

## **Toward a Disability Anthropology of the Middle East and North Arica**

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**Abstract:** Disability anthropology, the study of disability and impairment in different cultural contexts using anthropological methods, is a growing field of inquiry that has recently begun exploring the Middle East and, to some degree, North Africa. One reason for this is the expansion of disability rights movements. As these movements in the Middle East and North Africa (MENA) lead to more legal and social changes, and as anthropologists call for more research outside of North America and Europe, a disability anthropology of the MENA region is increasingly relevant. This article provides a review of disability research in the region, as well as explores ethnographic research in Morocco from my perspective (a white, physically disabled American). I suggest that an anthropological focus on disability in the area would reveal much, not simply about how impairment is conceptualized in this context, but about how people relate to one another, to politics, to medicine and to society at large. Furthermore, I outline the potential for a disability anthropology of the MENA region that denaturalizes disability and understands both local and global dynamics of impairment.

**Keywords:** Disability, Impairment, Disability Anthropology, Middle East and North Africa, MENA Region.

### **Introduction**

On a sunny summer day in Fes, during preliminary ethnographic fieldwork in Morocco in 2015, my spouse and I ventured out onto the busy thoroughfare of Avenue Hassan II Boulevard in the Ville Nouvelle. A jaunt down this popular street may seem unremarkable, however, it felt like a leap into the unknown for my spouse and me, both wheelchair users. This was the first time we had left our hotel without the assistance of a friend or family member because, if we went further than only two blocks, we would encounter curbs too large for us to navigate in our wheelchairs without help.

We had decided to try our luck in the city to see if we could go grocery shopping. Simple as the task may seem, in order to get to the store, we would have to make it through two intersections with curbs at least twelve inches high and no curb cuts (ramps built from the top of a sidewalk to the street for wheeled objects), into a mall with several steps in front and no ramp, and down to the basement floor without an elevator. In other words, we were attempting to move through an environment that would not accommodate our independent navigation. However, we expected that we would be able

to complete our task because, despite the lack of wheelchair accessibility in most of the country, we had encountered many helpful people who would assist us over, through and around barriers.

On this particular day, we pushed up to our first curb at a hectic intersection with continual car and pedestrian traffic. We arrived at the curb and sat there. Within seconds, strangers realized our plight and offered to carry us over curb and help us through the intersection. One person grabbed the front of my wife's chair, another the back, and they lifted her down the curb at which we were stuck, and over the curb at other end of the intersection where we wanted to cross. Onlookers noticed and soon did the same for my wheelchair. Though the helpful people, all men, seemed not to know each other, they quickly coordinated with each other, helped us, and dispersed. Thankfully, they did not need much direction from us because my mastery of the only language we likely shared, Standard Arabic, was limited.

Despite the navigational and linguistic barriers, we faced, my wife and I succeeded in making it to the grocery store and back with the help of strangers. The helping encounters we solicited by merely rolling up to a barrier and waiting for assistance were common throughout the country. As a linguistic anthropologist, I was fascinated by these interactions, because face-to-face interactions are important bases upon which the structure of society is built.<sup>1</sup> While wheelchair accessibility was (and is) not mandated by the government, and while people with disabilities generally face stigmatization and marginalization,<sup>2</sup> there was something intriguing about the intersubjective dimension of care that we were able to so easily receive. This differed from our rather awkward experiences soliciting help from strangers in the United States, where we had the sense that people were hesitant to interact with us because of our implied independence despite visible physical disabilities. Instead, these helping interactions in Morocco suggested another understanding and social relationship to disability than that to which we were accustomed. In this context, care for a person with a disability was a part of daily interactions and was seen as a responsibility that extended through community. These experiences hint at one of the many different cultural understandings of disability that merit further research on disability in the Middle East and North Africa (MENA) region, which often contrast with Western notions of disability.

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1. Erving Goffman, *The Presentation of Self in Everyday Life* (London: Harmondsworth, 1978).

2. Jean-Francois Trani, et al., "Disability and Poverty in Morocco and Tunisia: A Multidimensional Approach," *Journal of Human Development and Capabilities* 16, 4 (2015): 518-48.

Recent anthropological work on disability in the MENA region centering around the themes of family, community and morality,<sup>3</sup> has provided an alternative to the Western perspective of disability rights, which emphasizes independence. So what evidence is there to suggest that the helpful strangers who we encountered were operating from an understanding of disability quite different to ours? And, what fields of inquiry are suited to the task of understanding this? In this paper I review research on disability in the MENA region. While I have some proficiency in Modern Standard Arabic and French, my competency is too limited to access academic papers in these languages. Therefore, this review covers English books and papers, the language in which most research on disability in the region is written. I pay particular attention to disability anthropology, the study of disability and impairment in different cultural contexts using anthropological methods. This growing field of inquiry has recently begun exploring the Middle East and, to some degree, North Africa. I suggest that an anthropological focus on disability in the area would reveal much, not simply about how impairment is conceptualized in this context, but about how people relate to one another, to politics, to medicine and to society at large. The following sections provide a context for disability and review research (and the potential for research) in a disability anthropology of the MENA region. In particular, I suggest that the field could make contributions through its strength in the following areas:

1. Disability anthropology denaturalizes disability. Destabilizing the naturalness of the categories of disability and impairment is a tenet of disability anthropology. Through a focus on disability in the MENA region, scholarly inquiry can problematize the notion of disability as a natural category and destabilize the natural association between disability and stigma.

