

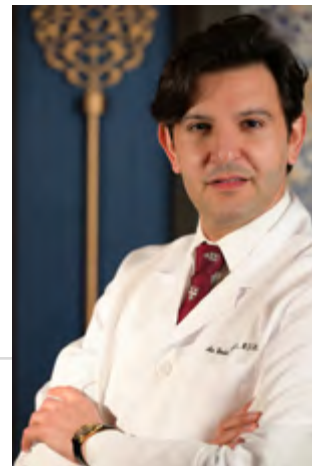
NOTHING ABOUT US WITHOUT US: A FULBRIGHT RESEARCH SCHOLAR PAVES THE ROAD TO EMBRACE THE DISABILITY WITH DIGNITY

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ABSTRACT

As a Fulbright research scholar at the School of Medicine, AGU (Bahrain), I became genuinely interested in how “*Nothing About Us Without Us*” concept is perceived in Bahrain, one of the most inclusive countries for people with disabilities. I started a series of qualitative studies with the people who have innovative perspectives to initiate a roadmap, which would pave the road for making positive and transformative changes for those individuals who have some form of disability.

Keywords: disability • attitudes • perception • inclusivity • Bahrain



According to the Centers for Disease Control and Prevention (CDC), a disability is any condition of the body or mind that makes it more difficult for a person with that condition to perform certain activities and interact with the world around them. An estimated 1.3 billion (16%) of the world’s population currently suffers from a significant disability, and almost everyone experiences a temporary or permanent disability at some point in life. In other words, disability is part of being human.

The political, economic, and cultural context to better understand and support the public awareness of disability rights has been widely studied in Europe and the United States. Less is known about disability in other parts of the world, such as the Middle East and the Gulf Cooperation Council (GCC). The evidence from the GCC shows that disability is viewed from different perspectives, taking into account historical time, epistemological outlines, and theoretical models, where the accuracy of disability statistics depends on how each country disaggregates disability. As reported by the Arab Digital Inclusion Platform (2022), high disability ratings are observed in Bahrain, Qatar, and the United Arab Emirates. There are three main causes of disability in these countries: congenital, disease-related, and accidental. In addition, birth-related causes have been reported in Saudi Arabia and Bahrain.

As a Fulbright research scholar at the Arabian Gulf University, School of Medicine, I became particularly interested in Bahrain, as it has become one of the first countries in the region to adopt regulations protecting the rights of people with disabilities. With this vision I was able to dive deeper into the concept of “*Nothing About Us Without Us*” which I became familiar with while at Yale University in New Haven, Connecticut.

The Bahraini government, the private, and the public sectors have developed various programs and initiatives to ensure that people with disabilities are included in all aspects of life. These include educational programs, employment opportunities, and access to health services.

Early in January 2023, on the occasion of the International Day of Persons with Disabilities, the World Health Organization Country Office and UN-Habitat in Bahrain jointly hosted the opening ceremony of an accessible public park, supporting inclusivity in all policies, planning and participation, thereby ensuring that “no one is left behind.” Another distinctive initiative aimed at inclusivity and equal opportunities for all is the Muhfiz.in.bh community in Bahrain. The community was created to collaborate with various sectors of the government and society of Bahrain in order to support the well-being of people with disabilities and find better opportunities for them to express and present their potential and talent.

This approach to care harmonizes with “*Nothing About Us Without Us*”, a philosophy that originated in the disability rights movement, allowing the inclusion and participation of people with disabilities in the development of their access to public spaces, transport, and the urban landscape or their inclusion in the social and cultural life of the country. People with disabilities have formed a wide range of organizations to meet political and personal needs, and the slogan “*Nothing About Us Without Us*” has become the core of these organizations, including social clubs, fundraising initiatives, national and regional alliances. The main goal was to understand anything about people with disabilities or the disability rights movement by recognizing their individual and collective needs.

With the brief evidence set out in this section, it would be fair to conclude that Bahrain is one of the most inclusive countries in the world for people with disabilities. However, what is less well known about Bahrain is whether and how the concept of “*Nothing About Us Without Us*” is being adapted for people with mental and cognitive impairments, as these impairments collectively constitute the largest “category” of disability in the country; as of 2020 n= 7468 cases. In my next series of studies on disability in Bahrain, I aim to sit down with the people who initiate and make positive changes in the lives of people who have some form of disability, and how they “include” people with mental and cognitive impairments, thereby diving deeper into the concept of “*Nothing About Us Without Us*.”

My first discussion was with Mr. Riyadh Al-Marzouq, Chair of the Bahraini Catalysts Disabilities Association. To maintain the transparency of the study for the purposes of reliability and validity, the discussion is presented in its entirety.

DISCUSSION

What is the strategic goal of the disability rights movement in the Bahraini Catalysts Disabilities Association (BCDA)? And what are the current challenges?

The Bahrain Disability Association aims to improve the accessibility and equitable opportunity to education, healthcare, and career services for disabled individuals. The laws created to preserve the rights of disabled individuals are already in place. However, the enforcement and moderation of such laws leave a lot to be desired. It is our goal to form a platform for disabled individuals in Bahrain, so we might help to ensure that their needs are met and their growth is facilitated.

