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Folklore and Disability: An Important—and Too Often Overlooked—Factor in Global Health and International Development Efforts

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In this paper, I argue that the field of folklore and folklorists can—and should— make more of a contribution to global health and international development efforts and should be more involved in conversations about social justice and human rights. Drawing on my invited comments at the webinar sponsored by the Fellows of the American Folklore Society entitled "Interrogating the Normal: Folkloristic Engagements with Disability," held on March 25, 2022, I provide some examples of research that my colleagues and I have undertaken where we have brought folklore and oral history approaches to disability-related global health and international development initiatives. I discuss how this knowledge has broadened our ability to ask and answer important questions. Based on my own experience, applied folklore can provide insight and generate new questions that can improve the lives of persons with disabilities. I encourage folklorists to seek out and undertake future collaborations with researchers and community groups working to improve health and well-being around the world.

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Applied folklore, disabled persons, anthropology, folk beliefs, world health, development, deaf culture, disabilities, disability rights, discrimination against people with disabilities

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The field of folklore and individual folklorists could—and should—make more of a contribution to global health and international development efforts and should be more involved in conversations about social justice and human rights issues.[1] As a medical anthropologist with some training in folklore who is working in global health and international development, there is rarely a day that goes by that I do not call upon my folklore background and orientation in my work.[2] Folklore has consistently been a cornerstone of much of what I do, including how I frame projects,

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what questions I ask, and how I approach individuals, communities, and organizations, both large and small.

Folklore overlaps with anthropology in its strong emphasis on what people say and how they think and act. Research in folklore provides a constantly evolving forum through which groups reaffirm what they believe, what they know, or what they think they know; process new knowledge; and deal with perceived threats—either internal or external. Folklore as a field helps us understand people and communities and underpins our sense of place and our expectations for the future. It encompasses a wide range of ideas, beliefs, and practices that inform and shape how individuals and communities respond to people with disabilities and how people with disabilities themselves frame the world around them.

I often find myself asking questions or pursing disability-related research based on my observations regarding folk beliefs, traditional practices, or subjects that come up in local stories or songs or legends. Unlike the experience of my colleagues trained in social sciences and/or public health, my folklore background frequently provides me with new and different angles or insights into disability issues and communities. In the following commentary, I offer some broad observations on the intersection between folklore and disability, and I provide a few examples from my own work to illustrate how folklore can be an important component of understanding the lives and experiences of people with disabilities.

Disability

According to the World Health Organization, people with disabilities make up more than one billion people or 16 percent of the world's population (2011). One in every four families worldwide has an immediate member who lives with a disability. The earliest human —indeed pre-human—populations also show evidence of disability. This evidence is based on skeletal remains, so individuals with certain types of disabilities—such as deafness, intellectual disabilities, or mental health issues—should be added to these prevalence rates, making the number of people with disabilities in prehistoric populations even higher. Disability is universal. No population has ever been found where there are not at least some people who experience disability. Moreover, no culture has ever been found that does not have a complex set of stories, myths, beliefs, and practices that explain why disability occurs, how people with disabilities should be treated, and what role(s) persons with disabilities should fill (or be denied) in their societies.

While many cultural and social entities consider disability as a single "group," others lack a unifying concept or single word for people with disabilities. Instead, they divide people with disabilities into specific groups—for example, people who are deaf or people who cannot walk. Sometimes, broad terms have negative connotations, such as "the unfortunates," "the cursed," or "God's children." Overarching words for "disability" have been introduced in many languages in recent years to reflect new legislative or social service initiatives. Health workers, government officials, and even disability advocates have introduced these new words because either no single word for disability previously existed or the existing one(s) in local language(s) were pejorative.

Whether people with disabilities are seen as a single group or as different groups based on their type of disability, all cultures have beliefs about why disability occurs. Often, but not always, there exist negative beliefs that focus on the idea of disability being caused by a curse from a God or gods, witchcraft, incest, or ill deeds in a previous life. However, beliefs are not always negative, and sometimes they are seen in terms of chance or fate. Regardless of how they are viewed, an explanation for disability is almost always sought.