2. Disability anthropology seeks to understand local and global contexts as they relate to disability. Disability anthropology is well suited to grasp the nuances of local and global discourse on disability. This is an important attribute of the discipline because, while disability discourse is a growing global phenomenon, local cultural, legal, economic, political, and historical contexts influence how and (whether) this disability discourse is adopted and altered. A focus on the MENA region provides alternative perspectives on global disability discourse, which is rooted in Western conceptions of impairment.

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3. See the roundtable section of the *International Journal of Middle East Studies* (2019): 109-34.

### Disability in the MENA Region

In the contemporary setting, words for disability have found their way into Arabic, like the noun, *al-'i'āqa* (disability) and the adjective, *mu'āq* (handicapped). These words are falling out of favor for the less pejorative sounding '*al-'ashkhāṣ dhawī al-iḥtiyājāt al-khāṣṣa*' (people with special needs). This linguistic shift may be indicative of shifting attitudes as the MENA Region joins the global movement toward prioritizing disability rights. The evolving linguistic preference is similar to the push for person-first language in English, the move to use language that emphasizes the person, not the disability (like “person with a disability” and “person with autism” instead of “disabled person” and “autistic person”).<sup>4</sup> However, even if the sense of political correctness regarding disability in the Arab-majority World is coming to resemble the category of disabled in a Western context, I argue that the embodied sense of disability and the social relationships into which disabled people are figured are different.

Research on disability is growing in the MENA region along with the expansion of disability rights movements in the area, where estimates indicate that anywhere between 1 and 16 percent of the population live with impairment.<sup>5</sup> I arrived for preliminary fieldwork in Morocco during the summer of 2015. This was less than a year before the Moroccan Parliament adopted Law 97-13, designed to guarantee rights for disabled citizens. The law, which allows disabled Moroccans to “enjoy full capacity to exercise their civil and political liberties and rights,”<sup>6</sup> formalized the commitment that the country made in 2009, when it ratified the United Nation’s (UN) Convention on the Rights of Persons with Disabilities (CRPD). Indeed, this convention has been ratified by all Morocco’s neighbors in the Maghreb: Tunisia in 2008; Algeria in 2009; Mauritania in 2012; and Libya in 2018, and by most Middle Eastern countries.<sup>7</sup> This is part of the growing discourse on

4. In the United States, person first language is seen by some as more politically correct, while many American disability activists prefer identity first language (disabled person, autistic person, etc.).

5. A report by the World Health Organization and World Bank estimates that 15% of the world’s population have some form of impairment and a majority of those people live outside Europe and North America. Estimates vary based on the way disability is defined and due to the difficulty of quantifying disability, which can be shameful to discuss. See Brigitte Rohwerder, “Disability in North Africa,” UK Department for International Development, 2018. [https://assets.publishing.service.gov.uk/media/5b2378d340f0b634cb3dd823/Disability\\_in\\_North\\_Africa.pdf](https://assets.publishing.service.gov.uk/media/5b2378d340f0b634cb3dd823/Disability_in_North_Africa.pdf); “World Report on Disability,” Malta: World Health Organization, 2011. [https://www.who.int/disabilities/world\\_report/2011/report/en/](https://www.who.int/disabilities/world_report/2011/report/en/).

6. “Framework Law 97-13 (Loi-cadre no. 97-13),” Official Gazette (Bulletin Officiel) (no. 6466), Royaume du Maroc (Kingdom of Morocco), May 19, 2016, 750.

7. “Convention on the Rights of Persons with Disabilities,” United Nations, Division for Social Policy and Development, [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html).

disability rights in the region, as evidenced by initiatives such as the “African Decade of Disabled Persons,”<sup>8</sup> and the “Arab Decade of Disabled Persons.”<sup>9</sup> Additionally, the attention to disability rights is linked to increased attention to human rights and oppression that grew in the MENA region in the wake of the Arab Spring in 2010. For instance, Law 97-13 builds on Morocco’s new constitution, unveiled in 2011 and meant to serve as a symbol of governmental evolution, that prohibited discrimination on the basis of disability (among other social identities).<sup>10</sup>

However, despite the strides that have been made towards disability rights in Morocco and the Arab-majority World broadly, disabled people in the region are often described as facing stigmatization and marginalization<sup>11</sup> and, in some cases, placing a cloud of taboo and shame over a family with a disabled child.<sup>12</sup> A recent study found that people with disabilities in both urban and rural Morocco and Tunisia are far more likely to experience poverty than their non-disabled counterparts. The study took a multi-dimensional approach to poverty and found that disability coincided with a lack of access to social inclusion and money.<sup>13</sup> This is largely because disability may deny people access to income through work, as well as access to traditional social structures. For instance, a disability might not only prohibit someone from working where a place of employment is not mandated to make accommodations, it may also limit someone’s marriageability, which limits prospects of expanding his or her kinship network through which his or her families might build social standing and community. Additionally, much of the literature on disability in the Middle East and North Africa, and the Arab-majority World find that disability, which is more likely to impact women, represents a ‘double burden’ for disabled women, as women already experience a heightened degree of oppression.<sup>14</sup>

8. “African Decade of Disabled Persons (2000-2009),” United Nations enable, [www.un.org/esa/socdev/enable/disafriacdecade.htm](http://www.un.org/esa/socdev/enable/disafriacdecade.htm).

