**SOCIAL NORMS ON DISABILITY** 

# The Role of Social Norms in Decisions to Provide Schooling to Children with Disabilities in East and Southern Africa

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Boy with cerebral palsy, his mom and sister in Zambezi, Namibia. (Photo Credit: Symen Brouwers, UNICEF ESARO, 2019)

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# Acronyms

C4D	Communication For Development
ESA(RO)	Eastern and Southern Africa (Regional Office)
MENA(RO)	Middle East and North Africa (Regional Office)
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund



#### **ABSTRACT**

In many Sub-Saharan countries, children with disabilities are the first to suffer from neglect, abuse, and violence and the last to benefit from reforms. Despite conducive legislation and policy environments, programs designed to have all children access education seem not to help them. As part of a much larger cross-regional social norm initiative to address harmful practices, UNICEF's Regional Office for East and Southern Africa has pledged to continue the investigation of the social context of disability, having made it a corporate priority. As a first step, the present UNICEF report is meant to capture the possibility of conceptualizing social norms surrounding disability and provide empirical evidence whether social norms are present in people's thinking on disability. A broad, context-based model of the social problem of disability was developed first, including components related to social expectations, similar to Bicchieri (2017), but further developing a richer contextual and cultural component. Included are dimensions related to behaviour systems of maintenance and control as well as the survival of behaviour over time. With the help of local governments, the model was then qualitatively tested in Eswatini, Kenya, and Namibia, through ninety focus group discussions, with parents, teachers, children (including those with disability) and local experts in two economically contrasting regions per country. Qualitative research is best suited to capture how people think about an issue, irrespective of differences in context, and offer input for psychometric assessment in later stages of the initiative. Analyses showed that: (a) widely held practices of actively hiding children with disability are related to three broad social norms: (1) overprotection, (2) a mind-your-own-business demeanour, (3) and avoidance of guick decisions by fathers; that (b) these norms are grounded in mechanisms of social maintenance; and that (c) all three countries show cultural differences in qualities of sociality. Together, the findings underscore a need for attention to intersectionality in addressing disability, rather than single-issue organizing, particularly when it comes to the combination of disability, culture, gender violence, and poverty. This can be addressed through various C4D strategies including publicising positive deviants' successful stories across the region.



# 1. INTRODUCTION

In the past several decades, the educational inclusion of children has seen strong progress all around the world: Between 2000 and 2015 the world-wide number of out-of-school children has declined from 100 to 61 million (UNESCO Institute for Statistics, 2017). Meeting universal educational inclusion needs is a great thing. School attendance has the power to really buttress the attainment of many other sustainable development goals because of a high multiplier effect: Children that go to school show improved health, social development and reduced poverty. Not all children have benefited in the same way from this positive development, though. Children with disabilities continue to be excluded at schools globally, having led some to speculate about the best ingredients of behaviour change and advocacy tools (UNICEF MENA, 2018a, 2018b; Sood, Cronin, & Gordon, 2017). As part of a much larger cross-regional social norm initiative to address harmful practises, UNICEF ESARO has pledged to continue the investigation of the social context of disability, having made it a corporate priority. As a first step, the present report will capture the possibility of conceptualizing social norms surrounding disability and provide empirical evidence whether social norms are present in people's thinking on disability; with a qualitative approach, the report captures how people think about disability in Eswatini, Kenya, Namibia, highlighting three pervasive norms irrespective of differences in context.

A very cursory estimate suggests that about 1 in 20 children below 14 years old must live with a moderate to severe disability – about 93 million children in total and designated by some as the world's largest minority. Literature reflects how fractured this group is in terms of attention received from scholars. For example, Goodall, Salem, Walker, Gray, Burton, Hunter, Rogathi, Shali, Mohin, Mushi, and Owens (2018), report on stigma for people with epilepsy in Tanzania, specifically in relation to marriage and employment. Other studies report on mental retardation in Kenya (Mutua & Dimitrov, 2001), on the danger of ending up in orphanages (Larsson, 2018), on the way parents cope in Uganda (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005), and traditional healers' belief about disability in Ghana (Kpobi, Swartz, & Keikelame, 2018). Despite these different challenges, though, children with disabilities are the first to suffer from violence and last to benefit from reforms. Based on the work of Bicchieri (2017) regarding expectations and social norms, together with work on contextualization and cross-cultural psychology (Brouwers, 2018), the research reported here moved to



develop and test a multi-dimensional model of the social problem of disability. Drawing from community beliefs and attitudes towards children with disabilities, the present report concludes that the treatment of children with disabilities is inextricably tied into social norms. Contribution of this report will be a sharp rejection of single-issue organization in developmental aid interventions and a strong call for attention to multisectoral coordination, particularly for the combination of disability, gender, violence and poverty. Application of a multisectoral paradigm will help to better reach children with disabilities and have them attend school and complete their education.

#### 2. GLOBAL CONTEXT

UNICEF has a strong track record of advocacy, especially by amplifying the voices of children, women and communities. Particularly at the level of policymakers and political or social leaders this effort has created an enabling environment that produces and sustains social transformation through legislation (UNICEF Advocacy Toolkit, 2010). However, the ultimate success of advocacy and legislation rests with people in communities in terms of behaviour change. Behaviour change does not solely consist of good advocacy for the voices of children and women at a government and legislation level, but also the commitment of societies to establish and maintain an enabling culture in that environment. Instead, UNICEF recognizes that persuading people in their everyday environment to change their maladaptive behaviour into more adaptive ones is an essential approach to make legislation work. A major problem is that an issue of interest is isolated from the larger context in which it resides. Disability, gender-based violence, and poverty are treated as isolated from each other. However, the decisions that people make and the behaviours they return to are grounded in complex adaptations to the physical, social, and economical environment, often together and in immediate collaboration with other people in one's community.

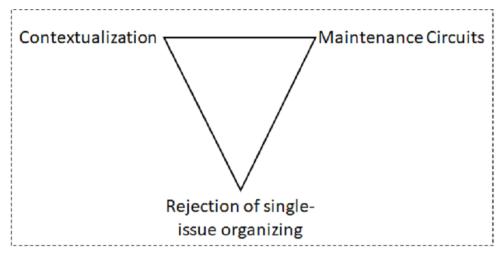
#### 2A: SOCIAL NORMS AND THE AMBIGUITY OF DISABILITY

At the heart of UNICEF's cross-regional initiative to fight harmful practises is a prominent role for social norms (e.g., UNICEF Middle East and North Africa (2018a, b). The prominent role given to norms is borne out of the knowledge that individual human beings are contextualized in local communities with practises, shared interests, and control (Bronfenbrenner, 1979) and the recognition that the visible willingness to give freely to the community and the ability to provide care are essential to healthy community life (Bliege Bird & Smith, 2005). Within local communities, people are concerned about their credibility (Sugiyama & Scalise Sugiyama, 2003) and take stock of whether others reciprocate what



# Figure 1

Visual outline of the theoretical argument in the study. Context and the social highlights the centrality of context. contextualization of disability require attention to the maintenance circuits of While credibility and recipions social norms and the rejection of single-issue organizing.



they receive (Kinzig et al., 2013). Figure 1 highlights the centrality of context.

