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Blindness Prevention in Mali: Are Improvements in Sight?

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Abstract

International public health policy for the prevention of disability is premised on the homogenizing stance that there is a universal, static conceptualization and experience of disability. A review of key debates in disability studies literature illustrates the extent to which subject formations, including the notion of the Disabled person, are shaped by social, cultural, political, and historical contexts. Research on blindness prevention in Mali is then presented as a case study of the lack of fit between WHO and local definitions of disability. In addition to engaging with disability studies scholarship, this article is also a response to the call made by medical anthropologists to think critically about the relationship between poverty and health inequalities.

I. Introduction

The World Health Organization estimates that today there are more than 38 million people who are blind and an additional 110 million people who have severely impaired vision (WHO 1997). Not surprisingly, more than ninety percent of all blind people live in the Third World (Thylefors 1998).

The main global causes of blindness are cataracts, trachoma, vitamin A deficiency, onchocerciasis, glaucoma, leprosy, trauma, diabetic retinopathy, and ageing-related macular degeneration. More than two thirds of all blindness is either preventable or curable. "Why," we might then ask, "is the number of blind persons still increasing, although adequate treatment of most causes of blindness is technically possible?" (Stilma et al. 1991: 285).

Unfortunately, public health professionals tend to focus studies of blindness prevention and eye health on epidemiological and economic factors. Increasingly, however, anthropologists

(Courtright 1995; Jaffre & Moumouni 1993; Lane & Meleis 1991; Lane et al. 1993) have begun to investigate social and cultural factors affecting the prevention and treatment of eye diseases.

This article presents results from research on blindness prevention in Mali in association with l'Institut d'Ophtalmologie Tropicale de L'Afrique (IOTA), a West African collaborating center for the World Health Organization's Program for the Prevention of Blindness. A semi-structured format was used to interview patients, the directors of health posts, itinerant eye surgeons, nurses, school teachers, adolescents, adults, and elders in two rural Malian villages. The research was designed to examine the status of blind people in Malian communities, Malian people's conceptualizations of the etiology of blindness and eye diseases, their eye care practices, and their perceptions of barriers to eye care. Particular attention was paid to gender differences in health-seeking behavior and health care provision, as the rate of eye disease and blindness in Malian women is twice the rate for men.

The central issue to have emerged from that research concerns the incommensurability of the WHO's disability prevention model in a West African context. Public health models for disability prevention and rehabilitation are premised on the homogenizing stance that there is a universal, static conceptualization and experience of disability. When the meaning of "disability" is itself destabilized - as I argue is the case in Malian society - disability prevention programs lose their salience.

In the following pages, a review of key debates in disability studies literature illustrates the extent to which subject formations, including the notion of the Disabled person, are shaped by social, cultural, political, and historical contexts. The research on blindness prevention in Mali is then presented as a case study of the lack of fit between WHO and local definitions of disability. In addition to engaging with disability studies scholarship, this article is also a response to the call made by medical anthropologists to think critically about the relationship between poverty and health inequalities.

II. The Universality of Disability

Definitions of "disability" have changed over the past few centuries. These changes have been reflected in disability prevention policies, human rights policies, labour policies, in disabled people's conceptualizations of themselves, and in popular attitudes toward persons with disabilities.

With the publication of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) by the World Health Organisation in 1980, an official distinction was made between "impairments" (at the level of physiological, anatomical, psychological function or structure), "disabilities" (the loss of ability to perform an action due to an impairment), and "handicaps" (the inability to fulfil one's normal role as a result of an impairment). The ICIDH has been aptly criticized for its implicit assumption that handicaps are a complex form of impairment and for not providing a clear framework for determining the relationship between external factors such as social prejudice and internal factors such as the impairment itself (Bickenbach 1993; Bickenbach et al 1999).

Models of disability, and disability policies, have always been political. Disability theorists distinguish between the medical model of disability which focuses on the prevention and rehabilitation of physical and mental impairments, the economic model of disability which focuses on potential losses of labor/skill capacity, and the social-political model of disability which focuses on handicapping phenomena and the stigmatizing and discriminatory aspects of society. Whereas economists are interested in the cost-benefit analysis of disability prevention and rehabilitation, political activists emphasize self-empowerment.

The disability rights movement's alignment with minority groups has emphasized disabled people's engagement with an identity politics which stresses that disability, like gender, sexuality, race, ethnicity, and class, is a central aspect of one's lived experience (Albrecht & Devlieger 1999; Asch & Fine 1988; Wendell 1996). In research on international disability prevention, theorists have argued that it is important to be wary of the endorsement of "standpoint epistemologies" - just as it is erroneous to assume that all women or people of color share a common understanding of the world or common experiences, it is erroneous to assume that persons with disabilities do so (Wendell 1996).

