



# OUT OF SIGHT OUT OF MIND

An inquiry into the patterns of exclusion for  
Persons With Disability in Tunisia

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## **TEAM**

### **Author**

Michele Scala

### **Design**

Valérie Nseir

### **Translation**

The Language Platform

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*The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed.*

[Goffman 1963: 12]

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## INTRODUCTION

Although socially (and legally) sanctioned today, stigmatizing terms such as “retarded, deformed, crippled, moron, impotent, etc.” associating a social identity with one’s health condition have long been of common use. The stigma, or the use of one’s attribute for discrediting purpose (Goffman 1963), has resulted, among others, into social, economic, and political discrimination and marginalization practices towards different social groups. From this perspective, research on disability can be understood as the study of the complex relations between health and social inequalities (Fassin 2000). As a consequence, the study of the disability framework offers an heuristic observatory to understand the way in which a given society and its institutions think and perform the principles of fair distribution of wealth and opportunities for all. In fact, the way in which “Persons with disabilities” (PWDs) political and social representation, economic inclusion, and social protection needs are taken into account does not only inform us on the reality of disability in a given society. It also tells us a lot about the way in which the latter thinks and practices the principles of social justice, i.e. understands and works forward the creation of equitable social frameworks in which all individuals’ rights are recognised and protected, and where decision making processes are fair. By focusing on the Tunisian case, this study intends to shed light on the reality of social justice in Tunisia through the specific, yet meaningful (and under-researched) lens of disability.

Since the pioneering works on the incidence of death in urban pauperized settings characterized by major insalubrity and exposure to disease (Vedrenne-Villeneuve 1961; Black 1980), health-related social inequalities have “essentially [been] thought of in the language of numbers” (Fassin 2000: 123). Studies on disability are no exception. As shown by several studies (Eide and Ingstad 2011; Palmer 2011) and international organization reports (WHO 2011, Mitra et al. 2011), statistical means constitute the main tool for the analysis of the relation between disability and social inequalities. The predominant use of quantitative methods has tended to read social inequalities related to disability in terms of rates: poverty rates, school system inclusion or labor market inclusion rates, and so on.

As per the Tunisian case, however, understanding the relation between disability and social inequalities through the statistical means appears to be highly problematic. Despite the use of sometimes sophisticated methodologies (Bakshi et al. 2014; Trani et al. 2015), quantitative data on disability in Tunisia is often misleading insofar as available figures are either unreliable or limited in scope. On the one hand, official data are largely biased, while on the other hand, independent surveys are often based on representative samples rather than on national surveys. Moreover, and more importantly, quantitative knowledge alone cannot fully catch the complex linkages between health - and health policies - and social inequalities. As pointed out by D. Fassin, social inequalities are also and often expressed in terms of “imponderables” that are difficult to catch through quantitative methodologies. Imponderables relate to the articulation of structural and subjective processes of a political, economic and social nature, linked to representation as well as self-representation models which are “difficult to identify and a fortiori measurable” (Fassin 2000: 129). Based on these introductory remarks, this briefing paper draws on quantitative analysis and qualitative methodologies in an attempt to shed light on the implications of disability policies on social inequalities and, subsequently, on the fair distribution of social, economic, and social opportunities in Tunisia. To do so, the paper attempts to provide a general - although non-exhaustive - overview of the disability context in Tunisia. It starts by reviewing the legislative framework for disability in Tunis as well as available statistics and then attempts a comprehensive social and political analysis of the Tunisian disability framework<sup>1</sup>.

This study begins by providing a statistical overview of the prevalence of disability in Tunisia, highlighting the quantitative under-evaluation of the account of PWDs at the national level. While the unreliability of the official statistical data is usually explained through technical and methodological arguments, highlighting the shortcomings inherent to national state-related institutions’ surveys (Bakshi et al. 2014; Trani et al. 2015), our analysis brings attention to the political dimensions behind the current downplaying of the disability rate. In the following, the paper discusses the definition of disability in the Tunisian legislative framework by contextualizing it within the broader international and historical debate. The paper provides an overview of the main regulations of the Tunisian legislative framework on disability,

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1-The qualitative fieldwork has been conducted between January and July 2022. Qualitative data are based on seven in-depth semi-structured interviews and two field visits to the so-called “Rehabilitation centres”, better known as “Associations (*jama'iyat*)” or “Centres d’éducation spécialisés (Specialized educational centres)” providing educational programmes and professional trainings to PWDs. Interviewed stakeholders include the management of two PWDs associations, a cadre at the National Committee for Social Promotion (NCPS) at the Ministry of Social Affairs (MoSA), NGOs practitioners and special educators, as well as other key informants interviews with researchers in social sciences. Some qualitative data have also been collected through informal conversations with some key interviewed stakeholders during the different phases of the fieldwork. Overall, the methodology of this paper is based on the triangulation of qualitative data with a literature review and a statistical analysis of available data. For the purpose of confidentiality, all names of interviewed individuals have been anonymised.

pointing out its legal and practical shortcomings and their impact on the accomplishment of social justice principles in the disability landscape. On the one hand, this study argues that although the Tunisian legislation related to disability is often hailed as one of the most advanced in the Middle East and North Africa (MENA) region, its model remains oriented towards an outdated medical approach. On the other hand, it provides a qualitative assessment of the gap between the legislation and the reality of its implementation by focusing on an analysis of the education system. We conclude by advancing some remarks on the PWDs-related social protection policies and on PWDs limited inclusion in the labour market. Overall, this paper aims to provide a qualitative assessment of the disability framework in Tunisia from a social justice perspective. By giving evidence-based insights of the reality of disability, it highlights the practical dynamics of discrimination and exclusion limiting PWDs citizenship, or more prosaically, their ability to fully participate in the social, economic and political life on equal basis with others.