9. “Arab Decade of Disabled Persons (2001-2012),” United Nations enable, [www.un.org/esa/socdev/enable/disarabdecade.htm](http://www.un.org/esa/socdev/enable/disarabdecade.htm).

10. Jefri J. Rucht, trans. “Morocco’s Constitution of 2011,” William S. Hein & Co., Inc, 2011. [https://www.constituteproject.org/constitution/Morocco\\_2011.pdf](https://www.constituteproject.org/constitution/Morocco_2011.pdf).

11. See Chris McIvor, ed, *In Our Own Words: Disability and Integration in Morocco* (UK: Save the Children, 1995), 59-62; James Reinl, “Arab Region ‘Lacks’ Disability Awareness: The UN’s Special Rapporteur on Disability Sheikha Hissa Khalifa Al Thani Wonders If Handicapped People in the Arab World Will Ever Get a Fair Deal,” *The National*, September 3 (2008): <https://www.thenational.ae/world/mena/arab-region-lacks-disability-awareness-1.545451>.

12. Zena Tahhan, “Meet the Woman Challenging Arab Notions of Disability,” *Al Jazeera English*, January 28 (2018): <https://www.aljazeera.com/indepth/features/meet-woman-challenging-arab-notions-disability-180125140800672.html>.

13. Trani, et al., “Disability and Poverty in Morocco and Tunisia,” 518-48.

14. Lina Abu-Habib, *Gender and Disability: Women’s Experiences in the Middle East* (Oxford: Oxfam, 1997); McIvor, *In Our Own Words*, 59-62.

### Research on Disability in the MENA Region

There is a sense that people with disabilities are invisible in the region, and this invisibility is upheld by the absence of adequate research. The research that has been carried out so far falls mainly into three categories – research dealing with: quantitative data; historical data; and qualitative data (see Table 1 for a detailed breakdown of the common themes in each type of research). During preliminary fieldwork, I sensed this invisibility as I was moving through the Moroccan cities, where I rarely saw disabled people out in public. This is likely not only a result of social stigma, but also the physical barriers that make it difficult for people with mobility disabilities to navigate the region. For instance, lack of infrastructure for the maintenance of public thoroughfares, like sidewalks, makes it extremely difficult for people on wheels, even strollers, to navigate (I will explore this point further in the discussion section).

Of the research that has been conducted on disability in the MENA region, research looking at quantitative data is the largest field of inquiry. Most of this research, originating from medicine, public health, and economics, examines the rates of certain impairments, illnesses, and chronic conditions, and asks what measures should be taken to lower these rates.<sup>15</sup> Many of these studies provide accounts of the complexity of disability in the region, and are useful for gaining perspective on the dynamics of impairment. However, some take a limited view of disability as a consequence of the current political, cultural, and economic landscape of the Arab World. For instance, Gharaibeh claims disability rates in the Arab World are due to high incidences of consanguineous marriage, large families, armed conflict, terrorism, communicable disease, and lack of family planning resources, among other contributing factors.<sup>16</sup> However, such an understanding of disability in this context fails to account for the many impairments and ‘debilities’<sup>17</sup> that are the consequences of Western-driven industrialization, colonialism, and imperialism.<sup>18</sup>

15. See Sharon Bloom, et al., “Congenital Rubella Syndrome Burden in Morocco: A Rapid Retrospective Assessment,” *The Lancet* 365, 9454 (2005): 135-41; Abdesslam Boutayeb and Abdelaziz Chetouani, “Dynamics of a Disabled Population in Morocco,” *BioMedical Engineering OnLine* 2, 2 (2003): <https://doi.org/10.1186/1475-925X-2-2>; Wiam Boutayeb, et al., “Estimation of Direct and Indirect Cost of Diabetes in Morocco,” *Journal of Biomedical Science and Engineering* 6, 7 (2013): 732-38. Hanan Rkain, et al., “Socioeconomic Impact of Ankylosing Spondylitis in Morocco,” *Clinical Rheumatology* 26, 12 (2007): 2081-88; Trani et al., “Disability and Poverty in Morocco and Tunisia,” 518-48; Kathryn M. Yount and Emily M. Agree, “Differences in Disability among Older Women and Men in Egypt and Tunisia,” *Demography* 42, 1 (2005): 169-87.

16. Numan Gharaibeh, “Disability in Arab Societies,” in *Disabilities: Insights from Across Fields and Around the World*, eds. Martha E. Banks and Mariah S. Gover (Westport: Praeger Publishers, 2009), 63-80.

17. Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham: Duke University Press, 2017).

18. Shaun Grech, “Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate,” *Social Identities* 21, 1 (2015): 6-21; Helen Meekosha, “Decolonising Disability: Thinking and Acting Globally,” *Disability & Society* 26, 6 (2011): 667-82; Puar, *The Right to Maim*.

In order to understand the full picture of disability in the Middle East and North Africa, it is necessary to interpret quantitative data along with historical and qualitative data, which can nuance the picture of disability through historical context and lived experience. While some of these fields of analysis are overlapping, for instance data can be considered both historical and qualitative, these distinctions have been made for heuristic purposes. Though this boundary is somewhat artificial, and the fields are overlapping, it is useful to gain perspective on the full picture of current research. Additionally, while some fields produce both historical and qualitative data, such as religious studies, the current research has emphasized historical analysis only. The remainder of this article explores the current disability anthropology that draws on both historical data and qualitative data in the MENA region. It also points out areas of potential future research.