How disability is framed within a society appears to be based in large part on what role(s) people with disabilities are expected to play as adults. What is considered appropriate behavior for a person with a disability, including what they can or should do themselves, what they can or should do for and to others, and what part they can or should play (or should be barred from playing) in their households and communities all contribute to how children and adults with disabilities are treated. In more accepting societies where people with disabilities are expected to become full, participating members of their communities, people with disabilities are more likely to be accorded more or equal access to the resources of their households and their communities. Where equal and full participation is restricted or denied, they are usually given less access to critical resources like education, employment, and social participation.

Unfortunately, in many societies, children and adults with disabilities face stigma and exclusion. This prejudice encountered by people with disabilities and their family members can pose a real barrier to the ability of people with disabilities to participate equally in the world around them. In the most extreme cases, infants born with a disability face infanticide, which is justified culturally by beliefs and practices. While infanticide in low and middle-income countries is often cited, statements may also be found in higher-income countries justifying the euthanasia of severely disabled infants and adults with cognitive disabilities, as in the work of Princeton bioethicist Peter Singer. Such arguments reflect a misunderstanding of what it means to live with a disability, which is comparable to attitudes found in many traditional societies (Johnson 2003). Stigma and prejudice about disability are not universal, and some cultures are more inclusive than others. People like the physicist Stephen Hawking, the Indian classical dancer Sudha Chandran, or the Italian singer Andrea Bocelli are regularly cited as celebrated examples of people with disabilities whose work is widely known to the general public. Unfortunately, however, such attention rarely translates into a better standing for the average disabled person in the societies where long-standing stigma and prejudice exist.

In many cultures, there is a mix of attitudes and stigmatizing behaviors: some types of disabilities are accepted while other types are shunned. For example, in some societies, people with epilepsy are considered bridges between this world and the next, as shown in Anne Fadiman's outstanding book *The Spirit Catches You and You Fall Down* (1997) about the Hmong community in the United States.

Traditional beliefs often stereotype people with certain types of disabilities, limiting their choices of what they are allowed or expected to do, who they are allowed or expected to associate with, and what work they can find (Groce, Murray, et al. 2013). Almost universally, individuals with intellectual disabilities and those with mental

health issues have even fewer options, compared with people with other types of disabilities (United Nations 2018). Such stigmatization can leave people with disabilities economically and socially isolated and at a higher risk of being abused or denied their equal rights in both public and private domains.

Importantly however, the barriers and limitations encountered by many people with disabilities have little to do with their actual disability. In many societies, the stigma, prejudice, and limited options available to people with disabilities are based on cultural, religious, and/or folk beliefs. This could mean that a child born with a disability is less likely to receive an adequate education (or still too often, any education) and is thus less able to find a job or to be fully included in the social, cultural, economic, religious, or political lives of their communities. An adolescent or adult who acquires a disability often faces job loss and the unravelling of social ties and community involvement. Results such as these demonstrate a negative feedback cycle that is often framed and reinforced by folk beliefs and cultural expectations that leave many people with disabilities disproportionately poor and socially marginalized (United Nations 2018). Finally, folklore about disability is usually discussed in terms of what the surrounding, non-disabled community says about people with disabilities. Yet there is well-established and expanding literature on folklore held and shared by people with disabilities themselves. For example, a growing body of work has documented the folklore of Deaf communities, including important early work, like that of Simon Carmel. His documentation of Deaf folklore in the United States, as part of a broader ethnographic study of the Deaf community, has spearheaded the development of work around Deaf folklore (Carmel and Monaghan 1991). Folk festivals organized by and for the Deaf community have shown the way. The pioneering Smithsonian Festival of American Folklore in 1985, which featured the program “Folklore of the Deaf,”[3] is a good example. And Washington, DC-based Gallaudet University’s “Deaf Way,” an academic conference and art festival, brought thousands of Deaf people to Washington in 1989 and 2002.[4] These early efforts are now regularly reflected in folk festivals in countries around the world, like Brazil’s 2017 Festival of Deaf Folklore.[5] The beliefs and practices of other groups, like the excellent work of anthropologist Joan Ablon on communities of people with osteogenesis imperfecta as well as people of short stature is another important example (Ablon 1984, 2010).