Disability theorists and anthropologists have suggested that the very notion of "disability" may itself be a Western cultural construct incommensurable with certain world-views and explanatory models. For example, Hubeer people in Somalia condone idiosyncracies (which would be classified as "disability" according to biomedical nosology) as a reflection of human variation. Physical deformities are only considered disabling, among the Hubeer, if they interfere with mobility or involve a high degree of pain (Helander 1995). Similarly, Pnan Bah people in Borneo, Malaysia, do not categorize people with physical impairments as deviant from the norm. This is because - within an ontological framework in which the person is composed of multiple souls - physical impairments are associated with the imperfections in one's "additional souls" rather than in one's primary "body soul." In short, physical impairments do not lead to people being conceptualized as Disabled, or as fundamentally different from their peers (Nicolaisen 1995).

Just as the concept of disability is shaped by the social, cultural, political, and historical contexts within which the body and subjectivity are imagined, such that a globally normalized model of "disability" is inappropriate, anthropologists and disability theorists have demonstrated that the corresponding concept of "rehabilitation" is not universally applicable.

The WHO's community-based rehabilitation program was tested in Botswana in 1979. The community-based rehabilitation approach encourages individuals, families and community leaders to adapt the local environment and to change local social attitudes in order to facilitate the inclusion of persons with disabilities within communities. Anthropological research among the Tswana suggests that community-based rehabilitation may not be appropriate in societies in which impairments are dealt with strictly on the basis of their perceived origin. Given that impairments are understood as the result of witchcraft, the Tswana are less interested in the improvement of people's quality of life or skills than in undoing the effects of witches (Ingstad 1995). Similarly, Songye people in Zaire explain disability as caused by God, or relations between humans and their physical environment or family members. The idea of rehabilitation is clearly incommensurate with their understanding of disabilities as one's just reward (Devlieger 1995).

The WHO's current policy for community-based rehabilitation may be flawed precisely because it takes for granted that "disability" and "rehabilitation" are universal phenomena with universal solutions. As a venue to examine current public health doctrine, in April, 2001, the WHO and the Norwegian Ministry of Health and Social Affairs co-organized the Global Conference on Rethinking Care. Papers presented at the conference touched on everything from mental illness, mobility, parenting and aging, to raising awareness about land mines and human rights. Although two of the aims of the conference were to analyze barriers to the provision of effective worldwide medical care and to improve the outcome of community-based rehabilitation programs, the dominant themes in panel presentations were the need to shift our focus from the management of disability to the political economy of disability. Speakers called for the need to challenge conceptualizations of difference and to recognize patterns of provision and exclusion, or the circumstances which disable and enable people at the local, national, and international levels (Meekosha 2001; Newell 2001).

Having discussed disability theorists' engagement with the notion of "disability," it is apparent that subject formations - with respect to the conceptualization and experience of disability - are shaped by social, cultural, political, economic and historical contexts, interacting at all levels. I turn, now, to a discussion of blindness prevention in West Africa.

III. Programs for the Prevention of Disability in Mali

As I alluded to in the introduction to this article, my own research on programs for the prevention of blindness in Mali destabilized the WHO's notion of disability. I will focus here on what I refer to as the "monocularity" of the WHO's disability prevention models.

The WHO's disability prevention models are monocular insofar as they have an eye for the prevention of only one category of disability at a time (be that blindness, deafness, a mental disability, or something else). In certain European or North American contexts, disability prevention models may provide effective public health strategies. In a country such as Mali, however, where the conditions of everyday life are unfathomably disabling - communities lack basic infrastructure such as access to clean water, adequate housing, roads, electricity, health care, and education; malnutrition and infectious disease are commonplace; the infant mortality rate is high and life expectancy is low - every person experiences multiple, interwoven disabilities.

I would not feign to argue that people living in conditions of extreme poverty and destitution are unaware of specific impairments and handicaps associated with disabilities. The people with whom I spoke in Mali were certainly able to articulate the ways in which one's life can be affected by a physical impairment such as blindness. I am hesitant, however, to concede that the disability prevention model is congruent with the conceptual framework used in a Malian context. My argument is best illustrated in the following manner.