	<b>Quantitative Data</b>	<b>Historical Data</b>	<b>Qualitative Data</b>
<b>Academic Fields</b>	<ul style="list-style-type: none"> <li>- Medicine</li> <li>- Public health</li> <li>- Economics</li> </ul>	<ul style="list-style-type: none"> <li>- History</li> <li>- Religious studies</li> <li>- Disability studies</li> <li>- Comparative literature</li> <li>- Anthropology</li> </ul>	<ul style="list-style-type: none"> <li>- Social sciences, especially anthropology</li> <li>- Disability studies Middle Eastern studies</li> </ul>
<b>Theoretical Focus</b>	<ul style="list-style-type: none"> <li>- Rates of risk for diseases and impairments</li> <li>- Population control</li> <li>- Cost analyses of impairments and illnesses</li> </ul>	<ul style="list-style-type: none"> <li>- Specific impairments and illnesses in particular historical contexts</li> </ul>	<ul style="list-style-type: none"> <li>- Disability discourses</li> <li>- Lived experiences of disabled people</li> <li>- Legal, political, and social structures concerning disability</li> </ul>
<b>Key Takeaways</b>	<p>These studies typically point to factors contributing to impairment and illness. Some call for legal, economic, medical, and social resources to enhance the quality of life for disabled people; others call for reducing rates of disability to reduce economic burden.</p>	<p>Through examining disability experience in pre-colonial, colonial, and post-colonial contexts, it emerges that disability and impairment are not universal categories, nor are they categories with a long history.</p>	<p>Legal structures and disability discourses may stigmatize and constrain people with impairments. At the same time, disabled people have agency to resist oppressive structures and creatively use disability discourses and structures to their benefit.</p>

**Table 1:** Research on Disability in the Middle East and North Africa

### **Disability Anthropology Denaturalizes Disability**

Despite the growing global discourse on disability, aided by the UN CRPD,<sup>19</sup> introduced in 2006, and the World Health Organization's first report on disability,<sup>20</sup> published in 2011, disability is not a universal category. This came to light during preliminary fieldwork before we even arrived in Morocco. In the bustling Charles de Gaulle Airport in Paris my wife and I approached the ticket counter to gate-check our wheelchairs for our flight to Casablanca. The Moroccan flight attendants refused to issue us the little pink tags that would signal to the airport staff in Casablanca that they should bring our wheelchairs to the gate of the plane upon our arrival, rather than send them with the rest of the luggage to the baggage claim. The flight attendant assured us: "Someone will bring airport wheelchairs for you and push you to bag claim, where you can pick up your wheelchairs." But we resented the fact that we would have to be pushed by a stranger, when we were capable of pushing ourselves. I responded to the flight attendant that we *needed* our chairs at the gate. Taking them away from us would be akin to taking away our legs.

Our justification for demanding our wheelchairs at the gate was that our wheelchairs are tools that allow us to function. With access to assistive technology, our disabilities are diminished. Relying on a person to push us and be in control of our navigation at the airport would strip us of the fundamental right to control where and how our bodies moved in space. Furthermore, it felt like a threat to our notion of disability as something that we had the right to manage independently. This stance, that disability is a consequence of the environment and that it is an individual right to determine the means of accommodation, is a platform upon which the Disability Rights Movement rests. We had been falsely working under the assumption that such an understanding of disability would be the operational logic in Morocco, as it was in European and American settings. However, it was more logical for the flight attendants to figure us into a social setting in which help would be provided for us to deal with mobility barriers. This was how disability would be minimized in their perspective. After the fieldwork, I had the sense that people with disabilities conceptualized bodily autonomy differently than we had before arrival. As I will discuss later, the physical environment and cultural context results in a greater sense of interdependence than that to which we were accustomed. Research that sheds light on different conceptualizations of impairment helps unpack the assumptions about the natural-ness, or the underlying logic, of disability as a category.

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19. United Nations, "Convention on the Rights of Persons with Disabilities."

20. World Health Organization, "World Report on Disability."

Destabilizing the naturalness of the categories of disability and impairment is a tenet of disability studies and the disability anthropology that emerged from it. One main theoretical contribution of disability studies has been the social model,<sup>21</sup> introduced in the 1980s and expanded over the following decades, which questions disability as a medical category and, instead, claims that disability is a consequence of exclusionary environments. For instance, a wheelchair user is not inherently impaired, only disabled if they find themselves in an environment with stairs and no ramp. While this stance has been critiqued and nuanced over the past three decades,<sup>22</sup> the tendency to question the assumption that disability is a natural biological category has been largely influential to disability anthropology and has implications for the MENA region.

Much of the historical research on disability in the area supports this perspective that disability is not a natural category. Historians working in Arab-majority contexts have demonstrated that disability did not exist as a unified category until recently. In early texts of Islamic jurisprudence, including the Qur'an, the hadith, Islamic scholarship, and fatwas, dated from the early Islamic period to contemporary times, the category of disability, as we know it today, did not exist as a monolithic group.<sup>23</sup> Rispler-Chaim argues that the closest corollary in the Qur'an is Arabic modifier 'marīḍ' (masc.) or 'marīḍa' (fem.) meaning ill,<sup>24</sup> while Ghaley argues that people with disabilities fell under the larger umbrellas of 'ahl al-balā' meaning people with afflictions, or 'aṣḥāb al-'adhār' translated as people with excuses (particularly excuses from religious obligations).<sup>25</sup> Beyond simply the semantic category of disability, evidence suggests that, prior to European and American colonization and imperial projects in the Middle East, "Ottoman, Arab, and Muslim-majority society *tended* to include rather than exclude, victimize, or stigmatize impaired and non-normative bodies."<sup>26</sup>

21. Michael Oliver, *Social Work with Disabled People* (Basingstoke: Macmillan, 1983).

22. See Oliver, Michael, "The Social Model of Disability: Thirty Years On," *Disability & Society* 28, 7 (2013): 1024-26; Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2006), 195-203.

