Standards of Disability in Arab Society:

Understanding Challenges or Challenges in Understanding?

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Introduction

Most Arab countries have recently been undergoing turmoil. It began with a series of demonstrations condemning political, economic, and social conditions, as well as counter marches in support of regime policies. These demonstrations have been paving the way, in theory, for a new, more open political stage in the future that is different from current or previous eras. While numerous studies have discussed this turmoil, they have generally downplayed the importance of a silent section of the population that for several reasons remains in the shadows of Arab society: people with disabilities. This section of society is silent because it lacks the tools to attract people's attention to its political positions, regardless of whether it supports or opposes current Arab regimes. Until recently, people with disabilities had not been given the opportunity to explain their demands or discuss their needs; they had been ignored. There is still no clear universal definition of disability, nor a common understanding of their current reality or capabilities. Cultural, political, and legal texts about these individuals, and their rights and responsibilities, suffer from misperceptions and misunderstandings. This silent section of society lives in the shadows, but not because of their poverty, social class, ethnic or religious background. There are no medical, social, economic, legal, or political mechanisms in the Arab world for discussing how disability is defined, or effectively explaining who disabled individuals are. Yet studying the standards by which the disability label is

defined and assigned may shed light on some of these issues. It is a first step towards establishing social justice that includes all citizens, without exception.

This research study is an attempt to respond to the following questions:

What standards are used to differentiate between a "normal person" and someone who is "not normal?" What does being a normal person mean? How is disability defined? What is the definition of a normal or ordinary person, and that of someone who is seen as not normal or not ordinary? In attempting to answer these questions, it was seen as important to investigate different aspects of the lifestyles of people with disabilities. These include their level of independence, their productive abilities, the idea of difference, and issues related to integration. The social and cultural environment of these individuals was also a subject of investigation .

In order to produce an in-depth study using an ideologically objective approach, we relied on a variety of Arab and foreign resources, including numerous articles and studies conducted by Arab researchers. In addition, we conducted fieldwork in Syria, Tunisia, Morocco and Kuwait, gathering rich testimonies and experiences that provided evidence that refuted or supported our hypotheses .

After this research was conducted, several experts asked us questions such as: Why choose this research in particular? What was the goal of the individuals running the project? What was the desired outcome?

To us, the standards that allow people to be divided into healthy and unhealthy categories seem to be mechanisms of veiled oppression. These standards lock certain people within fixed identities, ignoring the fact that human identity is multifaceted and diverse; it can change and develop in response to people's thoughts and behaviour, and corresponding hopes and aspirations. Such standards take a deterministic approach to the futures of individuals with disabilities, and—whether directly or indirectly—entrenches the importance of the disabilities themselves by impeding possible projects. By classifying people into narrow categories, these standards effectively destroy the future possibilities of many individuals. This is what prompted us to work on this research study. We hope to propose ideas that may help in the revolution against the oppressive standards that impose barriers between different sections of the same society, declaring that there is only one natural or ideal

way of life, and that anyone who goes against this is not a natural or normal human being .

Chapters and Central Themes of the Study

This study is divided into five chapters, the first of which is entitled "Defining Disability, and Problems Involved." According to the prevailing definition in Arab research, and among centers that care for people with disabilities, the concept of disability includes:

- Every person who is not self-sufficient and always dependent on others;

- People who find it difficult to adapt to the environment they live in;

- People of a limited productive capacity; and

- People who face limitations they are unable to overcome.

Yet after reviewing these definitions, aspects of it can be seen as unclear and imprecise. All four of these groupings are subjective measures of individuals' behaviour and lifestyle. These measures could be interpreted to include nearly everyone at one time or another, including both people who are termed normal and those classified as "disabled." We propose the term "people with disabilities," and aim to demonstrate its appropriateness by studying the standards of who is a normal or ordinary person, and who is not normal or ordinary.