The challenges we face here at the BCDA are largely financial and cultural. The majority of the BCDA's expenditure goes towards supporting disabled individuals who belong to disenfranchised or working-class families. The medical cost of catering to a physically disabled individual usually ranges from 100 to 1000 BHD per month. The BCDA reaches out to financially support those in need with the funds provided through government institutions and humanitarian charities, but regrettably, we lack the funding needed to support all our cases.

There is also a lack of awareness of the challenges disabled individuals face outside of the small circles that include them. In Bahrain, educational institutes are legally required to adapt to cater to their disabled students from the primary to high school levels. However, there is little support at the pre-school level and in higher education. The former results in disabled children being unprepared for the challenges they must face in their formative years, while the latter diminishes their chances of following a career path, about which they might feel passionate. Universities in Bahrain often deny prospective disabled students access to certain colleges and specializations, despite them proving exceptional capability, which is something they should not feel the need to prove in the first place.

There is still a lack of awareness of the problems faced by people with disabilities outside the circles to which they belong.

The laws that exist to ensure equitable opportunity for disabled individuals need to be revised to include those endeavors that disabled individuals find needlessly challenging. Moreover, the legal enforcement of such laws needs to be approached with greater vigilance to avoid tokenization.

How is the concept of “Nothing About Us Without Us” incorporated in the mission of the Bahraini Catalyst Disabilities Association?

The concept of “*Nothing About Us Without Us*” perfectly aligns with our mission statement. It is imperative to our goals that we listen intently to the needs and struggles of the people who need our aid. Having open lines of communication with disabled individuals and their families is a fundamental part of our job as mediators on their behalf, to interested parties, and government institutions.

How does culture influence public attitudes towards disability in Bahrain?

One of the primary motives for founding this association was to fight our culture’s preconceived notions regarding the capabilities, rights, and struggles of disabled individuals. Research shows a troubling degree of ignorance towards these issues among communities that do not have close ties to disabled individuals. That very ignorance further propagates the struggles disabled individuals face, and we intend to help rectify that by communicating our community’s perspectives through literature, seminars, etc.

Much work has been done for people with physical disabilities, but less is known about people with mental disorders. Please discuss initiatives aimed at promoting inclusivity for this particular group. Do they or their relatives participate in the development of such initiatives?

Our association also dedicates itself to aiding people suffering from mental disability of varying degrees of severity. This is often achieved through arranging counseling with professional psychiatrists, and through communicating their struggles to the relevant institutions with the highest degrees of discretion possible. However, we still lack the funding and experienced professionals among our ranks to provide reliable aid to a significant number of individuals suffering from mental disabilities. Regrettably, we are unable to help individuals suffering from severe cases of autism or other mental disorders that deem them a threat to themselves or those around them. Whenever we are approached by individuals who need that kind of aid, we do our best to connect them to other institutions whose skill sets fall within this specific kind of disability.

What can you tell us about your experience with your own disability, and what drove you to help find this association?

Growing up as a disabled kid in a time when public facilities were not equipped to accommodate disabled individuals was very difficult. I was the kid in a wheelchair whose brother was a known athlete in our community. The kid whose father would carry him to class every day. I suffered endless

disrespect and belittlement; at best, I was the weak and fragile kid who lacked physical and - presumably - intellectual autonomy, and at worst, the class magnet for ridicule. My struggles were lost on them, and I came close to losing my once indomitable spirit.

I was later admitted into a special needs program formed in 1982, and with the abuse I suffered behind me, I recomposed myself once more. I was adamant about making sure that my voice was heard; that I and others like me be treated like peers, not ridiculed nor patronized. I wanted to prove that I was just as capable as my athlete brother. And I wanted to honor my late father, who, like many parents of disabled children, was endlessly supportive and kind to those who needed it. With those goals set before me, I felt in my heart that I could do anything, and I remain grateful for that strength.

CONCLUSION

For decades, the “*Nothing About Us Without Us*” philosophy has called for strengthening health care providers, governments, educators, and community training in responding to the needs of people with disabilities. However, there is still a lack of awareness of the problems faced by people with disabilities outside the circles to which they belong. Therefore, having open lines of communication with people with disabilities and their families is fundamental to the progress of inclusion in Bahrain and the GCC.

The experience gained through this qualitative study allowed me to rethink how inclusive communities truly are in the United States. Recent data shows that the United States is among the countries that provide an inclusive and equitable environment for people with disabilities, as disabilities affect approximately one in four (26%) of the US population. In addition, The Americans with Disabilities Act (ADA), passed by the US Congress in 1990, provides equal opportunity and the right for people with disabilities to be accommodated in the United States, when necessary so they can study or work. However, a question that arises that will inform new research, beyond large community and national studies, is how the concept of “*Nothing About Us Without Us*” is practiced in small communities in the United States and what is the level of participation of people with disabilities in inclusive programs and projects. This became my vision for future research based on the experiences I had embraced in Bahrain.

NOTES

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Introducing the concept of “Nothing About Us Without Us” to my students in the Gulf

BIOGRAPHY

Alexander Woodman (Fulbright Scholar, 2023-2024) is a licensed public health and clinical researcher. The primary focus of his research is advancing global reproductive health, medical education, and practice. He graduated with honors from UCLA, Harvard Medical School, and Yale University. In his research, Alexander merges epidemiological data with state-of-the-art laboratory technologies to find new ways to understand a variety of health conditions impacting the daily life of the public. He can be contacted at alexwoodman.ucla@gmail.com