23. Mohammed Ghaly, *Islam and Disability: Perspectives in Theology and Jurisprudence* (London: Routledge, 2009); Matthew L. Long, "Leprosy in Early Islam," in *Disability in Judaism, Christianity, and Islam: Sacred Texts, Historical Traditions, and Social Analysis*, eds. Darla Y. Schumm and Michael Stoltzfus (New York: Palgrave, 2011), 43-61; Vardit Rispler-Chaim, *Disability in Islamic Law*, (Dordrecht: Springer, 2007).

24. Rispler-Chaim, *Disability in Islamic Law*.

25. Ghaly, *Islam and Disability*.

26. Sara Scalenghe, "Disability Studies in the Middle East and North Africa: A Field Emerges," *International Journal of Middle East Studies* 51, 1 (2019), 110; see also Sara Scalenghe, *Disability in the Ottoman Arab World, 1500-1800* (Cambridge: Cambridge University Press, 2014).

Another important tenet of disability anthropology is the resistance to the association between cure and disability.<sup>27</sup> Shuttleworth and Kasznitz point out that, for many disabled people, life involves much more than simply cure.<sup>28</sup> This is because disability need not always be framed as a negative imperfection in a body. Some accounts of disability in the MENA region support this perspective. For instance, Haldane and Crawford found that, when they traveled with their daughter, diagnosed with Autism Spectrum Disorder, from the United States to rural Morocco, their daughter, who had been characterized in the American medical system as ‘lacking’ typical social characteristics, fit seamlessly into the social world of the children in the village where they conducted fieldwork.<sup>29</sup> Additionally, Hart, who has conducted ethnographic research with parents of autistic children in both the United States and Morocco, found that Moroccan parents, like those in the U.S., advocated for a neurodiversity model of autism.<sup>30</sup> According to this model, autism is figured as a different, and desirable, kind of personhood, rather than as a pathological condition. In these contexts, disability is not framed as a condition in need of cure, rather, it is simply an aspect of a person’s being.

While this research points to alternative conceptions of disability in the region, scholars have also pointed out the negative impact of stigma associated with disability in the MENA region. For instance, in a study of veterans in Turkey who became disabled fighting the Partiya Karkerên Kurdistanê (PKK; Kurdistan Workers’ Party), Açıksöz found that, (all male) veterans faced stigma, socioeconomic marginalization and “emasculat[i]on anxieties.”<sup>31</sup> However, in line with the denaturalization of disability, Açıksöz also identified the tendency for disabled people to figure themselves into social systems through which they had agency. He noted that the disabled veterans were also celebrated as Turkish national heroes. Counter to research that finds that disabled men suffer from stereotypes that portray them as passive,<sup>32</sup> Açıksöz points to the (potentially violent) agency of these disabled men in their particular national and political context. Aside from demonstrating a

27. Russell P. Shuttleworth and Devva Kasznitz, “Stigma, Community, Ethnography: Joan Ablon’s Contribution to the Anthropology of Impairment-disability,” *Medical Anthropology Quarterly* 18, 2 (2004), 142.

28. Shuttleworth and Kasznitz, “Stigma, Community, Ethnography.”

29. Hillary Haldane and David Crawford, “What Lula Lacks: Grappling with the Discourse of Autism at Home and in the Field,” *Anthropology Today* 26, 3 (2010): 24-26.

30. Brendan Hart, “Autism Parents & Neurodiversity: Radical Translation, Joint Embodiment and the Prosthetic Environment,” *BioSocieties* 9, 3 (2014): 284-303.

31. Açıksöz, Salih Can, “Sacrificial Limbs of Sovereignty: Disabled Veterans, Masculinity, and Nationalist Politics in Turkey: Disabled Veterans, Masculinity, and Nationalist Politics in Turkey,” *Medical Anthropology Quarterly* 26, 1 (2012): 5.

32. Shuttleworth, et al., “The Dilemma of Disabled Masculinity,” *Men and Masculinities* 15, 2 (2012): 174-94.

unique social context of disability, this analysis expands disability and gender research that has centered around passivity. Further research in the MENA region is called for to similarly expand the field.

In another sense, using disability can be an interesting (and destabilizing) theoretical lens in contexts where it is not traditionally used. This is particularly true for research in the MENA region, where there is limited discourse on disability. In their research on infertility in Egypt and India, Inhorn and Bharadwaj write that, in the Middle East, infertility has not been discussed as a rights issue, “despite its profoundly disabling social consequences.”<sup>33</sup> This lack of discourse is especially hard in a context like the Middle East and North Africa, where “infertility is an inherently stigmatizing condition, particularly for women, who bear the physical evidence of the failure to conceive;”<sup>34</sup> where “men with infertile wives are expected to divorce them;”<sup>35</sup> and, generally, where infertility is associated with stigma and presents a threat “to both personhood and marriage.”<sup>36</sup> Without a discourse about these hardships of fertility, which fall within the definition of disability outlined by the World Health Organization,<sup>37</sup> the cycle of stigma and marginalization continue un-disrupted.