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## A STATISTICAL OVERVIEW ON DISABILITY IN TUNISIA

As already highlighted, the reality and social implications of disability are usually and mainly assessed through statistical analysis. When it comes to the Tunisian case, however, the quantitative data produced on disability are fragile and widely contested insofar as, from a comparative point of view, they seem to largely underestimate the prevalence of disability. Thus, they risk hiding, rather than illuminating, the social realities of disability in the country.

According to the most recent official data pertaining to a household survey of 2014 (INS 2017), disability concerns 2.2% of the Tunisian population, i.e., 241.240 people (of which 119.160 women and 122.080 men). This figure is definitely below the expectations and the world average which situate the prevalence of disability around 15% (WHO 2011: 44). Incidentally, a limited study conducted on a sample of about 12,000 people in the regions of Tunis and Bejà detected 5.7% of PWDs (Bakhshi et al. 2014). This figure is closer to more realistic data but is still below the 13% hypothesized by some civil society organizations advocating for PWDs civil rights in Tunisia<sup>2</sup>.

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<sup>2</sup>-Interview with a member of the National Committee for Social Promotion (*Comité national de la promotion sociale*), Ministry of Social Affairs, February 2022.



Data from the National Institute of Statistics (INS) only take into consideration five types of disability, including visual, hearing, muscular and motor disability and attention disorders. Thus, apart from attention disorders, these data do not consider psychological-related forms of disability, i.e., the so-called “psychosocial disability”<sup>3</sup>.

Overall, despite a fragmented and still developing literature on disability in Tunisia, authors agree in highlighting the statistical under-evaluation of the prevalence of disability in the statistical measurements carried out by state-related institutions (Bakhshi et al. 2014; Trani et al. 2015; Campos Pinto et al. 2016). However, the political implications of such quantitative downplaying of the reality of disability are rarely discussed.

The surprisingly low official rate of disability is usually described as related to technical issues pertaining to the measurement techniques and/or to the definition of disability (Bakhshi et al. 2014; TCPRPWDs 2011) that, as we have seen and will further develop, does not take into account certain categories of PWDs such as victims of psychosocial disorders. Indeed, our own triangulation of data collected shows that INS data on disability are seemingly based on the number of disability cards delivered to the population rather than on other research criteria able to gauge the actual number of PWDs (having, or not, a disability card<sup>4</sup>). In fact, according to one informant at the National Committee of Social Promotion (NCSP) at the Ministry of Social Affairs (MoSA), 242000 disability cards have been distributed in Tunisia, which matches the 2.2% official rate of disability given by the INS household survey of 2014. Being (seemingly) based on the number of delivered disability cards, INS and MoSA data are very much misleading since this figure is based on the cumulative number of cards delivered starting from the 1980s<sup>5</sup>. Therefore, this account does not take into consideration PWDs who had a disability card and died or PWDs who have left Tunisia<sup>6</sup>, as well as PWDs that could not obtain a disability card because of several different possible reasons, most of which are not strictly “technical”.

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3-Psychosocial disability can be defined as a condition that arises when someone with a mental health condition, interacts with a social environment that presents barriers to them that others do not experience. Psychosocial disability includes - but is not limited to - attention disorders: “some examples of psychosocial disabilities include schizoid disorders, such as schizophrenia and schizoaffective disorder, anxiety disorders, such as obsessive compulsive disorder, post-traumatic stress disorder, agoraphobia and social phobia or mood disorders, such as major and dysthymic depression and bipolar” (see the disability support guide here: <https://www.disabilitysupportguide.com.au/information/article/psychosocial-disabilities> [last accessed on July 21, 2022]).

4-Holders of a disability card have access to a number of benefits such as free public transportation, a 50% discount on air and sea transport, free treatment in public hospitals, fee waves and exoneration of costs on certain equipment, among others.

5-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

6- Which may explain the slight difference among INS and MOSA data, respectively accounting for 241,240 PWDS and 242,000 PWDS.

To name only one of the reasons why some people are not able to obtain a disability card, its delivery is subject to eligibility criteria, most of which are based on a medical assessment. The applicant must present a medical file to an appointed commission that decides on the provision of the disability card. Hence, people who cannot access or afford medical care cannot produce the medical supporting documentation that constitutes a fundamental prerequisite for the obtainment of the card. Theoretically, obtaining a medical assessment should not constitute a (financial) issue in Tunisia. According to the Centres de Recherches et d'Études Sociales (CRES) data, almost all Tunisians (94%) have access to basic medical coverage (64% through social insurance, and 30.3% through free healthcare programmes<sup>7</sup>) (CRES 2015). Besides the rate of medical coverage at the national level, however, what counts more is the effective access to the healthcare system. In practice, access to basic medical care remains very unequal at the national level and follows variable geographies reflecting longstanding regional disparities. As C. Hmed points out based on data from the Ministry of Health and Population, “the inhabitants south of the Gabès-Gafsa line have almost no access to basic healthcare offered by the Ministry of Public Health, unlike the inhabitants of the capital as a whole” (Hmed 2016: 141). So, although data show that virtually almost all Tunisians are eligible for medical care services, not all Tunisians have effective access to it. For the same reason, it remains difficult to ascertain how many Tunisians are unable to require a disability card because of the health system's shortcomings. However, it appears quite clear that inhabitants of certain regions, namely the inland and southern ones, traditionally neglected by the political elites (Bono et al. 2015), have little or no access to basic healthcare.