Conceptual framework A: Classificatory Grids

Disability prevention models draw upon a classificatory grid of disabilities and diseases. This two-dimensional grid is organized according to specific criteria (such as morphology and pathology) which are defined in official texts such as the International Classification of Diseases. The size of the grid may expand or contract with shifts in medical politics (for example by including poverty and illiteracy as disabilities and excluding homosexuality) and disability categories may overlap somewhat, but the basic structure of the grid does not change.

Popular, as well as medical, conceptualizations of disabilities are informed by this grid. At the coordinates for blindness one expects to find a person who cannot see, relies upon a white cane or a seeing-eye-dog for mobility, who requires various medical, rehabilitative, educational, and other social services, and whose personal characteristics are affected by the blindness. The specific content of these popular conceptualizations will be influenced by historical, social, and cultural factors, but the general idea persists that blindness is a state of being represented by coordinates on a map of disabilities.

The disability prevention framework is based on the tacit assumption that there is a broad term, "disability," which encompasses each sub-type of disability (i.e., a blind person, a mentally impaired person, and a quadriplegic person are all Disabled). In this respect, the framework is homogenizing. The framework is also based on the tacit assumption that it is individuals who are the locus of disabilities. In this respect, the framework is individualizing. There are no coordinates on this model for: 1) a visually impaired individual who does not consider herself Disabled; 2) an individual with multiple disabilities, rather than a single disability; or 3) disabilities located in families or communities rather than in individuals.

Conceptual framework B: Disabling Conditions of Everyday Life

Disability as it is conceptualized in Mali is not congruent with the WHO's disability prevention model. In Mali, disabilities are ubiquitous and disabilities are intricately interwoven. Needless to say, separate disabilities as classified on the disability prevention grid are medically identifiable in a West African context. The lived experience, however, is not consonant with that model because people experience multiple disabilities simultaneously. There is no broad term, Disability, in this framework; rather, there are myriad disabling conditions. Within this framework, people do not identify themselves as Disabled. Indeed, disabilities exist outside of the individual. For this reason, individuals do not conceptualize themselves as the necessary focus of treatment and prevention.

My intent, in drawing this contrast between the disability prevention model propounded by public health professionals and local people's conceptualizations and experiences of disability in Mali, is to use the lack of fit between the two as a basis for explaining the failure of programs for the prevention of blindness. In the following three steps, I will elicit how the Malian research brought me to this argument. First, I will briefly describe the type of eye disease, trachoma, which is prevalent in Mali. In doing so, I am laying out the Trachoma Prevention model's two-dimensional classificatory grid. Then, I will describe the Malian health system and the WHO's strategy for the prevention of trachoma. Finally, I will turn to interview material to present Malian people's conceptualizations of trachoma, conceptualizations which belong to a framework that is incommensurate with the disability prevention model.

The Definition of Blindness and Trachoma: "Blindness" was defined by the WHO in 1972 as "the inability to count fingers in daylight at a distance of three meters" (WHO 1979: 275). At the same time, visual acuity of less than 3/60 was described as "a level of handicap" which "precludes an individual from functioning effectively in his community without special assistance and rehabilitation" (WHO 1979: 276).

Trachoma - derived from the Greek words "rough" and "swelling" - is an infectious eye disease caused by the microorganism, Chlamydia trachomatis. Trachoma was once endemic to parts of Europe, North America, and northern Asia, but disappeared with improvements in living standards following industrialization and economic development (WHO 1981). Severe trachoma is now endemic in communities situated in dry, rural areas of sub-Saharan Africa, central and east Africa, Morocco, Egypt, Mexico, Guatemala, Northeast Brazil, Viet Nam, and elsewhere (WHO 1996). Trachoma is the second most common eye disease in developing countries (cataract is the most common). It has been estimated that 150 million people currently suffer from active trachoma and that it has caused blindness in 6 million people (WHO 1993).

Trachoma is transmitted through direct or indirect contact with infected material (hands, clothing, towels, etc.) and flies can transfer bacterially infected discharge from the eyes of one child to another. Trachoma progresses from an inflammation of the conjunctiva, the inner lining of the eyelid (this typically occurs in children between the ages of one and eight), to scarring of the eyelid, and finally to a blinding stage known as "trichiasis" when in-turned eyelashes rub the cornea causing it to become opaque. This latter stage occurs in adults as their tear functioning decreases with the aging process and is most common in women who have been in continuous contact with trachomatous children.

The basic treatment for trachoma involves the application of topical antibiotics to the eyelid. Tetracycline 1% eye ointment, for example, can be applied to the eye twice/day for six weeks. Individuals, families, and entire communities are targeted for antibiotic treatment. Corneal scarring due to in-turned eyelashes can be prevented through eyelid rotation surgery (WHO 1996).