While credibility and reciprocity concern anyone in a community, the issue is exacerbated with disability, where combinations of gender and disability, race and disability, and family history and disability make it difficult to say things with confidence (Carruthers, 2018; Clare, 2015/1999; Piepzna-Samarasinha, 2018), an idea known as intersectionality (Nash, 2019). People in the community might not know what the

significance of the disability actually is; whether it constitutes an unwillingness or real disability – and they choose to protect their economic self-interest when they are not sure, taking the safer option where they can. Faced with ambiguity, people look at the reactions of peers to get a sense of security, thus strengthening social norms (Lapinski & Rimal, 2005). An example from Kenya illustrates this mixture of care and resentment to a child with epilepsy (El Sharkawy, Newton, & Hartley, 2006). During a child's epileptic attack at school, bystanders were quick to provide care, but later at the child's house chiding the parents to keep their child away from their own.

The academic field of cross-cultural psychology has given a lot of attention to the social relationships between the individual and his/her environment. Various models capture it as a series of concentric circles, with the private psychological world of a person at the centre, surrounded consecutively by family, community, country, and history, each a larger layer of context with unique constraints and affordances (Bronfenbrenner, 1979; Cole, 1996). For children's development and schooling, the developmental niche model is used to convey the same principles (Super & Harkness, 1986). Communication for Development (C4D) builds on this thinking. The ecocultural model goes further in emphasizing direct causation from ecological and sociopolitical context to observable behaviours and inferred psychological characteristics like personality (Berry, Poortinga, Segall, & Dasen, 2002).

Social norms are part of these surrounding contexts to facilitate credibility (Ostrom, 1999). People organize themselves with social norms, while sanctions help prevent violations to others' caring (Foss & Lorenzen, 2009). In this sense, social norms are very tangible (Frese, 2015). And this is natural – people absorb social norms engaging with the many elements from the contexts in which one partakes (Rogoff, Paradise, Mejía Arauz, Correa-Chávez, & Angelillo, 2003).



For example, a child growing up in a traditional tailoring industry in Liberia will learn the trade and all the norms involved not from instruction but from participation, measured by the initiative he takes in the daily work context, first through observation and gradually by taking on ever larger responsibility.

In healthy community life, this participation and social norms are naturally connected and, according to MacLachlan, Carr and McAuliffe (2010), attempts to end harmful practises through aid have damaged indigenous cultural identities. Resources accepted ways of social participation, and inclusivity were threatened (Ager, Stark, Akesson, & Boothby, 2010), having led to the weakening of self-organized criticality (Brunk, 2002) and loss of community participation (Gugerty & Kremer, 2008). The availability of extraneous information, the motivation and ability to form a correct attitude, a congruence between message content and accessible knowledge, and true interest are variables that could attenuate such a disruption (Maio & Haddock, 2007). Bicchieri (2017) also speaks of introducing testable expectations that show the value of new behaviour when conducting an intervention, showing its potential utility in context (Hammond, 1978).

# **2B: PRINCIPLES OF SOCIAL MAINTENANCE**

Given the integral connection of layers of context, participation, and social norms we propose a three-pronged approach to model social norms on children with disabilities, adding two social foci over Bicchieri's (2017) single modelling dimension of expectations. Following the ecological, community-based research of Barker (1963, 1968; also see Schoggen, 1989) the basic underlying mechanism of social norms is maintenance. Figure 2 outlines this tri-part model.

# 1. Program circuit = substantive content

The basis for strong social expectations, medical thinking has been a fertile ground (Finkelstein, 1980; Oliver, 1983). People with disabilities are impaired, they suffer, cannot participate in the real world, and should be protected. With the emergence of the social model of disability this changed substantially and particularly in developed Western countries the social model has done a lot for the emancipation of people with disabilities (see Albrecht, Seelman, & Bury, 2001). What the social model did was show and highlight that the exclusion of people with disabilities from society depended for a large part on the structure of society and how education and employment are socially organized. Critical for economic success was the continuation and restoration of mainstream society (Thomas, 2004). The model has contributed to changing children with disabilities' own internalized oppression (Tregaskis, 2002).

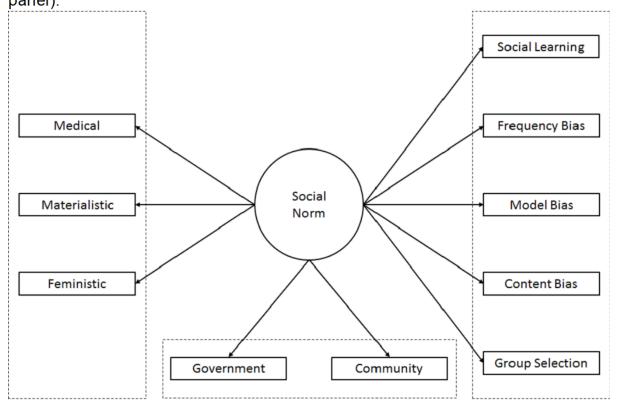
The social model of disability, whether from a materialistic or human rights angle, is the most popular in international aid, but medical thinking still prevails with many recipients of the aid. Kpobi, Swartz and Keikelame (2018) showed that traditional healers in Ghana believe that disability is caused by witchcraft, curses from the past, or through influence of the moon. Such a negative medical view is matched by parents' experience in very different parts of the continent: In Kilifi, Kenya, parents of children with a disability report harassment and discrimination (Gona, Mung'ala-Odera, Newton, &



# Figure 2

A taxonomic model of social norm parameters, with content (left panel), head is reported as treatment of transmission processes (right panel), and compliance mechanisms (bottom disability (El Sharkawy, Newton, & panel).

Hartley, 2006); and adult responsibilities,



Hartley, 2011); also, in Kilifi burning the head is reported as treatment of disability (El Sharkawy, Newton, & Hartley, 2006); and adult responsibilities, community membership, and educational attainment of children with mental disability in Kenya is limited (Mutua & Dimitrov, 2001).

# 2. Goal circuit = transmission processes

Meant to connect others to the program circuit, social sharing is a defining component of social norms. Mesoudi (2009) summarized a diverse series of transmission models. Transmission is at the core of evolutionary psychology and also a component of Wimsatt's (2013) generative entrenchment theory: How

do behaviours survive in a community, across members and over time? Mesoudi distinguishes five types of transmission: social learning that consists of social comparison, frequency-dependent biases based on popularity, model-based biases based on success and prestige, content biases based on social memory and reasoning, and cultural group selection based on intergroup processes and identity.