Recently, scholars have pointed to the tendency in disability studies to focus on the United States and Europe<sup>38</sup> and to ignore the impact of colonialism on disability in post-colonial contexts, including the settler colonial context of the U.S.<sup>39</sup> Therefore, a disability anthropology of the MENA region could be an important intervention into this absence of research. In an interesting historical analysis of the transformation of assistance to the blind in Algeria from the early 20<sup>th</sup> century through the Declaration of Independence (1962), Brégain<sup>40</sup> demonstrates the potential for this work in North Africa. He explains that, while colonialism introduced innovative disability practices from France, like the use of Braille, schools for the blind, and eye clinics, it also disrupted indigenous means of care. However blind indigenous

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33. Marcia C. Inhorn and Aditya Bharadwaj, “Reproductively Disabled Lives: Infertility, Stigma, and Suffering in Egypt and India,” in *Disability in Local and Global Worlds*, eds. Benedicte Ingstad and Susan Reynolds Whyte and (Berkeley: University of California Press, 2007), 79.

34. *Ibid.*, 85.

35. Inhorn and Bharadwaj, “Reproductively Disabled Lives,” 89.

36. *Ibid.*, 92.

37. World Health Organization, “World Report on Disability.”

38. Shaun Grech and Karen Soldatic, “Introducing Disability and the Global South (DGS): We Are Critical, We Are Open Access!,” *Disability and the Global South* 1, 1 (2014): 1-4; Meekosha, “Decolonising Disability;” Puar, *The Right to Maim*.

39. Grech, “Decolonising Eurocentric Disability Studies.”

40. Brégain, Gildas, “Colonialism and Disability: The Situation of Blind People in Colonised Algeria,” *Alter; European Journal of Disability Research* 10, 2 (2016): 148-67.

Algerians and even blind French people living in Algeria were, in some cases, granted less access to social services than blind people in metropolitan France. Thus, the introduction of services for the blind in colonial Algeria also introduced a system of discrimination for people with disabilities. Despite the discrimination, Brégain points to the agency of blind people in Algeria, who organized politically and demanded increased social services, such as higher pensions to match the standard pension in France. Such a nuanced account of disability and colonialism in Algeria hints at the potential for a disability anthropology of the MENA region to both expand disability studies and enrich colonial and post-colonial studies.

The examples discussed in this section demonstrate theoretical approaches to disability that denaturalize the category. This research provides context to quantitative research and counters the naturalness of disability as an environmental consequence of the MENA region. In addition to the tendency to re-theorize disability by close examination of disabled peoples lived experiences in the region, disability anthropology can also attend to the local and global context, which is explored in the next section.

### **Disability Anthropology Attends to the Local and Global**

As fields of scholarly inquiry, social and medical anthropology (influential in the genesis of disability anthropology), typically attend to overarching patterns of behavior through in-depth research in local contexts. Disability anthropology, then, is a field well suited to grasp the nuances of local and global discourse on disability. This is an important attribute of the discipline because, while disability discourse is a growing global phenomenon, local cultural, legal, economic, political, and historical contexts influence how and (whether) this disability discourse is adopted and altered. Sometimes, global discourses are forced inorganically into local contexts with different disability discourses to no avail.

In a chapter of an edited volume that was groundbreaking for disability anthropology,<sup>41</sup> Ingstad outlines the failure that occurred when a Norwegian approach to rehabilitation was applied in Botswana, essentially transferring Northern European discourses on disability to Botswana.<sup>42</sup> Ingstad explains that this is a common approach to rehabilitation, in which an organization, typically an NGO, sets out to create a badly needed rehabilitation program

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41. Benedicte Ingstad and Susan Reynolds Whyte, eds., *Disability and Culture* (Berkeley: University of California Press, 1995).

42. Benedicte Ingstad, "Public Discourse on Rehabilitation: From Norway to Botswana," in *Disability and Culture*, eds. Benedicte Ingstad and Susan Reynolds Whyte (Berkeley: University of California Press, 1995), 174-95.

in a developing country. In the process, Northern (read North American or European) perspectives on rehab drive the creation of this program. It is common for issues to arise when the developing country has different priorities or social systems than those underlying the Northern approach to rehabilitation. Ingstad discusses the example of a Norwegian NGO, driven by over a century of discourse and advocacy for disability, that attempted to establish a community rehabilitation program in Botswana, where only recently had there been any public discussion about disability and rehabilitation. Instead, the cultural norms in Botswana tended to figure care for disabled people as the responsibility of the family. The program failed because the notion of rehabilitation was new and did not fit within the indigenous norms and value systems. When the program that Ingstad describes failed, it was Botswana that was blamed for the failure.