As shown by this example, sociopolitical dynamics contribute to the under-evaluation of the prevalence of disability in the country. On the one hand, the under-evaluation of the prevalence of disability is one of the main results of structural issues such as limited access to basic medical care in unprivileged peripheral regions. On the other hand, it permits, or justifies, limited social policies (e.g., limited allocation of budgets) dedicated to the protection and the promotion of PWDs. As summarized by a civil servant at the MoSA NCSP, the rationale for the measurement of the prevalence of disability for the MoSA is the following:

*“For the MoSA it is a matter of counting [PWDs] in terms of service provision to people who request it. The Ministry has not given itself the mission to identify all people with disabilities in Tunisia. It is a question of responding to the declared needs and also of fitting into the available budgets for these services”<sup>8</sup>.*

<sup>7</sup>Namely the “Assistance médicale gratuite (Free Medical Assistance)” (AMG) 1 and AMG 2 respectively giving access to free healthcare services (AMG 1) and fee waivers (AMG 2). It is worth noting that AMG 1 and AMG 2 are subject to regional quotas and the delivery of AMG cards depends on the availability of budgets for each Governorate.

<sup>8</sup>Interview with a member of the NCSP, MoSA, February 2022.

In other words, the definition of disability in the MoSA perspective depends above all on the types of services it offers and on the budget it has to cover them. Thus, the measurement of the prevalence of disability is based on a minimal estimation of PWDs based on “objective” criteria (number of disability cards issued) and on the number of people who actually request services from the MoSA. This allows to keep a lid on the reality of disability, and to limit an already failing budget that is largely dependent on time-bounded transfers from international cooperation projects. According to the data obtained through the MoSA, the total spending for disability-related programmes amounts to around 100 Million Tunisian Dinars (TND, approximately 30 Million USD) in 2021<sup>9</sup>, i.e. to 0.42% of the total social spendings amounting to TND 23.620 billions in 2020 (approximately 73 Billion USD)<sup>10</sup>. According to the same sources at the MoSA NCSP, MoSA’s budget allocated to disability-related programmes is highly dependent on United Nations (UN), Non-Governmental Organizations (NGO) and International NGOs partnerships most of which are coming to an end in 2022. If these partnerships are not renewed, MoSA’s budget will soon come short on disability programmes<sup>11</sup>.

As it will be further highlighted, notwithstanding an advanced legislative framework on the matter of disability, the Tunisian disability framework is characterized by limited social policies and by a huge gap between regulations and practices. In order to situate the Tunisian legislative framework and its shortcomings, it is essential to address some definition issues pertaining to the notion of disability. This will permit, on the one hand, to shed light on the incomplete coherence between the Tunisian framework and the international legislative standards and, on the other, to better understand the relation between regulations and current practices.

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9-Interview with a member of the NCSP, MoSA, February 2022.

10-INS data. The most recent data on social spending pertain to 2020.

11-Interview with a member of the NCSP, MoSA, February 2022. Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

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## DEFINING DISABILITY: FROM THE INTERNATIONAL DEBATE TO THE TUNISIAN LEGISLATIVE FRAMEWORK

Despite its integration into different international and national legislative frameworks, the notion of disability is (and has been) subject to debate. In order to propose a reflection on the Tunisian disability legislative framework, it is essential to briefly outline the evolution of the international debate on the definition of disability. In fact, while the so-called “social model of disability” has progressively established itself during the last two or three decades, the Tunisian legislative framework is still very much linked to the so-called “medical model of disability” that had been dominant starting in the 1970s.

According to the World Health Organization’s (WHO) current definition, “disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support”<sup>12</sup>. Inspired by the so-called “social model of disability” (Olivier 1990) and by the works of the Canadian anthropologist Fougeyrollas (1995; 2019) the current WHO definition highlights how a person presenting permanent or transitory impairment is not, ipso facto, a PWD. Rather, it is the relation to, and the interaction with the social and infrastructural environment that makes his/her personal health features dis-abling in the political, economic and social arenas. In other words, the notion of disability refers today to a social disadvantage related to one’s health condition and sheds light on the complex relations between health and social inequalities (Ravaud and Mormiche 2000) in contemporary societies.

The introduction of a social approach to disability is, however, relatively new. Public policies targeting people with permanent infirmity and impairment of congenital or acquired origin date from the end of the 19th and beginning of the 20th century (Ville, Fillion and Ravaud 2020). During this period, disability was mainly thought of in medical terms, steadily linked to the individual’s health condition and to the various forms of physical, mental, intellectual or sensory impairment or infirmity. Persons with disabilities (PWDs) were medicalized, often isolated and segregated, especially when affected by mental disorders (Goffman 1961; Basaglia 1968), and public policies were oriented to the rehabilitation of people with disabilities in an ambition to reduce the gaps between PWDs and “the others”. The close and indistinguishable relationship between disability and the body has certainly contributed to the medicalization of the treatment of disability at the expense of social approaches and a broader reflection on social identities and the right to citizenship for PWDs.

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12-See: [https://www.who.int/health-topics/disability#tab=tab\\_1](https://www.who.int/health-topics/disability#tab=tab_1) [last consulted June 22, 2022].