# 3. Deviation countering circuit = compliance mechanisms

To punish non-compliance and veto community members, communities differ in how tight or loose they are, and how strong they emphasize compliance with norms (Gelfand et al., 2011). Communities would be more strongly focused on norm compliance in the face of threat, such as famine, war, and political uncertainty. The outcomes of threat would be strong social institutions, such as law enforcement and government to manage non-compliance. Government spending on teacher education and assistive technology products, such as hearing aids, crutches, and adapted toys, has the potential to shape the substantive content of social norms. Thinking against big governments, Sen (2009), Neocosmos (2016) and Harriss-White & Heyer (2010) argue that people are rational beings and that within local communities they can manage social life themselves through plural grounding and overlapping consensus. Also, these will go into our social-relational



# 3. THIS STUDY



Girl with learning difficulties at school in Manzini, Eswatini. (Photo Credit: Symen Brouwers, UNICEF ESARO, 2019)

The study is the first phase of a three-part project, meant to develop insight and input for two later steps. Following the UNICEF cross-regional initiative on social norms, the long-term objective is to evaluate interventions across the region with a valid and broadly applicable tool. The first phase is qualitative to look for justification. Qualitative research is best suited to capture how people feel and think about some issue – to find out whether norms are an inherent part of human functioning, irrespective of differences in context. Thus: Are social norms the same everywhere? The second quantitative phase is then meant to see how norms vary in their size of impact between contexts. The current ESARO research project had two objectives:

an evidence-based test of the universality of the literature-based model developed in the review part of the study and;
 substantive input for a social norm measurement tool that can later be validated on a larger scale in countries where UNICEF is active.

Between April 1 and July 19, 2019, qualitative data was collected in Eswatini, Kenya, and Namibia on behalf of the UNICEF ESARO. The data collection followed a systematic procedure, both in its selection of local settings, as well as

interview protocol. The three countries were fully involved in the study and provided an extensive geographical spread and diverse sampling of regions and schools. In each of the three countries, representativeness was increased by sampling two economically distinct zones, one more arid (Kunene in Namibia, Shiselweni in Eswatini, and Garissa in Kenya), the other better able to rely on existing natural resources (Zambezi in Namibia, Manzini in Eswatini, and Kisumu in Kenya). The inclusion of Garissa in Kenya also has the added benefit of offering a strong Islamic perspective to the data. Design and use of our interview protocol specifically addressed the mapping of the a priori, literature-based theoretical model.

# **3A. DESIGN AND METHODOLOGY**

# **Participants**

The study was undertaken over the course of three stints of two weeks in which two economically contrasting communities were visited, one rural and arid, one more developed. The number of interview participants was N = 470 associated with 42 primary and combined schools/hostels that were part of the study (see Table 1 for an overview) and 90 focus group discussions, separately for school teachers and Boards of Management (BoM), parents, children, and regional experts such as social workers and school inspectors. The division of groups at the regional level in each country were 34 (18/16) in Eswatini, 26 (12/14) in Kenya, and 30 (18/12) in Namibia. There was a good representation of the different types of stakeholders in the six regions, averaging five participants per focus group.

# Interview setting

The interviews were conducted by the lead researcher assisted by oral translators and sign language interpreters, provided by the Ministries of Education in each country. Translators had access to the interview protocol and questions before the start of the group discussions to familiarize themselves with the questions. They received training from the lead researcher with regards to the interview content and protocol. All the group discussions were captured on a digital recording device. Consent forms were explained and distributed at the start of the group discussions and questioning only began after everybody understood the meaning of consent and had signed the forms. For children younger than 18 years, a parent or teacher was required to give consent.

# Interview protocol.

The interviews followed a semi-structured format with fixed introductory and lead questions and a set of flexible probe questions. The questions were formulated based on the recommendations of Mackie, Moneti, Shakya, and Denny (2015). Care was taken to ensure that the questions asked were not leading and could not be answered by simply 'Yes' or 'No' answers. Based on the model in Figure 2 the following questions were asked:

0. Do you know any children with a disability? Are there any children with a disability in your community? Can you describe



# Table 1

List of the schools and hostels participating in the study, by country and region. school? What would be the reasons that

Country	Region	Number	School/Hostel name	
Namibia	Zambezi	1	Cheshire Home (=Hostel)	
		2	Mulumba Primary	
		3	Katima Combined	
		4	Brendan Simbwaye Primary	
		5	Isize Combined	
	Kunene	1	Outjo Primary	
		2	Eddi Bowe Primary	
		3	Kameru Senior Primary	
		4	Opuwo Primary Hostel	
Eswatini	Manzini	1	Khuphuka Primary	
		2	St Joseph's Primary	
		3	Kwaluseni Central Primary	
		4	Usuthu Forest Primary	
		5	Nyatsini Primary	
	Shiselweni	1	Joppa Primary	
		2	Eqinisweni Primary	
		3	Mavukutfu Primary	
		4	Hluthi Primary	
		5	Nsongweni Primary	
Kenya	Garissa	1	Garissa School for the Deaf	
		2	Garissa Primary	
		3	Saka Primary School*	
		4	Goryale Primary School*	
		5	Garissa School for Intellectual Disability*	
		6	Iftin Primary School*	
		7	Jaribu Primary School*	
		8	Dekabuur Primary School*	
		9	AI-Farouq Primary School*	

that child to me? Is he/she going to school? What would be the reasons that the child is not going to school? [*Entry*]

- 1. Who is important to consider when thinking or talking about keeping children with disabilities out of school? Why are these people important to listen to? Is exclusion of children with disability socially accepted by these people? [*Transmission*]
- 2. What do people say are the disadvantages of keeping children with a disability out of school? What would they say the advantages are? [Content]
- 3. How easy would it be in your community to start including children with a disability at school? What makes it so difficult in your community to start including children with a disability at school? [Compliance]

The interviewer had at hand a list of covert categories (the micro-categories in the model) to map responses and necessarily probe for clarification or in the event not everything was covered. The principle of saturation guided the finalization of the entire interview



Table 1, continued		
Kisumu	1	Joyland Special Primary
	2	Magadi Primary
	3	St. Ann's Ahero Primary
	4	St. Martin De Pores School Special Needs
	5	Maseno School for the Deaf*
	6	Rabuor Primary School*
	7	Migingo Primary School*
	8	Okanja Primary School*
	9	Karanda Primary School*
	10	Lutheran Primary School*
	11	Nyabondo Day Primary School*
	12	Agai Primary School*
	13	Olwa Primary School*
	14	Ndori BC Primary School*

Note. \*Teachers, parents, and pupils of this school took part in discussions at one of schools that were visited; the school was not visited itself.

communities visited. The five steps in the scheme are:

- 1. Building an etic record. What is going on?
- 2. Researcher interpretation
- 3. Dialogical, emic data generation; collaborative stage
- 4. Describe system relations to broader context
- 5. Explain relational systems

The scheme captures a mixture of etic and emic approaches. The emic-etic distinction refers to the level of universality (etic) or cultural specificity (emic) of a concept (Pike, 1967). Etic methods or steps are usually concerned with the replicability of universal psychological models across cultures. The models are typically created by the analyst and examine behaviour from outside the cultural, linguistic or social system (Church & Katigbak, 1988). Emic methods or steps are largely concerned with the identification of concepts that are especially relevant in one cultural context, irrespective of

thirty minutes and two hours, for teachers typically the longest, approaching two hours, for children the shortest, between thirty and forty minutes.