Towards this end, we turn to Georges Canguilhem's ideas on the divisions between normal and pathological, and demonstrate the diversity of aspects included within these standards. His ideas stress diverse meanings of what is normal and not normal, depending on the particular functioning and circumstances related to people's bodies, as well as their mental and psychological capabilities. He also emphasises that what is average for a normal person in certain circumstances might be considered an illness in other circumstances, and that a person is the best judge of his own condition since he is the one that suffers when he feels he lacks physical functionality or stability. One idea we discuss at length in this first chapter is Canguilhem's idea that we can only assess what is not normal, or what is not standard, relationally. In other words, we cannot term a sick person, or someone with a specific disability, as not normal or not ordinary for the simple reason that the idea of what is not normal is relative to specific conditions and circumstances; it is dependent on the social, cultural, and physical environment in which a person lives.

With regards to terminology, we propose to avoid saying that people are "disabled," but instead to say that they are "people with disabilities." In other words, they are people with disabilities as a result of poor conditions and circumstances, or as a result of a relationship with their surroundings that increases the obstacles and barriers the person faces, instead of mitigating them. Thus, standards of health and disease, balance and imbalance, or common and uncommon, cannot be arbitrarily generalised to include everyone, because the rules of standardisation are relative—both in terms of what they comprise, and in how they reflect the conditions of people and society. Furthermore, the results of what these standards propose, and their provisions and values, are only speculative.

In the second chapter, entitled "People with Disabilities: Between Illness, Confusion, Health, and Stability," we discuss the differences and commonalities between illness and disability. We cite a variety of ideas, experiences, and cases of people with illnesses or disabilities, and conclude that even if the medical establishment were to provide all the necessary tools, knowledge, and solutions for illnesses and disabilities, this would not necessarily mean it could break with previous theories and find solutions beyond its current medical tools and knowledge. Though the medical establishment is unable to deal with some severe mental, functional, physical, and sensory disabilities, it will not necessarily always be unable to do so. This it is a temporary failure due to the limits to medical knowledge of disabilities at a given time. Medical knowledge is subject to change, thanks to the constant work of people in the field, and their commitment to new research and new developments.

We discuss several important ideas in the third chapter, entitled "People with Disabilities, Between Past Control and Present Injustice." In the interviews we conducted in Syria, Kuwait, Tunisia, and Morocco, and in testimonies from Arab research studies and books, we noted the number of religious phrases used when people discuss their experiences. Certain beliefs that help people with disabilities be patient with their near-daily suffering are important. Yet at the same time, it was clear that most people whose experiences we reviewed also consulted medical knowledge, tools, and means of treatment, and that doctors were their first resort. When they learned that all knowledge has its limits, and that medicine does not possess a magic wand that can do the impossible, they looked elsewhere for something that could give them hope for a better tomorrow—to religion and prevailing beliefs. These include ideas such as: disabilities are a predetermined fate, and he

who determines them can eliminate them; disabilities are a lesson, a test for the person who has them and their family; and patience and perseverance despite suffering lead to a better life filled with tranquility, comfort, and no pain.

At the end of the third chapter, we argue that it is possible that people's beliefs—especially personal ones—are effective and useful for them. However, some Arab researchers—several examples of which we provide in our research study—invoke texts with such beliefs and use them when speaking about disability and people with disabilities, and comment on the advantages that "people with disabilities" enjoy, exempting "the disabled" from certain religious duties. This way of thinking creates an obstacle to people with disabilities that is counterproductive to their community's intellectual and technical development. It also indirectly reduces incentives to pursue scientific research that can lead to real solutions to their suffering. We noticed common ground between religious texts that exempt "people with disabilities" from various religious duties – these texts assume they have mobility, psychiatric, or mental disabilities – and the prevailing view in society that all disabled people are essentially incapable, likely unable to do what others can.

The analysis in the first three chapters led us to conclude that solutions to past control and present injustice will not be found by waiting, passively, for medical knowledge to evolve. Nor will we find them by calling to erase or negate religious texts. Instead, we must redefine the concept of disability, and discuss the standards used to define it, paving the way for changes in laws on the rights of "people with disabilities" and their duties as citizens, living under the roof of one nation.