It was not until the 1970s that the issue of disability became a priority in public health policies and an autonomous subject of study in the social sciences (Ville, Fillion and Ravaud 2020). The so-called “medical model of disability”, inspired by the works of the British rheumatologist P.H.N. Wood in the 1970s was reflected in the first version of the WHO International Classification of Impairments, Disabilities, Handicaps (ICIDH) published in 1980. In the latter, disability is defined as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO 1993 [1980]: 143); while handicap is defined as “a disadvantage for a given individual resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.” (*Ibid.*: 182). As noticed by some scholars, this first definition of disability adopted by the WHO in 1980, recognizes the relationship between health and social inequalities, establishing however a univocal and causal relationship among them (Ravaud and Mormiche 2000). These are the individual characteristics of an individual and her/his health condition that determine her/his social disadvantage. In this definition, the plural barriers contributing to prevent or limit the participation of PWDs in the political, economic and social arenas are not taken into consideration. The medical model of disability was progressively put into question under the pressure of collective actions organized by PWDs in the framework of the 1970s social movements (Olivier 1997). Civil rights movements led by PWDs shed light on the social constraints and obstacles impeding their full participation in the social, economic, and political life, criticizing the medical-based approach to disability. In this framework, the WHO, international organizations, and public policies gradually moved towards a social model of disability considering social and environmental factors leading to or amplifying disability. However, it was only in 2006 that the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) founded on the right of PWDs to access full citizenship and on the non-discrimination principle<sup>13</sup>.

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13-The Convention was opened for signature on March 30, 2007 and entered into force on May 3, 2008.

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## LEGISLATIVE OVERVIEW ON DISABILITY IN TUNISIA

Tunisia is often praised for its social protection model, considered among the most advanced and comprehensive in the MENA region (ILO 2021). Its approach to disability is no exception. The first legislations on disability date back to the 1960s and address certain categories of PWDs such as visually, hearing and mental impaired (Bakhshi et al. 2014: 11), making Tunisia one of the first countries that legislated on disability in the MENA<sup>14</sup>. A “national responsibility” over PWDs was established on May 29, 1981 through the enactment of the Law No. 81-46 of May 29, 1981 (Bakhshi et al. 2014: 11). More recently, Tunisia was among the very first signatories of the UN CRPD, ratified in 2008, and was elected on November 4, 2008 as a member of the Committee of Experts on Disability at the United Nations. Prior to the adoption of the UN CRPD and in the framework of its discussion, the government very early promulgated the orientation Law No. 2005-83 of August 15, 2005 related to the promotion and the protection of disabled people (Loi relative à la promotion et à la protection des personnes handicapées) (Bakhshi et al. 2014) which integrates a non-discrimination principle and states the equality of chances for PWDs in article<sup>15</sup>. This text is inspired by the social model of disability as it advocates towards the promotion of equal rights rather than towards the inclusion of PWDs in society through rehabilitation strategies. However, the definition of disability contained in the orientation Law of 2005 does not take social barriers and hindrances into account.

While the definition of the UN CRPD at that time states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which *in interaction with various barriers* may hinder their full and effective participation in society on an equal basis with others”<sup>16</sup>, the Law 2005-83 does not mention environmental external social barriers and states: “is considered a PWD any person who has a permanent impairment in physical or mental or sensory abilities and capacities of congenital or acquired origin which limits his or her ability to carry out one or more basic daily, personal or social activities and which reduces the chances of his or her integration in society”<sup>17</sup>. From this perspective, the definition of disability enshrined in the Tunisian legislation is closer to the so-called medical model in that it understands the social impact of disability as a direct consequence of the health condition of the PWDs rather than as the interaction among the individual health condition and environmental (social, cultural, political and infrastructural) factors, as defended by the social model of disability.

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14-Egypt, for instance, legislated on disability only in 1975 enacting the Rehabilitation of Disabled Persons Law (SIDA, 2014: not paged).

15-Although Tunisia has been amongst the first countries to legislate on disability in the MENA region, Law 2005-83 constitutes the first general law on disability in Tunisia.

16-CRPD, Art. 1. Emphasis ours.

17-Law 2005-83, Art. 2.

In a similar way, the current legislation does not fully comply with the UN CRPD despite its ratification in 2008. For instance, people with intellectual disabilities such as those suffering from mental disorders like autism “are the ones left out of the legislation” (Bakshi et al. 2014: 11) as they are excluded from accessing the disability card (carte handicap) and the basic services related to it. Treated as dangerous people, people with mental disorders are very often and quickly medicalized, and compulsory interned into mental health rehabilitation centres “more similar to asylums”<sup>18</sup> without thoughtful prior examination of their specific case. Therefore, they are treated as dangerous patients rather than as PWDs and often (too) quickly committed and deprived of their primary citizen-related rights because of their compulsory isolation.

In addition to the exclusion of certain categories of PWDs from the current legislation, the hiatus between the regulations on the one hand and social policies and social norms on the other is still very significant. Some observers notice that, despite the ratification of the UN CRPD and the adoption of the orientation law 2005-83 “Tunisia’s disability policies and social norms remain rooted in a paradigm that views persons with disabilities as ‘unfortunate charity-cases’ who require care” rather than as potential active citizens which hinders the possibility of an effective equality of chances for PWDs (Trani et al.: 2015: 3). In a report, the Tunisian Collective for the Promotion of the Rights of PWDs (TCPRPWDs) also emphasizes the limited implementation and impact of the current legislative framework highlighting that it has:

*“a very limited application in practice. Indeed, the texts include very few measures of sanction in case of non-application of the law; in addition, there is a lack of control over the structures concerned by these texts. This legislative failure leads to a real paradox between the texts and the reality experienced by Tunisians with disabilities: thus, the Tunisian law recognizes the right to a dignified life but does not integrate the notion of discrimination based on disability and therefore does not include any clear sanction in case of discriminatory abuse<sup>19</sup>. Similarly, the law recognizes the right to an autonomous life, but the means made available are insufficient to allow people with disabilities to have a dignified life” (TCPRPWDS 2011: not paged).*

<sup>18</sup>-Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022.

<sup>19</sup>-This last statement is slightly inaccurate as the Law 2005-83 includes a non-discrimination principle at its article 1. It remains though that discriminatory practices are not, or not effectively, sanctioned by the existing regulations.

