionals at the levels of prevention, early detection, diagnosis, and management of

disabilities and disabling conditions. The NDPR documents were also committed to the provision of all necessary rehabilitation services, assistive devices and communication aids to persons with disabilities who needed them. Moreover, the documents undertook to include persons with disabilities in health promotion programs, specifically sexual and reproductive health and HIV/AIDS programs. Community health promotion programs would likewise be initiated to prevent disability and ensure that access to health information is available to persons with disabilities. Counseling for persons with disabilities and their families was also promised.

Acceptability: To ensure the inclusion of persons with disabilities in all services including health care, the NDPR documents pledged that different sectors would forge relationships with disability policy organizations in Eswatini. The documents also vouched that all health care services would be provided to persons with disabilities in an equitable manner. Persons with disabilities in health care facilities were promised access to communication technology and information in accessible formats. The NDPR documents pledged that health care facilities would be made disability friendly and that an audit would be conducted to ensure that facilities comply with the requirements. Health care professionals would also be trained on relevant communication skills (such as sign language) and on disability sensitivity skills.

Financial Accessibility: In the NDPR documents, free health care services and free assistive devices were promised to persons with disabilities in public health care facilities, while those making use of private health care facilities would also receive affordable health care and assistive devices. Social support was promised to persons with severe disabilities.

Geographical Accessibility: The NDPR documents promised to ensure physical access to buildings for persons with disabilities and undertook to make transportation accessible for them.

Perceptions Regarding Success of NDPR Documents in Facilitating Access to Health care for Persons With Disabilities

Two overarching themes came to the fore, namely, a lack of awareness of the NDPR documents and the factors that influenced stakeholders' awareness of these documents (see Table 3). Excerpts from the interviews with participants are quoted verbatim as examples of each theme or subtheme. End users perceived the NDPR documents as ineffective in facilitating access to health care for persons with disabilities. This was evident from the following quotes:

> I wouldn't say that the policies are effective, because so far I haven't seen anything tangible, because so far there is nothing that has been done because there are still a lot of challenges. (P12: Person with disability; developer and beneficiary of policy reforms)

> It's not like we have been treating persons with disabilities doing based on a particular document that guides us. So, we are just providing services the same as before, nothing has changed. The challenges are still the same. (P20: Health care professional; beneficiary of reforms)

> I think that any difference that we see is out of the push of the disability organizations to say that they feel like they should be doing this and that and not necessarily as a result of any policy. And in some instances, it is things that the govt can do easily. But for a lot of things, you find that they haven't been done, for example, there is the issue

of social protection in the policy, but we are not getting it. (P8: Person with disability; beneficiary of reforms)

Table 3. End User's Knowledge of the National Disability Reform Documents of Eswatini.

Themes	Subthemes	Extracts from participants
Lack of awareness of national disability policy documents	Poor awareness of the policy	• "I have never ever had about the policy. I am unaware of it. I have never heard, or even read about it. I would therefore say that I am unaware of the policy" (P17). • But I feel like it works but not well because the people with the disabilities, if you were to go and ask them about it, they don't know anything about it. I think that if there was another way, fine it's been done it's here there's even the act, but I feel like the people don't really know about it, you see" (P10).
Factors that influence awareness of national disability policy documents	Poor dissemination of the policy documents	• "But the problem there was dissemination; there was a lack in dissemination. When the policy was done and was launched and the booklet printed, the MPs were supposed to take it to their constituencies, but that did not happen" (P7).
	Involvement in the policy drafting process	• "So, I feel like it's important for them to be informed and taught about the policy because the people who were drafting it know about it but those who weren't there don't know about it" (P8).
	Membership of a disability organization	• "Joining our organisations and organisations of any kind is voluntary and it helps you to be active and to get information on what is happening. That is how some of us got to know about the policies" (P9).
	Poor communication in organizations	• "Back and forth meetings were held in the boardroom by certain handpicked individuals to contribute ideas mostly for the plan of action, I however don't recall this information being communicated to all departments of the hospital. Nothing about policies" (P23).