For this, we worked with a research team on the fourth chapter, entitled "Classification: Administrative Need, and Reductive View on Identity." Reading a variety of Arab and foreign studies, we understand the degree to which classification is an issue, and how it has complex effects, on personal, institutional, and social levels. At the root of this problem lies a contradiction between administrative, legal, or medical classifications that are rigid and fixed, and the belief that individuals who have been classified into these fixed, rigid groups have rich, multifaceted personalities. In other words, classifying people with disabilities organises their lives, but ignores some of their inner potential, often cutting them off from the so-called majority.

One part of the fourth chapter of our study concerns a 13-year old autistic Syrian boy named Khaled N. We asked his mother about the idea of a minority and a majority, about her impressions of her son and about how he is classified by society as "disabled." Without hesitation, she responded, "I consider my son part of the healthy majority; he fits in with healthy people more than with people with disabilities in his school. He doesn't like to interact with friends at school as much as he fits in with practical people; he does what they ask of him." Yet her certainty—in which there is much to discuss—did not last long. After several questions about how different her son is from others, and whether it is possible to forget the hindrances of his disability, she shared something else significant. "I've had some very hard times; other children harass my son when I walk with him to school. He starts to talk with them, but he talks about things they don't understand, so they think he's strange and make fun of him. Often when I want to cross the road, he rushes out into the way of traffic without regard for the cars; they stop and the drivers get angry, they shout at me and insult me. I arrive back home and cry, and he cries with me, and tells me 'Don't cry, momma, who made you cry"?

Khaled's mother's words are not an exception. They capture a mother's hope that her son will fit in with people and be socially accepted. She doesn't just insist that he is part of the healthy majority. She also tries to point out the differences between him and other students—those who have disabilities like he does—and ways he does not fit in with them. It is as if she is saying that he goes to a center for autistic children, but that he does not belong there, or as if she is justifiably trying to say that her son's personality cannot be reduced only to the center he attends. Here, it seems clear that the purpose of this center is to care for children and help them to integrate in society, yet it is also often a source of shame, thus the family tries to dissociate themselves from its name, or avoid publically stating that their children go there. Khaled's mother spoke as if with society's tongue; she wants her son to be a member of society, productive and effective, not at all one of the marginalised. How Khaled's mother responded to the question of the minority and the majority captures a mother's hopes that her son will be part of society, able to integrate and not be excluded, that his behaviour and ideas will be like the others, and not different to them. But when asked a question about the suffering that the family experiences daily, she acknowledged the harsh reality in which she lives. She spoke of the differences in her son's behaviour compared to the standards he is surrounded by. She also pointed out the

punishment he received when he went against the norm. This is the life of a family filled with daily trials and acts of resistance. The family tries to minimise how different its son's actions and behaviour appear, as these differences have serious consequences on psychological and social levels.

Clearly, classifying disabilities has an important administrative and organisational function. Yet classification must not confine the self or fetter someone's capabilities. The self is able to overcome boundaries of whatever group it is placed within, and the conditions or circumstances that surround it. People are not duplicates of one another; they are not exact copies of a singular original form. They are not slaves who submit and surrender to whatever social group they belong to. People—whether they have visible disabilities or not—are products of their surroundings, and these surroundings eventually influence them, whether positively or negatively.

The fifth chapter, entitled "People with Disabilities: Between Independence (Freedom) and Integration and Rehabilitation (Dependency)" addresses several important ideas in the field of disability. We begin the chapter by asking the following questions: Is it possible to differentiate "people with disabilities" according to the idea of independence, or the extent to which they rely on others? Do "people with disabilities" feel a greater need for the presence of others nearby, compared with people without disabilities? Or do all people, as social beings, need the presence of others? Does the fact that "people with disabilities" rely on others for eating, drinking, and dressing themselves accentuate their disabilities in the eyes of others? If so, where do newborn children or the elderly fit within that framework? Can it be said that independence is a spectrum, and that the less independence someone has, the closer they are to the category of disability and the "disabled?"