# Data collection and analysis procedure

Carspecken's five step scheme towards critical ethnography and cultural reconstruction (Carspecken, 1996; Georgiou & Carspecken, 2002; Hardcastle, Usher, & Holmes, 2006) was used throughout the entire project, from the written protocol to the data analysis and reporting, to develop as closely as possible an insider's position with respect to the conceptualization of disability and schooling in the



whether they are represented in a universal model. The analyst discovers the structure between concepts in the context and the criteria describing or causing the structure are conditional upon the different elements within this cultural context (Berry, 1969). In steps 1, 2, 4 and 5 of the protocol, the researcher draws information from existing models using etic procedures. Step 3 are the actual fieldwork group discussions using emic procedures.

Analysis procedure. Analysis was conducted on field notes taken during the interviews, using a mixture of inductive and deductive principles similar to Grounded Theory approaches. Core categories were extracted first using open coding, followed by selective coding to find supporting evidence or grounds for rejection for each tenet of our theoretical model, separately for each of the inductively extracted core categories, and by region.

**Statement of ethical principles**. The head researcher is a trained psychologist (PhD) and followed ethical principles as postulated by the American Psychological Association, the globally accepted general standard of ethics in psychology, as well as UNICEF ethical standards on research and interviewing children. In addition, compliance was sought with the complementary national requirements that each government may request

# **Practical arrangements**

Ministries of Education in each of the three countries were highly instrumental in making arrangements with the schools. The Ministries identified the selected schools, contacted schools in official writing, and communicated with schools about participants and space for the focus group discussions. At each day of the group discussions, a representative of the Ministry was present to oversee the arrangements and coordinate practical matters.

# Timeline

Namibia was visited first, from April 1 to April 13, 2019. Eswatini was visited from June 10 to June 22, 2019. Finally, Kenya was visited from July 8 to July 20, 2019. The timing for each visit included two full working weeks, planned for data collection in two different regions at large geographical distance.

# **3B. FINDINGS**

Before addressing norms and data fit of the model, we will look at structural barriers. Then, in Step 1, three core social norms are identified. In Step 2, the data is selectively coded to see whether evidence of social maintenance exists for each norm. Table 2 summarizes the findings. In Step 3, the data is scanned for unique country related qualities. Table 3 lists those qualities.

#### **Preamble: Structural barriers**

The ninety focus group discussions held to support the project covered a large ground of thinking about disability and schooling, including everything from physical and economic constraints, to social factors, and private emotions.



"Yes, there are children with disabilities who do not go to school, even though the parents or child want, the distance itself, for a person with a wheelchair." (Namibia, Ministry of Health Official)

Concerns about physical, social and economic constraints were perhaps the most frequently mentioned in all regions. Study participants mentioned things like distance between home and school, the cost of transport, lack of qualified teachers, and safety issues for children traveling alone. Parents and teachers expressed concern about the vulnerability for children who are in a wheelchair or who are in danger

of an epileptic attack, or similar challenges. Several groups, of parents, teachers, as well as social workers, went so far to insist that physical distance, and the constraints it entails, is the single overriding challenge and that addressing this will surely enable children with disabilities going to school. The claim aligns with a situation in which parents want to help their children with disabilities going to school, but do not know how to manage it – practical concerns can be overwhelming and children with disability taking up time parents prefer to spend otherwise.

In many cases, the concerns of parents are realistic. While visiting schools it is clear that they are all differently prepared for children with disabilities, some having a ramp for access of wheelchairs, while others do not, some with adapted toilets for children with disabilities, or teachers with adequate skills in sign language, and who knows how to

support learners with disabilities. Also, even in close proximity to one another, two schools can have very different knowledge about special needs teacher training; one school can have a number of teachers already trained and working with children with special needs, while a school close-by does not even know of the existence of available trainings. Based on the discussions, one observation is that much depends on the internal drive of a principal or passionate teacher, perhaps faced with a difficult situation and going out to find a solution

"Children 50 kilometres away who want to come to St. Mulumba but facilities are not available and they cannot drive 50 kilometres every day to bring their children to school. My prayer is to have facilities to allow wheelchair bound children to have access to school."

(Namibia, service provider)

to the problem. Often, government or the Ministry of Education do not proactively reach out to schools to build capacity through in-service training or to provide information about the availability of resources.

The capacity of teachers to address the individual needs of children with disabilities was highlighted as one of the key barriers for impacting on the education of children with disabilities. For example, in Namibia, all the teachers and parents pointed to the challenge with regards to teachers who are not qualified or trained to provide quality teaching to learners with disabilities which results in these children failing or dropping out of school. However, some teachers explained that despite not having ben trained in inclusive education or how to teach children with disabilities, they try their best to accommodate and support them in class. In addition to the capacity, teachers also highlighted lack or absence of assistive technology, including teaching and learning materials for children with disabilities.





Sign language teacher in Zambezi Region, Namibia. (Photo Credit: Symen Brouwers, UNICEF ESARO, 2019)

"poorly educated" Islamic believers, meaning laypersons do not understand many positive central tenets of the religion very well,

However, in stark contrast to a situation in which parents want to take their children with disabilities to school, many focus groups spoke of hiding children, and keeping their children at home, while their non-disabled siblings attend school, despite similar challenges of distance, transport, safety, and finances. All groups mentioned the deep belief in witchcraft and curses as a widely accepted explanation for disability, in all six regions; a forbearer may have been cursed or perhaps the disability is a curse as the result of incestuous relations. Whether the dominant religion is Christian or Islam does not seem to

matter. With both, one often can see blends between witchcraft believes and the dominant religion. In the Garissa region of Kenya, which is strongly Islamic, elders spoke of

"I am not a trained teacher for disabled kids, but I have accepted them that they are the same and I say let me try my best to help. It's not easy to teach these ones- most teachers refuse to come to "our school" because they know but we have accepted to help these children. It's a blessing on our part that we have accepted these children. Some children need a teacher to be closer by them all the time-you marvel at teachers." (Sign language teacher, Zambezi, Namibia).

including those about care and love. However, the situation in the Kisumu region of Kenya is similar. Witchcraft beliefs are so pervasive that they guide most people's reaction towards children with disabilities, disqualifying the child completely.

It is important to mention that all the children with disabilities who were spoken to talked about their dreams. Dreams to become pilots, teachers, nurses, policemen, doctors, and to support their parents once they have completed their education. They talked about their likes for English, Mathematics, Natural Sciences, Agriculture, and Arts. Some like those subjects because of the teachers who support them. Children without disabilities talked about feeling bad when they see other children with disabilities not attending school.

# Step 1: Core social norms

Inductive engagement with the data, during the data collection period between countries, moving into the next



country, and afterwards when all data was collected, led to identification of three highly pervasive behaviour patterns in parents' active hiding of their children with disabilities, namely:

- [1] overprotection,
- [2] mind-your-own-business, and
- [3] avoidance of quick decisions.

# Step 2: Grounding in mechanisms of social maintenance

For each of these three social norms, deductive engagement with the data provides a test of their character and prevalence in each of the six regions/three countries: 1. Expectations that people can have giving rise to these norms, 2. The maintenance of these norms by getting others in the community on-board with preferred behaviours, and the maintenance towards these norms by countering deviant behaviour when it comes to treating children with disability. The result is a highly systematic 3x3 faceting of the two constructs, to deliver nine types of evidence presented in Table 2.