In the continuity of the enactment of the orientation Law of 2005, Tunisia established a “Higher Council for Persons with Disabilities” in the same year. The latter is intended as a coordination mechanism of programmes and actions dedicated to PWDs in the country. This was replaced in 2010 by a “Higher Council for Social Development and Protection of Persons with Disabilities” whose representatives belong to the government (the ministries), the trade unions (especially the CGTL<sup>20</sup>) as well as civil society organizations and the “youth parliament”<sup>22</sup>. Surprisingly enough, no PWDs and PWDs organizations’ representatives have been invited to sit on the board. Similarly, at the political level, PWDs have been largely underrepresented in the transitional authorities that emerged in the aftermath of the 2011 Tunisian revolution. For instance, as highlighted by the TCPRPWDs, the “Higher Authority for the Realization of the Objectives of the Revolution, Political Reform and Democratic Transition” which drafted most of the laws between January 14 and October 23, the date of the elections, has not included representatives of PWDs. (TCPRPWDs 2011: not paged).

This rapid and non-exhausting review of some of the main disability-related regulations shows that an accurate overview of disability in Tunisia must move from the texts to the practices. In contrast to the legislation in force, discriminatory practices can be assessed through an examination of the education system as well as in the field of social protection and labor market inclusion.

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20-Confédération générale des travailleurs tunisiens (General Confederation of Tunisian Workers).

21-Law No. 2010-23 of May 17, 2010, established the youth parliament, officially conceived as “a space for initiating youth to political participation” (Art. 2 of the law).



## AN OVERVIEW ON THE INCLUSION OF PWDS IN THE EDUCATIONAL SYSTEM

INS data indicate that 53,8% of the PWDs population is illiterate. Overall, 25,7% of PWDs has access to primary education during their life cycle, 16,5% to secondary education, and a mere 4% to higher education (INS 2017: 18). As a whole, 79,5% of surveyed PWDs are either illiterate or received only primary education. The PWDs illiteracy rate is particularly striking if compared to that of the whole population that is estimated around 16% of the Tunisian population according to 2014 UNESCO data<sup>22</sup>.

On the matter of the inclusion of PWDs into the educational system, however, the Tunisian legislation stands as one of the more advanced in the region. The Law No. 2002-80 of July 23, 2002 relating to orientation, education, and school teaching aims at enhancing and redesigning the educational system in order to make it accessible to all, especially to children with disabilities (CWDs). A national strategy to progressively include all CWDs in the ordinary educational system was adopted in 2003 by a National Commission, specifically appointed to address the inclusion of children with special needs. The national strategy establishes the principle of enrolling all disabled children in the school closest to their home. However, according to official figures (see below table), after 20 years from the adoption of the Law No. 2002-80, only 12.1% of CWDs within the 6-18 age bracket having access to education are enrolled in regular programs. The remaining 86,8% is hosted within what Tunisians simply call “associations [جمعيات [jama'iyāt]]”, referred to in the tunisian legislative framework and in the specialized literature as “Specialized educational centres” (in Arabic: مراكز التربية مختصة [Marākiz at-tarbiyya mukhtassa]; in French: Centres d'éducation spécialisés).

**Schooling of children with disabilities (6-18 age bracket) for the year 2020-2021**<sup>23</sup>

Institution	Number of CWDs	%
Primary school	1674	8,6%
Secondary school	671	3,5%
Associations [Rehabilitation centres]	17000	86,8%
TOTAL	19345	100%

Although not mechanically linked, the scarce inclusion of PWDs into the educational system and the high rate of illiteracy among PWDs, pose once again the question on the existing gap between the current regulations and their translation into practices and, in the field of PWDs education, about the quality of education.

22-According to UNESCO, 1.841.387 are illiterate in Tunisia out of a total population of 11.695 million. See: <http://uis.unesco.org/fr/country/tn> [last consulted June 30, 2022].

23-Data obtained through the NCPS, February 2022, based on the official definition of disability.

## FOCUS ON THE JAMA'IYYAT (ASSOCIATIONS): THE “ARMED WING OF THE MOSA”

According to MoSA's official figures, the “associations” constitute the predominant educational environment for the large majority of CWDs holding a disability card<sup>24</sup>. In 2021, almost half of the public total spending on disability-related programmes – amounting to 100 million TND (about 33 Million USD) – went to the financing of the associations (48 millions TND, about 15 Million USD). According to a Humanité & Inclusion (HI) report of 2016, 295 specialized educational centres exist around the country (Campos Pinto et al. 2016: 25) and are run by about 200 associations that fall under the Decree-Law No. 2011-88 of 24 September 2011, on the organization of associations<sup>25</sup>. Formally autonomous (private), their financing mostly relies on MoSA that provides most of the funds. Associations also receive donations from private donors such as citizens or religious institutions and sometimes participate in development projects funded by international donors and NGOs. Some of them also require fees from their students<sup>26</sup>. On the one hand, the ambiguous status of the associations, formally private, but organically dependent on public funding, puts them outside the direct control of the MoSA. This has, in certain occasions, resulted into cases of abuse, such as those reported by media outlets through hidden-cameras investigations<sup>27</sup>. On the other hand, dependence on public funding limits associations' capacity to run the expenses as the personnel's salaries are paid directly from the ministries (MoSA, Ministry of Education, Ministry of Health) and only 10% of the available budget is directly managed by the association. In this context, any exceptional funding such as rehabilitation works of the centres needs to be approved and financed by the MoSA, and is subject to the availability of budgets.

24-The associations' centres only admit owners of the disability card.