This case is similar to McIvor's retrospective article about Save the Children in Morocco, an interventional program created by people in the United Kingdom to provide services to disabled, ill, and homeless Moroccans beginning in the 1960s.<sup>43</sup> One major intervention was the creation of an institution supporting physically disabled children in Khemmiset. This program in which many took pride, and was "shown off to visiting royalty [and] local and international dignitaries at every opportunity,"<sup>44</sup> encountered major issues associated with introducing Northern ideals about disability rights and care into the Moroccan context. For instance, the program was not sustainable because the Northern model of care led to spending for staff and infrastructure that could not be carried on by the local community. Furthermore, the architects of the program "made little attempt to involve anyone but the expatriate professionals who thought they knew best about the interests of the constituency they were supposed to be helping."<sup>45</sup> This, understandably, led to resentment, but perhaps more importantly, the program missed out on providing opportunities to the disabled people it served by not seeking their input and advice.

As McIvor points out, this is not an issue unique to Save the Children.<sup>46</sup> There are likely many other organizations in the MENA area that are operating under assumptions about rehabilitation from foreign contexts. A disability anthropology of the MENA region could, thus, serve the important process of not simply describing the failures of Northern-based rehabilitation programs

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43. McIvor, *In Our Own Words*, 59-62.

44. *Ibid.*, 59.

45. *Ibid.*, 60.

46. *Ibid.*, 62

in the area, but of leading to more organic solutions for rehabilitation. In turn, this would have direct, real impact on people with disabilities in the area who are in need of services like rehabilitation.

Anthropologists have also pointed to novel ways global discourses on disability are taken up in local contexts. Sargent's research on cognitive disability in Amman reveals that, while Ammanis have adopted global discourses, such as the social model of disability that is an important piece of many disability rights movements, they interpret and utilize the social model based on the local beliefs and understandings, or, what Sargent refers to as "contingent assemblages of materials, qualities, and relations that produce the body and the social as seemingly stable categories."<sup>47</sup> For instance, Sargent explains, though typical disability rights discourses rely on a Western, liberal subject, families with cognitively disabled children deploy this discourse in a way that distributes the child's disability across the kin network. This "weave[s] together sedimented practices of kinship, religion, law, and economy with new mediating forces of transnational NGOs, social media platforms, and biomedical or therapeutic regimes."<sup>48</sup> Hartblay, explain how global discourses on accessible design are taken up in a local context in Russia. In the process she outlines, citizens critique the state's poor attempts at accessibility (or lack thereof) as moral failings of the state.<sup>49</sup> In this sense, global politics become entwined with local social relationships, and the morality that underlies them.

The attention to nuances of local and global discourses is revealing for the MENA region, where the Arab Spring harnessed new technologies, such as social media, to spread paradigms that were a mixture of local and liberal humanist ideologies. These newly accessible paradigms translated terms used in the U.S. or E.U. networks into languages used in the MENA region. One example of how this happens with disability discourses is explained by Hart, who describes the way parents of children with Autism Spectrum Disorder in Morocco learn new frameworks for cognitive disability, particularly, neurodiversity, through online research and YouTube videos, despite the fact that these discourses are popular mostly among autistic self-advocates in the United States and are not common in Morocco.<sup>50</sup>

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47. Christine Sargent, "Situating Disability in the Anthropology of the Middle East," *International Journal of Middle East Studies* 51, 1 (February 2019): 131.

48. *Ibid.*, 131.

49. Cassandra Hartblay, "Good Ramps, Bad Ramps: Centralized Design Standards and Disability Access in Urban Russian Infrastructure," *American Ethnologist* 44, 1 (2017): 9-22.

50. Hart, "Autism Parents & Neurodiversity."

While disability anthropology of the MENA region is still limited, research that attends to local and global nuances has potential to re-theorize the concept of stigma – a concept that has characterized the work on disability in the United States and Europe. In her fascinating ethnography with deaf people in India, Friedner<sup>51</sup> examines the sociality that emerges when deaf Indians come into contact with each other through overlapping social circles and work initiatives that hire deaf people. Despite the marginalization that deaf people in India face, the community that Friedner describes also finds a sense of value through ‘deaf sociality.’ Additionally, through mandates that the public sector hire a certain percentage of disabled employees, a value associated with disability emerges. This value contrasts with the stigma of disability. Through in-depth analysis of the local and global discourses on disability, there is likely theoretical perspective to be gained from indigenous Middle Eastern and North African notions of disability, value, and stigma, which provide alternatives to the Western conceptions that have characterized the research on disability thus far.

### Discussion

This article provides a review of disability research in the MENA region, as well as explores ethnographic research in Morocco from my perspective (a white, physically disabled American). I suggest that an anthropological focus on disability in the area would reveal much, not simply about how impairment is conceptualized culturally, but about how people relate to one another, to politics, and to society at large. I also suggest that, as a disability anthropology of the MENA region grows, the theoretical focus on denaturalizing disability and incorporating both local and global contexts on disability will strengthen understandings of the social structures of impairment. It is prudent that this field grow from diverse perspectives. As it stands, most of the research, including this paper, has been produced by white scholars based in the U.S. or E.U. This analysis suggests this positionality imposes specific, often limiting, conceptualizations of disability into research. The field will grow substantially as scholars shed light on these questions and “decolonize disability.”<sup>52</sup>

The research that has been conducted on disability in the MENA region falls into three main categories, research dealing with quantitative data, historical data, and qualitative data. Disability anthropology contributes important dimensions to the quantitative research on disability through its focus on historical context and the lived experience of people with impairments. In particular, it destabilizes some of the stereotypes associated

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51. Michele Ilana Friedner, *Valuing Deaf Worlds in Urban India* (Rutgers University Press, 2015).