**Overprotection**. Parents believe that others cannot muster the same amount of love and care they have for their children, whether these are members of their communities, their direct families, or teachers at school. Some parents expressed concern about their children with disabilities been bullied. Being bullied at school or in the

"Never had somebody come and talk about us disability." 'How can we make others feel our pain?' 'How do we bring our children where fools are?" (Kenya, various parents)

community drives parents to take children from school and keep them at home. Being bullied or laughed at was highly common. Also, parents of children at school or in the communities do not want their children without a disability to play with children with disabilities, or to be in the same room where a child had an epileptic attack or otherwise.

The knowledge that other people in the community have strong believes about disability, even teachers in schools, is a strong factor in parents' decision making. Some parents respond with feelings of shame. Others do not want to expose their children to these beliefs and the hurtful behaviour that follows from it, even when they themselves are better educated about the true origins of disability. Some children mentioned how their parents bring them to school because of fear of

"Abuse is mostly coming from the belief system. If they believe it is from witchcraft, they lockup the child because they do not want the children to be seen by the community." (Namibia, Ministry of Health and Social Services)

them being hurt on the way and some parents keeping them at home because they fear that no one will take god care of them at school.

Mind-your-own-business. Children are mostly believed to be the parents' concern. This also relates to the tradition



Table 2
Summary of the results split by behavior pattern and maintenance circuit.

	Substantive	Transmission	Compliance
	content	mechanisms	
	(Program	(Goal circuits)	(Deviation
	circuits)		countering
Overprotection	Afraid others	Pervasive	Bullying; keeping
	cannot love in	beliefs in	children away for
	the same way.	witchcraft and	playing.
		curses.	
Mind your own	Afraid to be	No information	Reinforcement of
business	told what to do,	to allow	isolation through
	of interference.	ownership; no	(sexual) abuse.
		empowerment.	
Accuracy over	Afraid to make	Belief disability	Being shut down at
speed in	bad long-term	must come	general village
fathers	decisions.	from mother's	meetings.
		side.	

that children take care of their parents in old age, which may become a problem when parents believe that children with disability have no future of economic independence. Α 'mind-your-ownbusiness' attitude would stem from the fear that other people would not only help and show care, but instead interfere. People in all six regions are stubborn, generally perhaps participants from the Shiselweni region in Eswatini joking the most about it, of course the jest reflecting a more serious concern; in the focus group discussions there was a sharp distinction between help and interference, the latter not being accepted. However, lack of available information that would assist families to take ownership and empower

them is a critical concern. In Box 1 we have a positive deviant story of a young father who beat the odds and through his strength and patience was able to send his daughter with hearing problems to school and guarantee her safety.

All three countries have laws that make it compulsory for all children, including children with disability, to attend school. However, in remote areas these laws are largely unknown by the public and not enforced, or impossible to enforce, by local authorities. Within villages, the experience of being ridiculed and bullied is common for parents of children with disabilities and children with disabilities themselves.

In small sets of homesteads, neighbours do approach and provide advice to one another, also when it comes to disability in children. However, neighbours avoid getting involved when they see parents try to hide their child with a disability. People share news within communities and particularly moms visit neighbours when observing something is happening, such as a child being hidden or abused.

"They always try to hide, looking at the disability. Parents are not easily accepting, and they try to hide. Sometimes it's difficult to get to see these people because they are hidden." (Namibia, Village Council)





Father and his daughter with hearing impairment in Garissa, Kenya. (Photo Credit: Symen Brouwers, UNICEF ESARO, 2019)

Families are used to keep things close at heart and reject situations in which they are being judged.

A similar situation applies to teachers who teach to children with disabilities. Teachers who take care of these children are considered by the rest of the teachers as the "owners" of the children. Hence, these teachers mind the business of the children and not other teachers. It goes so far that also in case of an emergency or some misunderstanding, the special needs or life skills teacher is called from her own class of special needs children to take care of the situation.

Father's decision making. As in communities with a traditional gender role division, fathers are typically responsible for generating income for the families in the areas where we conducted our fieldwork. One mother in Eswatini that we spoke to counted herself lucky because the father still paid some of the bills, even though he was never around. A general complaint is that fathers are indecisive and, in most cases, absent. They spend time thinking about possible solutions, while mothers are more action oriented. The situation is made problematic by beliefs that disability comes from the mother's side of the family. Upon marriage, women move to live with their husband's family. When a child with disability is born, the observation will be, especially by the mother of the husband, that "we do not have that in our family". Also, in both Eswatini and Kenya fathers of children with disabilities have complained that they are being shut down at village conventions, not getting

on issues that concern him like his

"Fathers are very far, they can even say, this one is not mine because they are disabled."

(Namibia, parent)

peers do. While fathers were seen to be absent from supporting



their children with disabilities, there were also positive examples of cases where they not only provide financial support but also attend meetings at school and take care of their children with disabilities by themselves.

# Step 3: Context related qualities by country

While the social norms we identified act as universal norms across the three countries in this study, local conditions can markedly differ from country to country. These local conditions provide a contextualization to the functioning of the norms, constraining the size of their impact in one or the other setting, or affording greater impact. Also, these country qualities provide an illustration for those interested in directly working in those contexts, perhaps suggesting some direction in what to address in an intervention. See Table 3.

**Eswatini**. Participants in Eswatini appear very accepting of the challenges they tend to face, of sexual abuse, but also of village chiefs and church leaders. This acceptance includes an acknowledgement of the often very difficult nature of what is happening, but also an

"What you are doing, you are doing for yourself." "God knew what he was doing." (Eswatini, learner)

admission of not possessing the drive, knowledge, or energy to address these, even though they wish they could. In no way does this mean that their circumstances are really more difficult than the people in the other regions face, but where those are more reserved or show a deeply seated disposition to non-disclosure, people in Eswatini (at least the one's in our groups) stood out for the ease and bluntness with which they shared the problems they had on their mind.

Kenya. In Kenya, the two regions are markedly different in terms of the Islamic religion prevalent in the Garissa region, but also ecological occupation. While Kisumu is mostly Christian, like all four regions in Eswatini and Namibia, the Islam has a specific philosophy about the practice of law, mostly keeping their disputes close to them and having their own tribunals that are not subject to the broader legal system in Kenya; participants in Garissa emphasized their ways in which disputes between families are handled in the communities by elders, avoiding legal authorities, including the handling of sexual abuse. Participants in Kisumu talked about the wealthiest families being the most ashamed about children with disabilities, setting a bad example for the less fortunate.

Setting apart Garissa also is their ecological occupation, only sharing some similarities with the Himba from the Kunene region, Namibia in the sample: They are nomadic, leading their often-large herds of camels to find areas for grazing and water. Because they follow the camels, it is possible families never return to the same spot twice. For children with disabilities, this situation can have difficult consequences: They are often "dumped" or abandoned at hospitals immediately after they are born, or later in their childhood at schools or hostels. Parents are often never seen again. There was even mentioned that children with disabilities are sometimes dumped in the wild, behind a bush, left for wild animals, or just to die by itself, but this has not been verified.