25-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

26-Although some associations do not require entry fees, most of them do. The fees are, however, very low (between 5 and 15 TND) and “symbolic” according to the President of an association that we met. Moreover, if the families of the PWDs cannot afford the fees they are usually graciously exonerated from paying them by the associations' management.

27-In 2018, a scandal was discovered within an association of Autistic people [*Centre d'aide aux enfants autistes d'Ariana*]. An informant reported that “the personnel were abusing the students, making them eat their own vomit or things like that! Later on, it was discovered that the association wasn't even registered! Nobody went to jail and the association still exists!” (Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022). In a video published by an online newspaper, there are several different sequences. In one of them, a teacher slams a child against the wall. In another sequence, a nanny ties a child's hands and hits him several times on the head. In the final scene of the video, a child is tied to a chair with a piece of clothing and abused. This is not the first time that a scandal is discovered within a center for PWDs. See: <https://observers.france24.com/fr/20180219-video-maltraitances-enfants-autistes-tunisie-Tunis> [last consulted on July 1, 2022]. A report published by Humanité & Inclusion (HI) and the Fond des Nations Unies pour la Population (UNFPA, Tunisie also highlights cases of sexual violence directed towards PWDs, some of them happening within the PWDs centres (HI and UNFPA 2020).

The ambiguous nature of the associations and their centres is also reflected into their denominations. As already mentioned, while the Arabic and French official legislative denomination refers to the idea of Specialized educational centres<sup>28</sup>, the official English translation is “Rehabilitation centres” as it can be deduced by the fact that this translation is used in the official correspondence between the Tunisian government and the Committee on the rights of Persons with Disabilities at the UN<sup>29</sup>. This translation is very telling about the ultimate goal of the associations – at least in the eyes of the Tunisian Government – as it explicitly reflects a medical model of disability oriented towards rehabilitation strategies rather than to the provision of equal opportunities for PWDs, as defended by the social model of disability.

As we could assess during our own field visits, despite the existence of several very pro-active and engaged associations, “doing their best in the given situation”<sup>30</sup>, the centres still constitute a microcosm of the current discrimination practices witnessed by PWDs and CWDs more particularly. A practitioner described them as “parkings for PWDs”<sup>31</sup>. According to an ex-Special educational needs (SEN) teacher they express:

*“the reality of a society that is not inclusive of PWDs. There is no integration, they are simply neglected and segregated. Most of the PWDs are hosted within associations – rather than in schools – and the associations do what they can... Nobody cares about asking CWDs and PWDs their opinion about what they would like to learn or to be trained on...”<sup>32</sup>.*

As we could assess through field visits, associations can host PWDs in a very wide age bracket (between 3 to 40 and even more). They are usually specialized on one kind of disability and lack funding and personnel, especially specialized ones. The salary of the (scarce) specialized personnel is provided by the MoSA, the Ministry of Education (MoE) and the Ministry of Health (MoH) and ranges between 500 and 800 Tunisian Dinars (between 160 and 260 USD) according to various informants. Considered as a very good salary by the staff of some associations<sup>33</sup>, especially those active within very complex and pauperized urban and non-urban settings,

28-Respectively: مراكز التربية المختصة (*Marākiz at-tarbiyya mukhtassa*) and *Centres d'éducation spécialisés*.

29-See for instance the “Combined second and third periodic reports submitted by Tunisia under article 35 of the Convention, due in 2018”, received on September 4, 2018 by the UN Committee on the Rights of Persons with disabilities.

30-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

31-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

32-Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022.

33-Field visit to an association in a peripheral neighborhood in the South of Tunis, June 17, 2022. In Tunisia, the minimum wage ranges between approximately TND 365 and TND 430, following the hour/week working rate.

these salaries are not attractive for many in the medical sector, that usually prefers working in the private sector:

*“I tried to convince some speech therapists originating from the region to come back to Ghafsa and work at the association, however they refused because of the poor salary offered by the Ministry of Health. There was nothing to do”<sup>34</sup>.*

It goes without saying that specialized – and much needed – therapists clearly prefer staying in the private sector, mostly in the capital, as the financial prospects tremendously differ from the associations’ salaries.

As highlighted with emphasis by an ex-SEN at one association situated in the capital city of Tunis:

*“The associations are just associations. If they were centres that would be great! That would mean they actually provide services that a centre must offer to PWDs. Now, that is not the case. Calling them ‘centres’ it’s only out of [MoSA’s] propaganda. The reality is a totally different one. The personnel are not specialized, are undertrained, not qualified, and underpaid, working under a number of different contracts, which are mostly precarious, and need renewing every year. Association’s personnel are recruited out of friendships, directly from the president of the association or people within the MoSA that redistribute jobs among friends or families they know have somebody in need of working, because nobody would like to work for such salaries! There is a lack of specialized personnel, medical personnel above all. Of course, there are guidelines: when you create an association you must present a project specifying a list of personnel that is adapted to sustain the project. But at the end of the day, in practice you have a shortage of, and undertrained personnel. For instance, every association should have a psychologist, but it is seldom the case in reality”<sup>35</sup>.*

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34-Interview with the Secretary General of one association in a peripheral neighborhood in the South of Tunis, June 14, 2022.

35-Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022.