Strategies for the Prevention of Trachoma: Unlike many other diseases, the prevention of trachoma does not require expensive vaccines or mass-spraying with chemical insecticides. The WHO has distributed trachoma prevention guidebooks to district and community health workers throughout Mali and has encouraged community health workers, teachers, women's associations, mothers, men, and other volunteers to be involved in trachoma control. In these guidebooks, trachoma control is broken down into a four-component strategy known as SAFE: Surgical correction for trichiasis; Antibiotic treatment for cases of active trachoma; clean Faces to prevent the disease from spreading; and Environmental improvement (water and sanitation). The guidebook provides procedures for determining the rate of trachoma in a community, it provides lists of questions for community health workers to use in group discussions about people's eye health practices and concerns, and it offers suggestions for how to promote SAFE activities when community members express that they are constrained by factors such as a lack of water.

In Mali, hospital-based and private ophthalmic clinics are found in Bamako and in smaller cities and towns along the Niger River. Researchers, administrators, and physicians responsible for the design and implementation of blindness prevention programs travel to health posts in villages across the country to assess eye health, perform specialized procedures, and distribute pharmaceuticals, equipment, and information.

WHO reports on eye health in developing countries have pointed to a shortage or maldistribution of personnel and financial resources as the main obstacles to blindness prevention (Thylefors 1985). Problems of access, motivation, infrastructure, and organization as well as the "lack of public demand for appropriate goods and services" are other obstacles to blindness prevention frequently cited in public health literature (Sommer 1989). In addition, people's traditional beliefs and practices have often been blamed for the failure of public health programs.

One particularly interesting report on the prevention of blindness suggests that programs aimed at changing behavior are rarely successful even in the First World. As Sommers (1989: 545) aptly points out, convincing people that they need goods or services is not a problem in the commercial realm as evidenced by sales of Coca Cola worldwide. Nevertheless, when it comes to health, motivation is as much a problem in the First World (where people cannot be convinced to give up smoking) as in the Third World (where mothers do not feed their families fresh leafy vegetables or wash their children's faces). The same author explains people's reluctance to seek eye care in part by the normalization of blindness: "Just as your hair grows white with age, so do your eyes" (Sommers 1989: 546).

While I was in Bamako, a public health consultant for an international development organization happened to cross paths with me at IOTA. When he asked me what I was doing in Mali, I described my mandate from the WHO to examine social and cultural obstacles to the prevention of trachoma. Laughing, he responded, "We all know what the problem is: It's poverty, ignorance, and dirt!" Shocked by the conditions of life in Mali, I had a sinking feeling that this consultant might be right.

The Malian Framework: It was not until long after I had left Mali, however, that I realized the fundamental flaw in this argument: blaming the failure of the Program for the Prevention of Trachoma on poverty, ignorance, and dirt is taking for granted that the Program is hindered by obstacles external to it. The interviews I had conducted in Mali were comprised of questions quite similar to the interview questions outlined in the SAFE guidebook - a line of questioning that fails to problematize the internal logic of disability prevention. If I had stepped out of the model of disability prevention, I might have realized that the Program for the Prevention of Trachoma is premised on a conceptualization of disability that does not exist in Mali.

During interviews several of the people with whom I spoke commented that adults in their village suffer from nyen dialan dimi (the local language, Bambara, translated as "eyes dry hurt"). When pressed, people were able to name symptoms and local treatments of trachoma. Yet, people knew little, if anything, about the etiology of trachoma. To them it was a disabling fact of life and not a categorized disease or disability. Even a medical delegate to the community health association in one of the villages was unsure of the causes of trachoma listing mosquitos, heat from the sun, bites from other insects, and sand blowing in the wind as potential causes of blindness. In local health education campaigns, village medical staff armed with eye health kits (a set of instructional audio tapes and paintings) had visited schools. On the walls of the health centers there were also posters written in French and Bambara about eye health and there had been general assemblies to discuss eye health in each of the villages. It was nevertheless clear that public health education about the etiology of trachoma had not been successful in these villages.

When I asked people about the most common types of illness in their communities, they listed abdominal and digestive illnesses (especially diarrhea), chest pain, back pain, muscle injuries, headaches, earaches, and hernia ("difficulty urinating"). Maternal and infant mortality were mentioned by several people as significant village health concerns. As farmers reliant on the cultivation of millet, peanuts, cotton, corn, beans, and rice, the possibility of droughts also weighed heavily on people's minds.