# Table 3

Context related qualities, by region, that stood out the most as threats to children with disabilities in the focus group discussions.

	Quality/Framework
Eswatini	Participants in Eswatini seem the most resigned
	about anything that is a challenge, when it comes to
	sexual abuse, but also about village chiefs and church
	leaders.
Kenya: Garissa	Participants in Garissa mentioned the way in which
	disputes between families are handled within their
	communities; families moving with their camels to
	find food.
Kenya: Kisumu	Participants in Kisumu talked about the wealthiest
	families being the most ashamed about children with
	disabilities, setting a bad example for less fortunate
	financially.
Namibia	Participants in Namibia strongly emphasized the
	important role of village chiefs as the key to networks
	of sharing knowledge and news, in detecting children
	with disabilities, but also solutions.

Namibia. Participants in Namibia strongly emphasized the important role of traditional or community leaders and village chiefs (or Indunas) as the key to networks of sharing knowledge and news. In a country that is sparsely populated and people cover greater distances, networks of sharing news and information are critical. While within the Zambezi region the mechanisms of sharing seem to be more centrally managed by the village chiefs, people in Kunene region seems to have adopted very deliberate and self-conscious sharing practises. People move mostly on foot and when they run into each other, they share what they heard, environment where creating everyone has the same, best information. Radio is often mentioned as a key way to share news and insights, also when it comes to disability; people

recall items and stories they heard on the radio.

# **3C. DISCUSSION**

Within UNICEF's global effort to meet the learning needs of all children and youth, children with functioning disabilities pose a significantly bigger challenge than children without disabilities. Children with functioning disabilities are often invisible; they are not enrolled in schools like their peers without any disabilities. Even when they are enrolled in school, they drop out quicker (Waltham, 2016, 2018). Disability really is a complex phenomenon requiring multiple coordinated interventions to solve. Attempts to stop negative behaviour towards children with disabilities will inevitably have to deal with socio-economic and cultural challenges and isolation.



Poverty and economic challenges that come with disability may be particularly critical. Schoggen (1989), for example, warns that behaviour settings that are not adequately populated must make great use of deviation-countering control mechanisms because their inhabitants are functionally too important to be casually eliminated. The findings of this study show that parents are caught between fear for the well-being of their children with disabilities and perceiving their child as a source of income. For example, using the benefit that children with disability get, for other purposes, such as alcohol or clothes for siblings. The situation is changing for the better, with some people being receptive to advocacy and communication for behaviour change interventions, but traditional beliefs do hold a strong grip on people's thinking. Trust is a critical issue, in some cases informed by bad experiences in the past. In Namibia, one group told of trust for outsiders being damaged by corrupt medicine salesmen selling fake products for large amounts of money, or advocates from the capital briskly intruding in local community affairs, telling how things work.

The ways that families deal with income, particularly in resource challenged environments, and guarantee the safety and well-being of their child after their own deaths is difficult. The problem was brought to us in a very heart-breaking discussion in the Kisumu area of Kenya, where a mother of a twenty-year old young man with autism was diagnosed with HIV ten years ago and in recent months started suffering from health complaints. The boy is happy and generally fine, in the care of his mother, liking soccer very much and good at it, but taken advantage off by members of the community to chop wood and other physically straining tasks, beyond his physical capacity and for too little pay. Being taken advantage off in ways like this is common for children with disability. The mother was crying, at her wits end, afraid for the future of her son.

This observation repeats findings from earlier UNICEF research that children with disabilities do not benefit from programs or interventions that children without disabilities do; it also validates the research question of this project, which was to investigate the role of social norms in decisions regarding children with disabilities. Identifying a core of social norms and grounding these in processes of social maintenance was the purpose of this research study and this is what we report here.

People purposefully share news and village chiefs (called "Indunas" in the Zambezi Region of Namibia), who act as local centres or hubs of intelligence, calling meetings in the villages to deliver information and knowledge. There is thus strong evidence for a social component to the treatment of children with disabilities, even though 'Indunas' are sometimes powerless when parents ignore them. In one way, communities organize themselves in such a way to make sure that best practices are known by every member. At the same time, social modelling is often mentioned as a way of transmission: People copy other people's behaviour. But alluded to in many times of the focus groups is some sort of tipping point or power effect: More visibility will be necessary, with time, to accelerate the spread of the desired treatment of children with disabilities. Anticipating people's negative responses to their children with disability makes parents choose to keep their



children at home, even hide them. Expectations include the absence of help at school, the absence of economic pay-off for the children later in life, and the presence of bullying of their children during school hours by peers. Portraying and publicising positive deviants' stories of families that despite all the challenges managed to support their children with disability, keeping them in school is key in order to spread the idea that positive change is possible.

## 4. RECOMMENDATIONS

Looking at the shape of the results, specifically as captured in Table 2, this first study has recommendations for immediate interventions that can be organized by schools, local leaders, or others players, recommendations for communication purposes, as well as recommendations for next phases in the larger social norm and disability initiative of UNICEF.

#### **Recommendation 1: For immediate interventions**

Key elements of any practical recommendation regarding some harmful behaviour would be to alleviate and strengthen the program and goal circuits of cultural maintenance. In basic terms: to get people to have good ideas and proactively share them. The step of proactively sharing provides a line of helpful recommendations over and above the reasoning of Bicchieri (2017), which only focused on having good ideas by changing expectations. Governments, with the assistance of UNICEF, could enable both good ideas and proactively sharing to happen. The primary recommendation from the analysis is a rich multipronged approach, rejecting a single-issue organization of the problem of disability but instead focus on intersecting factors that increase the child's vulnerability. Gender violence needs to be addressed simultaneously with disability. Health and early identification need to be included. Parents need responsible parenting skills and a positive outlook in terms of vocational training and future economic independence. Through community based-systems or networks, such as Child Protection Community Committees, Parents-teacher associations and others, it is important to identify isolated CWDs that require multi-sectoral support, prioritising referrals, case management, psycosocial support and/or parenting skills training for their parents and, ultimately, enrolment in Social Protection programmes.

For universal/structural barriers. Transport, long distance and safety issues associated with these are structural barriers that inhibit children with disabilities from coming to school. One very helpful solution would be to provide safe and properly maintained accessible transport for children, like busses or other means considered appropriate by them and their guardians. Also helpful would be to create better awareness amongst the general public about road safety. Safety



issues that need attention are the prevention of speeding where many children are, how children with disabilities in emergency situations (such as an epileptic attack) can be helped, and protection and safety for girls from sexual harassment and rape. The general public could be more watchful and learn how to intervene in situations where children's vulnerability is exposed. The visibility of police trained to identify and address problems of this nature around schools could assist in this general process.