Another informant highlights the same difficulties related to the lack of specialized personnel and the recruitment dynamics:

*“it is just impossible that truly specialized people accept to work for a monthly salary of about 500 TND!”<sup>36</sup>.*

Despite their multiple and serious difficulties and inadequacies, associations play a fundamental role as they are the only ones currently providing systematic services to the PWDs population. Their shortcomings reflect those of a failing system of which they appear to be the main actor - as well as one of the main victims - by absorbing almost 50% of the total disability-related programmes budgets and by hosting around 86% of the 6-18 age bracket of CWDs. In other words: “they constitute the ‘armed wing’ of the MoSA: they are the ones who do things... badly, of course, but still!”<sup>37</sup>. In the end, associations constitute the only real form of support for PWDs not only in the education system, but more broadly, as it will be further detailed, in the Tunisian social protection framework as they are the only ones providing services specifically oriented towards PWDs:

*“Some associations’ centres keep PWDs until they are 35-36 years old, knowing that after that there is a total void. [...] In reality, no one wants to send their own children to these centers because everyone is aware of the despicable situation in these centers. Even the most ‘ignorant’ - forgive me for this expression - do not want to send their children there. Nobody wants to send their own children to a parking lot! But is there any alternative?”<sup>38</sup>.*

As we could assess during our field visits, the associations can host PWDs in a very large age range going from 3 to 40 years old PWDs, far more than the official age bracket (6-18). Despite the outlined shortcomings, to better understand the role played by the associations in the Tunisian context, it is important to quickly analyze three other dimensions: firstly, the practical criteria for the inclusion of CWDs in the ordinary educational system; secondly, the inclusion of PWDs into the labor market and, thirdly, the PWDs’ social protection framework.

<sup>36</sup>-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

<sup>37</sup>-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

<sup>38</sup>-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022. During our field visit to one association, we could assess that it hosted PWDs in the age bracket ranging from 3 to 42 years old.

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## THE ADMISSION PRACTICES OF PWDS IN THE ORDINARY EDUCATION SYSTEM

Prior to 2011, school integration for CWDs was managed by the MoSA. Since 2011, school integration has been transferred to a Commission for the inclusion of CWDs within the MoE. By Law 2002-80 on inclusion of PWDs within the regular education system, public schools are required to accept PWDs. In practice, most of them refuse to accept PWDs because of architectural barriers and lack of specialized personnel. According to an informant at the MoSA NCPS, “the criteria for the admission into the education system are pedagogical and linked to the physical capacities of CWDs to adapt to ordinary structures”<sup>39</sup>. However, as per the Law 2002-80, it should be quite the opposite. Schools should adapt - and be adapted - in order to include CWDs. In addition to that, schools very often do not accept CWDs if the family cannot afford to pay for a SEN teacher. The latter is provided by the MoE but the cost needs to be sustained by the family. Of course: “poor people cannot afford that!”<sup>40</sup>. Consequently, the associations stand as the only alternative to no education, especially for disadvantaged households.

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39-Interview with a member of the NCSP, MoSA, February 2022.

40-Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022.

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## THE INCLUSION OF PWDs IN THE LABOR MARKET

But what are the opportunities for PWDs once out of the education system? A system of quota exists in the Tunisian legislative framework. The orientation Law 83-2005 provides for a 1% hiring quota for PWDs in any public or private company with at least 100 employees. Draft bill 30/2015 modifies the quota to 2% and adds that any public or private company with between 50 and 99 employees must hire a disabled person<sup>41</sup>. Currently the public sector employs 2,8% of PWDs, while the private sector only 0,3%<sup>42</sup>. Besides these figures, the question is also about “who” are the PWDs that are able to secure a job in the Tunisian context. As pointed out by one interviewee:

*“The famous 2.8% of PWDs employed in the public sector is made up of PWDs belonging to the middle and upper class families able to afford to send them to college either here in Tunisia – mostly in private education – or abroad, especially in France. Those are not the PWDs that come from the ‘associations’, which are the large majority of the average PWDs population that gets any education in Tunisia. By the way, how many PWDs work at the MoSA? Zero! That is a scandal!”<sup>43</sup>.*

Despite our attempts, we were not able to obtain data on the number of PWDs employed by MoSA to verify this interviewee’s statement.

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41-This quota is below the international averages. In France, for example, the legislation requires all companies with more than 20 employees to reserve a 6% quota to PWDs.

42-Interview with a member of the NCSP, MoSA, February 2022.

43-Interview with an ex-special educational needs (SEN) teacher, Tunis, April 2022.

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## ON THE SOCIAL PROTECTION FRAMEWORK FOR PWDS

Beside poor education and low rates of inclusion in the labor market, how does the Tunisian social protection framework protect PWDS enhancing their capacity to participate in the social, economic, and (therefore) political life? In the context of non-contributory social assistance programmes, it is worth noting that no specific income support mechanism for PWDS exists in Tunisia. PWDS can only access the National Programme for Needy Families (Programme National Aux Familles Nécessiteuses – PNAFN), which is the general national program for fighting poverty. This means that only “poor” PWDS are eligible to social assistance programmes in the Tunisian social protection framework. The PNAFN covers around 8% of the Tunisian population<sup>44</sup>. According to some very outdated data (ILO 2016) referring to 2004, 17% of the PNAFN beneficiaries are estimated to be PWDS<sup>45</sup>. In order to understand the functioning of this social assistance mechanism, it should be added that while the PNAFN is assigned on the basis of the resources of the entire household, disability does not constitute a specific criterion to access this grant. Therefore, the extra-costs linked to disability - supported by the family - are not taken into consideration in the applications’ evaluations. At the impact level, the PNAFN provides direct cash transfers on a monthly basis of approximately TND 150 (approximately 50 USD) (CRES 2017) in a context where a) the minimum wage is TND 429.312 for a 48-hour week and TND 365.732 for a 40-hour week, and where b) the national currency has been progressively devaluating in the last few years due to soaring inflation (TOE 2021). Reduced to the PNAFN, social assistance mechanisms put PWDS under an increased dependence on their families, preventing them from autonomously building an individual life project.