Only when I asked people specifically about their attitudes toward blindness did they mention that blindness is "the worst possible fate." People remarked, for example, that "Healthy eyes mean that one is useful to one's self and to the entire world: Eye illnesses make a person useless to society," and "Without sight, life is lost." On several occasions, villagers expressed concern that without eyesight one would be unable to see food, that cultivating a field would be difficult, and that blind women would not be able to fulfill their domestic tasks. Again, these topics were only discussed at my behest and it was clear that the phenomenon of blindness was not a preoccupation in people's daily lives.

In response to my questions about the status of blind people in Malian communities, I was told that to be blind is thought of as neither shameful nor prestigious, but rather as destiny (the doing of Allah). Not surprisingly - given that many Malians today are Muslim - begging is considered an acceptable means of survival for blind people. I was also told (and observed) that blind people undertake manual tasks such as spinning rope out of cotton, shelling peanuts, and weaving plastic to make cots and chairs. Significantly, one 75 year-old woman informed me that there are "No blind people in our village - only people who are mal voyant" (meaning people who have difficult seeing).

Without knowing she had done so, that woman provided the answer to the question, Why aren't disability prevention programs successful in Mali? There are no blind people in Mali. Every person in Mali is faced with multiple disabling conditions - sore eyes, difficulty seeing, hunger, festering wounds, leprosy, illiteracy - but nobody is Disabled. Public health advocates could lecture Malians unendingly about the importance of hygiene which, incidentally, was not a foreign concept. At least once every day I saw men, women, and children bathing themselves from head to toe with Koulikoro soap and water pumped into buckets, but the idea of washing children's faces to prevent trachoma would still be incommensurate with local people's conceptual framework. Even if medical care were physically and economically accessible and community health workers focused on the education of women and children, blindness prevention would still not become a priority because Malian villagers do not conceptualize blindness as a disability. It is a fact of life, perhaps far less disabling than other aspects of people's lives.

IV. Conclusion

If disability prevention programs are incommensurate with local conceptual frameworks, what can be done to prevent trachoma in Mali and in other similar contexts? Are improvements in sight?

It is first necessary to step out of the disability prevention box. Again, this is best illustrated by the following sketch: the model for disability prevention is based on a two-dimensional, monocular grid. By recognizing that disability in the Third World is ubiquitous and that people experience multiple disabilities simultaneously, the depth of focus in public health strategies will increase. The resulting vision may then be binocular (instead of a square, we have a cube), but the strategies will still not succeed unless one fully steps out of the box. The idea of disability has to be discarded. The final strategy would be based on a multi-dimensional model in which the disabling conditions of everyday life are the focus of public health intervention. The results of my research in Mali point to the necessity of making a real shift from thinking about disability and its concomitant, disability prevention, to thinking about disabling conditions.

Given statements such as "Without sight, life is lost," one might object to the conclusion that the disabling conditions of everyday life in Mali overshadow the significance of individual disabilities. Is blindness simply a fact of life in Mali, among other disabling facts of life? While, on the one hand, Malian folklore may define the lack of sight as a profoundly negative phenomenon, there was nevertheless no indication from people's behaviors or general attitudes towards others that blindness is something that defines a person as "Disabled." Following the stance taken by other disability theorists, I reject the notion that disability signifies an essential, fixed subject formation. At a given moment in time or space, it is possible that a person in Mali may define blindness as "the worst possible fate." On an ongoing basis, however, that same person is preoccupied with experiences of hunger, poverty, maternity, work, and witchcraft. When one emphasizes the heterogeneity, instability, and fluidity of subjectivity, the category "Disabled" disappears. This is true not only in a Malian context, but elsewhere, too.

The proposed shift from a model of disability prevention to an understanding of disabling conditions also entails an evolution from advocating for disability rights to advocating for human rights. I endorse the call made by medical anthropologists to problematize the relationship between poverty and health inequalities.

The development of the technology to prevent disease and disability has not resulted in marked improvements in global health not only because that technology is cost-prohibitive or otherwise unavailable to most of the world's population, but also because of the historical, systematized, structural inequalities which perpetuate ill health (Navarro and Shi 2001). This situation of global disparities in the health of populations has been referred to as a "modern plague" (Farmer 1999: 279). It is vital to analyze the outcome of global initiatives, including the

WHO's disability prevention programs, taking into consideration the political economy of health. Improvements will only be in sight when the conditions of everyday life are no longer disabling.

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