52. Grech, “Decolonising Eurocentric Disability Studies;” Meekosha, “Decolonising Disability.”

with disability. Furthermore, it problematizes the category of disability as a sedimented reality. Additionally, a disability anthropology of the MENA region is important because the field seeks to understand the local and global dynamics of impairment. While disability discourse is a growing global phenomenon, local cultural, legal, economic, political, and historical contexts influence how and (whether) this disability discourse is adopted and altered. A focus on the MENA region provides alternative perspectives on global disability discourse, which is rooted in Western liberalism and individualistic values.

Philosopher Martha Nussbaum astutely points out that a society that demands only access for people with disabilities is a society that assumes individuals are inherently self-sufficient.<sup>53</sup> This logic, largely operational in the American and European context, ignores the network of people required to care for disabled people. During preliminary fieldwork in Morocco, this was a hard realization for me because I value my ability to be independent – a value that is circulated in my local context of the United States. Ultimately, I decided to abandon the fieldwork because it was difficult to get around using a wheelchair. One of the greatest difficulties was that I needed to shift into a different operational logic around disability, in which I could not be independent, but instead, would need to depend on a deep network of care for which I had little infrastructure in the country. The question of what I could have learned if I had dedicated more research to disability in Morocco lingers, but many of the researchers outlined in this article have provided a glimpse at what a disability anthropology of the MENA region could entail. As disability studies and disability anthropology expand beyond the Western liberalism from which they originated, and as paradigms of impairment continue to grow, global ideologies of independence and local approaches to care will continue to have rich dialogue; even for those with a lived experience of disability more understanding is needed.

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53. Martha C Nussbaum, "Disabled Lives: Who Cares?," *New York Review of Books* 48 (2001): 34-37.

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### نحو أنثروبولوجيا الإعاقة في منطقة الشرق الأوسط وشمال إفريقيا

**ملخص:** تهتم أنثروبولوجيا الإعاقة بدراسة قضايا الإعاقة والضعف أو القصور في سياقات ثقافية مختلفة باستخدام الأساليب الأنثروبولوجية، وتشكل مجال بحثيا ما فتئت أهميته تتزايد مؤخرًا لاستكشاف أوضاعها في الشرق الأوسط، وإلى حد ما، في بلدان شمال إفريقيا. ويعتبر التطور الحاصل على مستوى الحركات المؤيدة لحقوق المعاقين أحد الأسباب وراء ذلك. وبحكم إسهام هذه الحركات في الشرق الأوسط وبلدان شمال إفريقيا في حدوث مزيد من التحولات القانونية والاجتماعية، وكما يدعو علماء الأنثروبولوجيا إلى مزيد من البحث خارج أمريكا الشمالية وأوروبا، فإن أنثروبولوجيا الإعاقة بمنطقة الشرق الأوسط وشمال إفريقيا تزداد أهمية. ويقدم هذا المقال مراجعة لأبحاث الإعاقة في المنطقة، كما يستكشف البحث الإثنوغرافي في المغرب من وجهة نظر صاحبة المقال (كمواطنة أمريكية بيضاء اللون، ومعاق جسديًا). ويبدو لي أن التركيز الأنثروبولوجي على الإعاقة في المنطقة سيمكن من الكشف عن أشياء كثيرة، ليس حول كيفية تصور الإعاقة في هذا السياق فحسب، بل أيضا بخصوص كيفية تفاعل الناس وارتباطهم ببعضهم البعض، في علاقة مع السياسة والطب والمجتمع ككل. وعلاوة على ذلك، فقد حددت إمكانات أنثروبولوجيا الإعاقة في منطقة الشرق الأوسط وشمال إفريقيا التي تشوه الإعاقة وتفهم الديناميكيات المحلية والعالمية للإعاقة.

**الكلمات الأساسية:** الإعاقة، القصور أو العاهة، أنثروبولوجيا الإعاقة، الشرق الأوسط وشمال إفريقيا، منطقة مينا.

### Vers une anthropologie du handicap au Moyen-Orient et en Afrique du Nord

**Résumé:** L'anthropologie du handicap, l'étude du handicap et de la déficience dans différents contextes culturels à l'aide de méthodes anthropologiques, est un champ d'investigation en pleine croissance qui a récemment commencé à explorer le Moyen-Orient et, dans une certaine mesure, l'Afrique du Nord. L'une des raisons en est l'expansion des mouvements de défense des droits des personnes handicapées. Alors que ces mouvements au Moyen-Orient et en Afrique du Nord (MENA) conduisent à davantage de changements juridiques et sociaux et que les anthropologues appellent à plus de recherche en dehors de l'Amérique du Nord et de l'Europe, une anthropologie du handicap de la région MENA est de plus en plus pertinente. Cet article présente une revue de la recherche sur le handicap dans la région et explore la recherche ethnographique au Maroc de mon point de vue (un Américain blanc physiquement handicapé). Je suggère qu'une focalisation anthropologique sur le handicap dans la région en révélerait beaucoup, non seulement sur la façon dont la déficience est conceptualisée dans ce contexte, mais sur la façon dont les gens se rapportent les uns aux autres, à la politique, à la médecine et à la société en général. En outre, je décris le potentiel d'une anthropologie du handicap de la région MENA qui dénaturalise le handicap et comprend la dynamique locale et globale de la déficience.

**Mots-clés:** Handicap, déficience, anthropologie du handicap, Moyen-Orient et Afrique du Nord, région MENA.