While much of the academic literature about disability features the perspective of the disability “community,” there are in fact many different disability “communities.” Moreover, millions of people with disabilities live isolated from groups of disabled people and do not consider themselves to be part of an overarching disability community at all. Some of these people maintain the same folk beliefs and attitudes about disability, or about people with certain types of disability, as do the rest of the population. Indeed, folk beliefs about disability among people with disabilities themselves is an important, and understudied, area of research.

Recent Research and Examples

Over the past few decades, research has focused on building a better understanding of the lives of people with disabilities and their families. New fields, such as disability studies, have emerged that allow us to acknowledge that disability is part of the human condition. Disability studies has also been combined with many other fields—gender studies, ethnic and minority studies, arts and theater, law, and medicine—thus becoming part of meaningful intersectional discussions: What does it mean to be both a woman and disabled? To be African American and disabled? To be a Native American woman with a disability?

Students and scholars now set out to concentrate specifically on disability as its own field of study. Some who work on these issues are people with disabilities themselves or researchers and academics who have family members with disabilities. These diverse and informed perspectives bring increased insight, depth, and a range of new questions to the field. Many others, like me, did not start out as disability researchers but rather came across disability as part of other work.

My own involvement in the field pre-dates disability studies (I recall being in a Mexican restaurant in Albuquerque in 1983 following a sociology conference when Professor Irving Zola from Brandeis University proposed establishing what is now the Society for Disability Studies). As an anthropology graduate student at Brown University, I spent a summer interning with Professor Edward (Sandy) Ives at the University of Maine and a semester in 1977 as a visiting graduate student at the University of Pennsylvania's Folklore Department, learning about folklore and oral history. A year earlier, I had stumbled across a disability topic while visiting Martha's Vineyard in Massachusetts where I was meeting the Island historian and fiddle player Gale Huntington (Groce and Kaplan 1994). His reference to the fact that there were a number of people born deaf on the Island led me to do my doctoral dissertation on the Island's hereditary deaf population and the response of the Islanders to this deafness. Calling on the oral history methods I learned during my time with Edward Ives and at the University of Pennsylvania, I interviewed anyone I could find who was above the age of 70 who remembered the old-time deaf inhabitants. It turned out that the majority of hearing Islanders were bilingual in American Sign Language and English, and what to off-Islanders was seen as a significant disability (profound prelingual deafness), was considered a normal human variation there. The resulting doctoral dissertation, published as the book *Everyone Here Spoke Sign Language*, was an oral history of a genetic disorder (Groce 1985).

My disability-focused doctoral dissertation led me to a career in international development and global health, where my training in folklore and oral history has since continued to be useful. For example, when my colleagues and I researched the impact of the HIV/AIDS epidemic on people with pre-existing disabilities in different countries, understanding the folklore around disability and sexuality was instrumental in helping to identify barriers to outreach and educational efforts (Groce, Rohleder, et al. 2013).

When my colleagues and I studied the links between disability and witchcraft in sub-Saharan Africa, I drew on what I knew about folk processes. I documented how traditional beliefs about the links between disability and witchcraft were rapidly evolving into widely held contemporary legends that intertwined lower middle-class expectations of prosperity and upward mobility, new Pentecostal churches' attention to "sin," and social media and film depictions of people with disabilities. For example, the frightening attacks on people with albinism in parts of East Africa during the past decade are not based wholly on older or rural beliefs. Instead, they are largely an urban- or peri-urban-driven phenomenon based on folk beliefs that possession of the skin or body parts of children and adults with albinism will bring the possessors great wealth, luck, or health. Body parts of people with albinism were selling for more than US $75,000 in some cases—too expensive for most people in poorer, rural areas but affordable by some upwardly mobile, educated, urban-based individuals (Groce and McGeown 2013).