One of the most powerful influencers of individual behaviours, social norms and collective action at community and societal level is religion. Religion has a profound impact on personal and collective values and social norms and as such can be a powerful catalyst for positive action to improve the lives of women and children. Religious leaders, whether Christian or Islamic, depending on the specific region, could help fight beliefs in witchcraft and curses. Uneducated believers were particularly mentioned in Garissa. Participants in the focus groups were not always convinced that new Christian religious leaders have similarly good intentions when it comes to outreach on disability, specifically in the two regions in Eswatini and Kisumu. Remedying this would often amount to developing a better understanding of the positive tenets. Religious leaders are typically highly motivated for this, and programs could be developed to assist them in this. Through the global Initiative on Faith and Positive Change for Children supported by UNICEF, Religions for Peace and the Joint Learning Initiative on Faith and Local Communities launched in 2019, there is a current opportunity to move beyond single sector, single denomination and message-based communication to support more focused, systematic and at-scale engagement with faith-based communities and actors to influence positive social and behaviour change towards improving the wellbeing of children, youth, women and families, particularly the most marginalized such as children with disability. Religious leaders could, for example, be taught didactic skills; thinking on disability within the religious context could be developed, religious leaders with disability could be mobilised and championed and communication materials provided with reference to the sacred scriptures to promote inclusion at different level of the society. High ranking church leadership could be supported to develop programs to create a stronger drive and passion for issues such inclusion for people with disability amongst the many ministers and pastors.

For teachers and schools. At schools, we see that children with disabilities are often ignored; they sit at the back of the classroom or even outside and may not always participate in lessons. In many situations, the child might only have a small visual or hearing impairment that could simply be solved by proper diagnosis and a visual or hearing aid. In other situations, the disability is more severe, with teachers unequipped to deal with it. Likewise, an attitude of 'mind your own business' is prevalent: the majority of teachers feel that children with disabilities are not their business, but rather of the one specific special needs teacher in the school, if there is one. Children with disabilities are often considered to be stubborn and a big bother. For example, difficulty for a child to express her needs could be met by a beating from the teacher, hampering the healthy social development of the child even further.



Schools can do a lot to help this situation. Classrooms can be made more accessible, placement of children in the classrooms could be more rational, and (temporary) remedial classes could help small groups of children in a very limited time on specific issues they did not catch in class. Above all, in-service training for teachers in schools could be strengthened, not just for life skills teachers. Some of the more successful teachers in the study were able to easily manage sub-groups of children in their classrooms with 70+ pupils by shifting their attention in quick succession when necessary, supervising many learning groups at once that are basically self-reliant and self-managing. Teachers could receive training for this and engage with colleagues in symposia or platforms on best practises. Also, ongoing advocacy at school level with regards to reducing stigma and beliefs might be helpful.

For parents and communities. A major problem that came out of the study is that parents and teachers do not communicate openly about disability. Sometimes teachers never realize a child in their class has a disability, mild or more severe, because the parents never told them. Programs could address ways to connect others to positive perspectives about disability. This could be prioritised with the support of the Parents-Teacher Associations, when developing their School Improvement Plans. One possible scenario can be to have social events at schools with a strong entertainment factor, where the different abilities of children with disability and the innovative teaching techniques identified by some teachers could be shared; to have teachers and parents mingling, sharing responsibility and participation in an event on equal footing, avoiding the tension that often comes with parent-teacher meetings, and avoiding no-shows.

Parenting practises are something should be addressed through different programs. Disability within a family home is often accompanied by violence and neglect; children with disabilities are sometimes used as cheap physical labour or see the financial social support they receive from government go somewhere else. Parents are also sometimes not aware of the existence of programs that could help and often government or social and community health workers do not volunteer to provide knowledge they might have. Chiefs could be a problem in keeping money for themselves or their families that was earmarked for families in the communities that need assistance. A mindset change amongst social and government workers might be achieved through in-house training, making them more pro-active in volunteering information. Also, a lot could be done to emancipate families. If a family does not know of good practises or some sort of funding that is the end. Programs could take away learned helplessness; teach about existing channels and structures that could be pursued. The bottom-line is that parents understand that abuse and neglect is unacceptable, that solutions must be found that help the child, and eventually the family benefits.

# Recommendation 2: For communication for development purposes

An advocacy-based recommendation is to have targeted communications for development (C4D), multi-channel media campaigns with positive deviant stories that reach a broad and rich audience, both through the national mainstream



# Box 1

Positive deviant stories that concern children with disabilities from across East and Southern Africa, involving parents (i and ii), teachers (iii), and communities (iv), by country and region.

### Namibia

A young mother brings her eleven-year-old son with cerebral palsy to preprimary school every day. She said she was happy to carry him or push his wheelchair to school in the morning and stay with him during the school day to assist the teacher and make sure he is well taken care of.

# ii. Kenya, Garissa

A father in Garissa with a young daughter with hearing problems kept his girl at home because he did not know what opportunities were available and because he did not ask others, even though he was living in town, with a school specially for children with hearing problems; he did not know. Upon finding out about the school he moved his family to live close to the school and enrolled his daughter.

# iii. Kenya, Kisumu

A special needs teacher in a mixed primary/secondary school in Kisumu takes care of her own pupils and other pupils with disabilities in the school, despite problems with resources. Other teachers tell her she is the "owner" of the children with disabilities, but she is huge inspiration to the children and has earned their trust. She even takes care of children with disabilities around her house by bringing them in and entertaining them.

#### iv. Eswatini

Now that soft-spoken missionairies in the region have been replaced by local ministeres that do not look after children with disabilities and their families, mothers have together started to set up "soup kitchens" to provide food and organize regular events where families can gather.

media abut also through local communication channels and interactive sessions at community level. Successful "It is about ability"'s C4D campaigns undertaken by UNICEF in Montenegro and/or Mozambique, among other countries, can be inspirational across the region. Box 1 presents four stories that followed from the fieldwork and meeting strong people that defy the odds. Positive deviant stories can do two things: (1). In target communities, positive defiance can be a good example for others. If enough people see positive defiant stories it will eventually create a movement on its own, with people directly copying or changing the conversation between people; (2) a more realistic perspective on aid and problems in economically challenged communities (not seeing people as victims) could create a broader positive perspective conducive to effective aid.

# Recommendation 3: For ESARO's follow-up

Recommendations with regards to the cross-regional social norm initiative to address harmful practices, of which this is the first complete phase, consist



of suggestions for moving to a second, quantitative phase of research, establishing social and behaviour change baselines in selected programme intervention areas in the three countries covered by this research (Eswatini, Kenya and Namibia) and beyond. Several concrete recommendations can be given: (1) The design of Table 2 is systematically faceted, combining three social norms with three maintenance mechanisms in nine distinct cells. An item pool for the measurement tool can be developed by creating items for each of the cells, let us suggest 10 items per cell, providing a pool of ninety items that each target one very specific element of social norm regarding disability. (2) A multi-group analysis can be used to assess the validity of this large item pool across multiple regions or countries and to reduce the item pool to a manageable set of items that have high validity in all the regions/countries.

The design of Table 2 acts as a guide in evaluating the analysis, seeing what type of factors we are getting in the factor analysis. (3) The final set of items can be used to create a social and behaviour change baseline, through a cognitive validated questionnaire. One type of assessment, looking at differences between countries, would be to statistically compare the effect sizes of the factors at a specified psychological outcome that can be assessed in addition to the norm items, such as wellbeing. (4). At any point in the next phases of the research, the quantitative data from this first phase can act as guide to make decisions, to illustrate, to better understand what is happening in the data. With this in hands, true comparisons can be made regarding the effectiveness of social norms interventions.