Participants acknowledged that the NDPR documents had, up to the present moment, been ineffective in facilitating access to health care. However, they were hopeful that there would be change if the policy implementation strategies were strengthened, as articulated by Participant 10, a caregiver of a person with a disability: "For now, it (the policy) is there, but it has not been passed, it will be easier for us once it is passed, for now there are still challenges that we experience."

Discussion

The research reported on in this article analyzed the actors, context, and processes of the NDPR documents of Eswatini, as well as the content stipulated within these reform documents. It further sheds light on the perceptions of end users regarding the success of these policy reforms in facilitating access to health care for persons with disabilities. Findings of the study suggest that the NDPR documents came into existence following Eswatini's ratification of the CRPD. This happened after constant lobbying by organizations for persons with disabilities for the country's conscientization toward the rights of persons with disabilities. Their rights were not respected, as was evident from the lack of accommodation of persons with disabilities, lack of disability mainstreaming and lack of social support.

Key informants reported that the development of the NDPR documents of Eswatini was a collaborative effort that involved multi-sectoral representation. High-level stakeholders' consultation and engagement preceded the development of the policy reforms, hence suggesting a bottom-up approach toward the policy-making process. The strength of Eswatini's NDPR documents lies in the processes adopted for their development. This was evident from

the quality of the NDPR documents' content and from the thorough manner in which the fundamental concepts that are core to disability rights have been addressed. The involvement of and contributions by persons with disabilities greatly enhanced the strength and quality of the NDPR documents. This finding is acknowledged in the policy itself (Swaziland Deputy Prime Minister's Office, 2013). Considering that these documents were developed against the backdrop of the CRPD, it was encouraging to see that the content of the NDPR documents related to health care mirrored most of the recommendations made in Articles 9, 25, and 26 of the CRPD (UN, 2006). Financial and attitudinal considerations related to geographical access to health care service could, however, have been considered in more depth. Buse et al. (2005) promoted a multi stakeholder involvement that represents various power dynamics and authority, not only at the developmental stage of policy making but all the way to implementation, as this would ensure a balanced representation of economic, political, social, contextual, and cultural interests. Other scholars who supported a bottom-up theory approach to policy implementation such as Hanf et al. (1982) and Matland (1995) also advocated the value of involving end users as policy implementers.

However, in contrast to what research suggested, responsibility for the implementation of the NDPR documents was left solely to Eswatini's government, with the role of organizations for persons with disabilities reduced to that of merely following up on government initiatives and advocating and creating awareness about the policy among their members. Eswatini's government thus went ahead and developed an inter-ministerial plan of action as the blueprint of policy implementation. Subsequently, the national disability bill served as a legal framework to authorize the policy without the involvement of organizations for persons with disabilities suggesting a top-down approach to implementation. The end users—especially persons with disabilities and caregivers of persons with disabilities—emphasized the significant role of the Eswatini government in the implementation of policy reforms. They did, however, articulate that the implementation of the NDPR should not be left solely to the government, hence inferring that they preferred a bottom-up approach to policy implementation.

The process by which the NDPR documents of Eswatini were implemented was found wanting by all participants in the study. Implementation was seriously hampered by the general lack of disability sensitization in the country, particularly among those who were responsible for implementing the policy. The lack of disability sensitization was evident from Eswatini's not committing financial and human resources to policy implementation, and not making adequate provision for training aimed at capacitating policy implementers with the knowledge and skills necessary for successful policy implementation. According to authors such as Alant et al. (2007), Duncan et al. (2011), Lang et al. (2019) and Shumba and Moodley (2018), a clear distinction between policy development and policy implementation, coupled with lack of human and financial commitment from state government, tend to negatively influence the implementation of disability policies. The lack of disability sensitization is also evident from the fact that the Eswatini government did not prioritize the passing of the national disability bill as a law, as 6 years have passed since it was proposed.