A traditional proverb mentioned in passing by a leader of a disability rights organization in Mozambique led me to realize that begging was not only considered the acceptable norm for people with disabilities but that people with disabilities who begged were all but invisible in their communities. This insight led me to organize an oral history project, working with the United Nation's International Labor Organization, documenting the experiences of disabled street beggars in Addis Ababa, the capital of Ethiopia (Groce, Murray, et al. 2013).

Another example of how folk beliefs impact the daily lives of people with disabilities relates to access to water and sanitation in many parts of sub-Saharan Africa. In some areas, the communal well and toilets are restricted for people with disabilities because of folk beliefs around cleanliness and contamination (Groce, Bailey, et al. 2011). It should also be noted that folk beliefs are not always negative and that people with disabilities in low- and middle-income countries do not always fare worse than their counterparts in higher-income countries. In rural Ecuador, for example, my colleagues and I undertook a basic child health study. We anticipated that children with disabilities would be less likely to be vaccinated than their non-disabled peers. After all, this was the case in studies from the United States and Canada, where it is not uncommon for children with disabilities to see a raft of specialists but lack a primary pediatrician who coordinates their care. Interestingly, the folk belief of the local people in the area of Ecuador where we did the study is that "all children have souls, and all souls are equal" (Groce, Ayora, and Kaplan 2007). People there thus believe that all children need to be vaccinated. Despite the fact that travel through the area was difficult (some households were visited on horseback), we found that vaccination rates for children with disabilities were no different than for non-disabled children (Groce, Ayora, and Kaplan 2007).

Folk beliefs and folk practices remain a viable and often vibrant part of many communities, which is reflected in a range of issues within global health and international development concerns. Oftentimes, when I or others raise the subject of traditional beliefs or folk practices with government officials, international development experts, or United Nations (UN) agency staff, they dismiss these ideas as "just folklore." To me, there is no such thing as "just folklore." Folklore is an integral part of how people in all societies think and behave. It is a body of information that most people believe is true, or at least "true enough," because they have grown up with these beliefs, because many people around them share these beliefs, and/or because these beliefs are rarely questioned, particularly when they involve the often-overlooked field of disability. New ideas or practices do not necessarily displace older beliefs or traditions; they often coexist comfortably, side-by-side. Recently emerging beliefs are sometimes taken as confirmation of older ones. The two sometimes expressly contradict each other without people being bothered by the contradiction. While working on a project related to improving access to health care for disabled children in Nepal in 2015, a mother of a disabled child explained to me, "I understand that my child is disabled because of a genetic trait and not because of anything my husband or I did. But what did we do in a previous life for us to have these genes?"

Additionally, traditional beliefs about disability are not always tied to a person's level of education. I once interviewed a Western-trained Minister of Health in East Africa who categorically denied that there are traditional health practitioners still operating in his country except, perhaps, in remote areas. By the time we finished talking, however, he admitted that he had taken his own father to a traditional healer just the night before.

It is not that all folk beliefs about disabilities are believed by all members of the community or that folk/traditional practices are the only ones in circulation. However, if we do not pay attention to these circulating folk beliefs, acknowledge their existence, and engage in discussions with community members about them, we miss important avenues of communication. Not all folk beliefs and practices regarding disability need to be or should be changed. Many are helpful or important to the communities in which they exist. But in cases where these beliefs are injurious to people with disabilities—for example, keeping them from using the new village well or overlooking their participation in a new HIV/AIDS campaign—we need to know what these beliefs are and how they affect the health and well-being of people with disabilities. Where needed, we should engage these beliefs and challenge counterproductive assumptions and attitudes.