In the communities where the fieldwork of this UNICEF research was conducted, children with disabilities and their families seems to carry the brunt of being isolated cases, carrying the whole of culture and community in them. When everyone would be working together, we might have a chance to address disability and improve the wellbeing of this vulnerable group of people, while respecting their integrity and ownership.

# 5. ANNEX

Out of all the focus groups and fieldwork, a few stories and issues stood squarely out: Personal impressions that gained a large depth. We share two impressions here, one a light in the difficult issue of disability, namely men and particularly village chiefs that show leadership, one more dark upsetting about the reality of sexual abuse that girls with disabilities face on a daily basis.

# **IMPRESSION 1: APPROACH NICELY; STORIES FROM NAMIBIA**

Indiscernible from afar, the seemingly disconnected homesteads scattered across the vast open landscape of



Northern Namibia belie a smart operating network. In this hard landscape, people have taken on roles and responsibilities, centred on Indunas to help them cope. People share the news they get from others or from the radio, making sure everybody has the best information; people speak to their local Induna about problems they face--such as drought, abuse or neglect--and in turn the Indunas collect their local information, like an intelligence library. Unseen to most but the locals, there is a strong drive towards self-management and problem solving.

We were in Namibia to kick-off the study of social norms regarding access to education for children with disabilities. To hear how teachers, parents, children, and local experts understand disability and access to school, we travelled across the North, and conducted 30 focus-group discussions. The Zambezi region in the northeast, tucked in between Zambia,



Girl and her younger brother at a school in Opuwo, Namibia. (Photo Credit: Symen Brouwers, UNICEF ESARO, 2019)



Zimbabwe, and Botswana a result of German expansion drift in the years running up to World War I, and the Kunene region, including Opuwo previously known as "Kaokoland" in the northwest, caught between the border of Angola and the Atlantic Ocean, are far away from even the capital city of Windhoek. We came to hear their untold stories, some heart-breaking, some happy.

With the support of UNICEF, governments could be a viable resource for Indunas and their informal intelligence networks, to reach parents of children with disabilities. But often distances are long, schools do not have the necessary qualified and trained teachers or the inclusive infrastructure to provide the necessary environment for these children. Combining UNICEF's Communication for Development (C4D) program with expertise from cross-cultural psychology and critical ethnography could help build and maintain shared social platforms for learning about disability, enrolment and retention in school. Central to this is the practice of cultural stewardship. Cultural stewardship starts from the idea that people in a local environment know best; they know what their problems are and can provide the best solutions. Stewardship entails asking a community about their history and cultural background to encourage them to think about the challenges, harmful social behaviour, and conditions that perpetuate the abuse and neglect of children with disabilities.

Hopeful stories underwrite the need for cultural stewardship. In Box 1 we have a story talking about a young mom and her son with cerebral palsy. In other stories, we heard about a young boy pushing his older sister in her wheelchair on a rocky surface to school every single day – incredibly shy but proving to have strength and character inside.

Indunas, school management, and social workers praised the methods we used in our focus-group discussions. All responded positively to questions about disability and schooling, outlining an "approach nicely and not imposing our ideas on them" model for working. With a cultural stewardship approach like ours, where development is grounded in local intelligence, UNICEF can help build trust between communities, service providers, and investors to benefit the inclusion of children with disabilities into school and their communities.

#### **IMPRESSION 2: INTERSECTIONALITY AND SEXUAL ABUSE**

In situations where parents already have poor expectations regarding the education of their children with disability and its expected economic outcomes, a viscous circle between secrecy and sexual abuse has a strong grip on its continuation. With communities stretching from small homesteads to houses scattered irregularly over the open countryside, children with disability are often close to home, many times held within their homes, vulnerable to those in their family and community. Families of children with disability often tend to isolate themselves, increasing an atmosphere of suffocation; sexual abuse is prevalent and recognized as the single major problem for girls with disability. This abuse is, however, not only an outcome of vulnerability, but also a social condition that perpetuates the status quo for this vulnerable group.



Traveling through the Eastern and Southern Africa Region, we learned of parents' struggle to be heard and find solutions for their situation having a child with disability who isn't going to school. The Education for All movement supported by the UN and its partners has worked around the world, with non-enrolment rates dropping from 100 to 61 million between 2000 and 2015. The biggest trials, however, are faced by children with disabilities. What we saw across the regions is that, many times, parents of children with disabilities do not know what to do: They don't know where to go for support; they may not even know it's possible to send a child with a disability to school; they don't realize it will pay off in immediate wellbeing and future economic independence of their children.

Sexual abuse of girls with disability, often at a time around their maturation, is highly frequent across the ESA region, sometimes in plain sight. Young children in the Shiselweni region of Eswatini see neighbourhood girls with disability being raped by groups of boys in the forest around their villages, threatened not to tell, labelled by local community workers as a "free for all". Social workers are particularly vocal about sexual abuse; they visit children in their homes and get to see the worst. When sexual abuse takes place in the family, for example by the father, male siblings, or an uncle, it often leads to secrecy and shame. When the perpetrator is from outside the family, it is sometimes reported to the village chiefs, who in cases act on behalf of the family to report it. Amongst the Muslims in the Garissa region of Kenya, secrecy is maintained by the families of the victims and perpetrators through traditional legal practices involving small payments, avoiding the reporting to authorities.

Keeping to secrecy and shame perpetuates the existing economic power balance in the favour of men. Victims and their families are disempowered, perpetuating or even increasing vulnerability. Positive expectations that parents might have for their children with disabilities are kept from fruition. That children with disability would complete some level of schooling, by finding applicable help in schools and their community, might entail a threat in an environment where economic participation is already under pressure. A feministic model says that the mentioning of medical and material causes of disability serves to maintain a social imbalance in favour of abled men. The prevalence of sexual abuse is in line with such a model.



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# **ACKNOWLEDGEMENTS**

Many people have contributed to the outcome of the project and I want to thank them. In Namibia I want to thank Aune Victor of the UNICEF Country Office and Regula Käser, Leopoldine Nakashole, Lizette Beukes, Aini Hoaeb, Mr. Peter, and Mr. Simushi of the Ministry of Education. In Eswatini, Victor Nkambule, Leonard Kamugisha, and Nonhlanhla Nkambule of the UNICEF Country Office, and Fikile Shongwe of the Ministry of Education. In Kenya, Rolando Jr Villamero and Janeanne Kiviu of the UNICEF Country Office, Linda Namusonge Kharemwa of the UNICEF Kisumu Zonal Office, Osman Mohamud of the UNICEF Garissa Zonal Office, and Fredrick Haga, Sheilah Lutta, and Martin Kavua of the Ministry of Education. From the UNICEF Eastern and Southern Africa Regional Office I want to thank Alvaro Fortin, Tizie Maphalala, Abhiyan Rana, and Massimiliano Sani. A very big thank you also to all the school principals who assisted the project by identifying possible participants and giving us space in their schools for us to conduct the focus discussion groups.