We present a number of cases in this chapter, including that of Mr. Khaldoun Sinjab. We explain his condition, how it developed, and what he can do despite the disability he suffers from. After reviewing his thoughts, and presenting videos and interviews that were recorded of him, we conclude that Khaldoun's perseverance and fighting spirit clearly resulted in independence. His family members and the devices around him continue to enable his independence. Khaldoun was a body lying in bed, dependent on devices and other people to eat, drink, and breathe. He transformed into a person with an imagination, with the ability to differentiate between things, and to understand what enabled him to become a source of knowledge, a programming

specialist, so that others could benefit from his information and experience. It is not always important to have hands to interact with a computer; more important is the ability to discover alternatives, and utilise them to independently express one's free, conscious self. We must change the prevailing notion of what it is to be human. Being human does not mean having four functional limbs, it is also means being mentally aware, thinking, and having a rich imagination that helps one discover new and innovative solutions to life's problems and mysteries. If hand and feet are what enable someone to be independent, imagination and desire are what constantly create that independence. In short, Khaldoun feels that he enjoys a kind of independence, and this is his lived experience for most moments of his life.

In the sixth and final chapter, we discuss ideas like difference and recognition. We stress that one of the most important things to work on is acknowledging and recognising the existence of people who are different in appearance, behaviour, lifestyle, and type of independence. Many kinds of people make up a diverse society, forming its foundation; these people are among them, and their existence must be acknowledged. They must be granted rights and duties, and everything that endows them with citizenship. Recognising the other—regardless of their physical, sensory, mental, or social differences—is creating this self-anew, giving them a green light to enter society. The other is a mirror for the self. Keeping this other at a distance, or isolating the disabled self with walls of common perceptions and rigid definitions, often sentences it to a slow death.

In concluding this research study, we propose the following definitions, which act both as viewpoints and starting points for further research.

Disability: a temporary limitation or impairment, which may be physical and/or sensory and/or mobility-related and/or mental and/or social. This limitation or impairment might temporarily impede the functioning of parts of a person's body without impeding other functions. Thus, the impairment does not negate the person's inherent mobility, sensory, or mental capabilities. The limitation or impairment is temporary, and will continue to be so. The possibilities of treatment and potential recovery are related to the limits of knowledge, and we do not know when these limits will be overcome .

Person with a disability: a human self with capabilities that are different from the capabilities of other selves. Just like everyone else, a person with a disability is

someone who can employ his freedom, senses, and consciousness when medical, social, cultural, economic, and political conditions enable him to. They are not disabled when they can find specific conditions that enable them to achieve a certain kind of social and personal balance and stability. Conversely, they are disabled when they are unable to create new standards, normal or not. They are people with different needs, but their differences do not prevent them from being effective, because difference and diversity are essential to our world and the individuals and societies it contains .

Defining disability: The extent of someone's health, balance, independence, or productivity cannot be determined by how similar someone is to others. These things cannot be determined by whether someone behaves as others do, or whether they share the same lifestyle. They can only be determined by whether that individual is able to enjoy health, balance, and independence, through their own capabilities and in cooperation with others around them. Conversely, everyone—without exception—who is unable to achieve health, balance, and independence without the right conditions can be classified as disabled. Difference—whether in appearance, type of independence, or usage of one's senses—is not what defines disability. Difference is not what determines whether someone is allowed to live like others. Disability is the failure to use one's capabilities and create new norms when circumstances allow one to do so, and ignoring one's capabilities when one is able to use them. Furthermore, defining disability is what produces classifications that can be refuted and altered—as opposed to fixed, rigid classifications. It leads to classifications that can constantly be changed; after all, human nature itself is rich, innovative, and creative, always seeking to realise its hopes, which will not be contained.

About the author

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About ARI

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