Although a national disability plan of action exists, no budget commitment has been allocated and the goals of this plan are not measurable, achievable, relevant, or time bound. This finding then raises the question of what organizations for persons with disabilities and other civil society organizations will use as a benchmark to hold the Eswatini government accountable for the progress with or lack of policy implementation. Lang et al. (2019) found that where a selection of African Union policies pertaining to inclusion was analyzed, budgets and measurable goals related to policy implementation frameworks were clearly lacking.

Considering the above-mentioned challenges to the implementation of the NDPR documents in Eswatini, it is not surprising that this study found that the end users lacked knowledge regarding the existence and the content of the policies. This finding was particularly true for end users who were not involved in the policy development and implementation process, or who were not members of disability organizations in Eswatini. Participants also perceived the policies as having failed to contribute positively toward the facilitation of health care access for persons with disabilities, as they continue to encounter challenges related to the availability of services, acceptability and accommodation in health care facilities, as well as financial and geographical access to services.

Limitations

Even though this article presents data and evidence about the development and implementation of Eswatini's NDPR documents, their provisions for health care for persons with disabilities, and the perceptions of end users on the success of these reforms, the study had certain limitations. Despite attempts to ensure that all stakeholder groups were represented in the key informant interviews, some of these informants no longer occupied the positions that they had held during the development and implementation of the NDPR documents. Current incumbents of the offices reported that they did not have a record of their predecessors' contact details. Although the focus groups yielded rich data pertaining to the research questions, the groups comprising participants with disabilities and caregivers of persons with disabilities were mostly persons involved in activism and lobbying, and they were mostly based in urban and peri-urban areas. However, the experiences of persons with disabilities and caregivers of persons with disabilities in rural areas are highly relevant to this study, since approximately 75.8% of the entire population of Eswatini and 86% of persons with disabilities resided in rural areas (Eide & Jele, 2011). Numerous attempts were made to attract and recruit medical and nursing professionals to participate in the study. Despite these attempts, there was poor representation from these health care professional groups, regardless of the method employed (focus groups or electronic questionnaires), and the participants were mostly rehabilitation health care professionals.

Conclusion

Even though the NDPR documents of Eswatini can be commended for including content that reflects the principles of the CRPD, the gap which is evident in policy implementation is a significant letdown for persons with disabilities. This may suggest a state that is committed only on paper (as "a tick the box exercise") to the fulfillment of the rights of persons with disabilities to access health care services, so that it may be seen as meeting the obligations of international treaties, in particular the CRPD. The ambivalent lens through which disability is viewed (Ndlovu, 2016) and the fact that disability issues are still a contentious subject in Eswatini, suggest a lack of disability conscientization. The latter is manifested in the lack of commitment toward disability-related issues, such as the lack of prioritization of policy reforms, the lack of acknowledgment of the significant role that persons with disabilities can play in the implementation of disability policy documents, and the slow pace of passing the national disability bill as a law.

This study, therefore, proposes that for the NDPR documents of Eswatini to meet the desired outcomes, it is important to shift the mindset of policymakers through deliberate disability sensitization programs. Policymakers are part of the community and are therefore likely to

reflect the disability stereotypes held by other community members. This suggests a need for sensitivity programs to start from within communities and to dismantle stereotypes and address the stigmatization and exclusion of disabled persons from community (grassroots) to official levels. The inclusion of disability-related issues on the political agenda of the country must be prioritized and resources be made available for successful policy implementation. Our findings also suggest that the state government should reconsider its current implementation plan (national disability plan of action), as it excludes the involvement of persons with disabilities—even though they are the intended beneficiaries of the policy reforms. If the intention of the policy reforms is indeed to meet the needs of persons with disabilities, this group needs to be part and parcel of the process. The implementation plan must be improved to include targets that are clearly and correctly documented, while costs must be determined and specific deadlines be set to ensure the state of Eswatini's accountability and commitment to organizations for persons with disabilities.

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