Where Folklorists Can Become Involved

Increasingly, global health and international development experts call upon scholars in the social sciences and humanities, law, public health, and the arts—as well as more focused fields such as gender studies and ethnic and minority studies—for help and advice. Unfortunately, in my experience, folklorists are rarely included in such discussions. Folklorists working on disability issues—whether locally or globally—should be encouraged to actively engage with advocates, experts, and organizations seeking to improve the lives of people with disabilities. I would like to see "applied folklore" more prominently represented in the cause of social justice and disability rights. This activism should be undertaken from two directions: folklorists could become more proactive in offering their expertise and insights on disability to global health and international development decision makers, practitioners, and advocates. Just as important would be to offer training about folklore to experts and advocates in global health and international development. Integration of some folklore theory, findings, and approaches into basic courses in epidemiology, public health, qualitative research, and development economics would be valuable. The next generation of global health and international development students do not need to become folklorists, but some background in folklore would, I believe, allow them to better understand and appreciate why and how people in the communities in which they work think, act, and sometimes interpret the world around them. Knowledge, awareness, and an appreciation of folk beliefs and practices may furthermore provide

insights, inspiration, and innovative approaches to improving the health and wellbeing of these peoples and populations.

Finally, over the past few decades, there have been rapid advances in the field of disability rights, spurred in part by the global Disability Rights Movement that, in 2006, successfully introduced the UN Convention on the Rights of Persons with Disabilities. Now ratified by 196 of the world's 201 countries, the Convention grants equal rights to all persons with disabilities (UN Department of Economic and Social Affairs 2006). It behooves folklorists to be familiar with the Convention and, where appropriate, to be guided by it in their research and teaching. The rights conferred on people with disabilities through the UN Convention are non-negotiable. Folk beliefs and traditional practices that contravene these human rights must be addressed and changed or modified. In the field of global health and international development, the UN Convention is also strongly reflected in the UN Sustainable Development Goals, which expressly include people with disabilities in all development efforts (UN Department of Economic and Social Affairs 2015). A vital question to consider is how existing folk beliefs or traditional practices related to disability support and/ or interfere with the implementation of the UN Convention and the UN Sustainable Development Goals.

Again, when we talk about people with disabilities, we are talking about 16 percent of the global population, the world's largest minority. Folklorists, with their unique disciplinary skills, insights, and background, are in a position to make important contributions to this ongoing discourse.

Notes

1. This paper is based on my comments during the webinar sponsored by the Fellows of the American Folklore Society entitled "Interrogating the Normal: Folkloristic Engagements with Disability," held on March 25, 2022. I was asked to speak specifically from my perspective on the relevance of folklore to disability issues in the field in which I work: global health and international development.

2. While I'm not disabled myself, I have done extensive disability research over the past 40 years. I have worked on applied research related to people with disabilities in 27 countries, and I regularly serve as an academic consultant to United Nations agencies, international development organizations, and grassroots advocacy groups. To me, research that can provide insight into and possibly improve the lives of persons with disabilities is a social justice issue and a human rights concern.

3. Smithsonian Folklife, *Deaf Folklore at the 1981 Smithsonian Folklife Festival*, YouTube video, September 27, 2019, 2:10 min., https://www.youtube.com/watch?v=1_2OQiQhv3A.

4. Manny Fernandez, Celebrating the Deaf Way, *Washington Post*, July 12, 2002, https://www.washingtonpost.com/archive/local/2002/07/12/celebrating-the-deaf-way/a86aa32d-929c-4252-82f9-5409b5b1bd70/.

5. Donna Williams, Brazil's Festival of Deaf Folklore Was a Rich, Rewarding Experience, *Limping Chicken*, February 2, 2017, https://limpingchicken.com/2017/02/02/donna-williams-brazils-festival-of-deaf-folklore-was-a-rich-rewarding-experience/.

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