For the sake of completeness, it should be added that a MoSA-funded “Income-Generating Project (Projet source de revenus) - PSR”, dedicated to PWDS currently exists. The PSR provides in-kind grants to selected PWDS candidates presenting a business project. However, the PSR programme is underfunded and very limited according to our interviewees that were not able to quantify the number of beneficiaries as well as its impact. Moreover, as stressed by an informant at the MoSA NCSP the managing of this fund is highly problematic and not systematized. Grants logics tend to favor the quantity of allowed grants over the quality of the applicants’ projects even if this means underestimating the amount needed for a given business project. Consequently, most applications are successful, however allowed grants are very limited or insufficient to sustain the projects’ sustainability. According to another interviewee:

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44-See: [https://civilsociety-centre.org/cap/timeline-social-protection-in-tunisia#event-\\_1959-creation-of-the-national-pension-fund-caisse-nationale-de-retraite-cnr-law-no-59-18-of-5-february-1959](https://civilsociety-centre.org/cap/timeline-social-protection-in-tunisia#event-_1959-creation-of-the-national-pension-fund-caisse-nationale-de-retraite-cnr-law-no-59-18-of-5-february-1959) [last accessed on 30 June, 2022].

45-Around 45000 people.



*“no monitoring processes are put in place, and it is not possible to ascertain if the grants actually go to PWDs or are captured by somebody within their family exploiting the PWD status of a member of his/her family”<sup>46</sup>.*

Concerning the contributory social security schemes, a negligible proportion of PWDs has access to formal jobs and, therefore, to social insurance. However, it is worth noting that, as in the case of social assistance programmes, PWDs access to social security mostly happens through a family member. The sample of a study commissioned by HI shows that 58% of interviewed PWDs are covered by some kind of social insurance (public sector or private sector social insurance), but only 26% of them are directly insured while the majority (74%) are insured through a family member (Campos Pinto et al. 2016: 29).

**Therefore, the social protection framework has little to offer to PWDs and mostly puts PWDs under the dependence of their family.** Overall, the main provider of social protection for PWDs is not the state, but rather the family.

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<sup>46</sup>-Interview with a worker of an NGO partner of the NCSP, MoSA, February 2022.

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## CONCLUSION

This paper has proposed an overview of the realities of disability in Tunisia through an analysis of the statistical, legislative, educational and social protection dimensions. By contextualizing the Tunisian situation within the international debate on disability, this study has shown that although the Tunisian legislation related to disability is often praised as one of the most advanced in the MENA region, its model remains oriented towards a medical approach rather than to a social one. The implications of such an approach on social justice are multiple, as the medical-based model implicitly operates towards the rehabilitation of PWDs rather than towards the assurance of their full participation in the social, economic and political life on equal basis with others. This rehabilitation model reflects on the whole PWDs-related social protection system that is structured around limited and underfunded disability programs with services provided out of an ad-hoc and charity-based, rather than a rights-based approach to disability. In addition to that, the gap between the legislation and the reality of its implementation is huge. The overview of the educational system, the labor market and the social protection framework clearly shows that despite the antidiscrimination principles contained in the legislation, social policies are not efficiently implemented and that different forms of marginalization and a two-tier education characterize the reality of PWDs in the country. On the one hand, the absence of dedicated social assistance programmes and the very limited inclusion of PWDs into the labor market organically put them under the social and economic dependence of their families. On the other hand, the lack of PWDs' inclusion into the ordinary education system translates into the development of a parallel education. The associations dedicated to PWDs education and vocational training express - as much as they sustain - the burden of a non-inclusive and segregating education system. Despite their numerous shortcomings such as the lack of specialized personnel, they ultimately constitute the only structures actively supporting PWDs on the ground on a day-to-day basis. Overall, this paper shows that in the context of limited state action on the subject of disability, PWDs rely on two main structures: the family and the associations, for the best and for the worst. In conclusion, the study of the disability framework offers a focused - yet meaningful - observatory to inquire, more broadly, on how individual characteristics - health characteristics in this case - (still) impact on the social, economic, and political inclusion and, ultimately, on social justice in the Tunisian context.

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## RECOMMENDATIONS

This assessment shows an important gap between the legislation and its practical implementation in the field of disability-related policies. Therefore, the main recommendations concern the implementation of the existing regulations through the constitution of operationalization strategies. Any step towards the enhancement of PWDs opportunities in the social, economic, and political arenas should be thought of and implemented through the active participation of PWDs-led civil society organizations advocating for the rights of PWDs and an active citizenship for all the members of the society.

### **The Tunisian state should**

- The Tunisian government should develop an effective, up to date, transparent, integrated disability registry and information system to support policy planning and monitoring and provision of social protection services.
- The Tunisian government should revise the definition of disability contained in the orientation Law No. 2020-83 of August 15, 2005, based on the CRPD definition, ensuring that persons suffering from mental, psychosocial and/or intellectual disabilities are included into the existing regulations. The attribution criteria of the disability card defined by the Law 2005-83 should be consequently amended to ensure the protection of the rights of the persons suffering from mental, psychosocial and/or intellectual disabilities.
- In accordance with the CRPD, the Tunisian government should revise the legislative provisions on the professional integration of PWDs, in order to increase the guarantees provided and fight against recruitment discrimination practices. Incentive and enforcement mechanisms should be strengthened and effectively implemented in order to provide legal tools to PWDs and civil-society organizations defending their rights.
- The Tunisian government should take the necessary measures for a real implementation of its school integration strategy, guaranteeing access to education for all.
- The Tunisian government should operate towards the abolition of a two-tier education for PWDs by reforming the “associations” (Rehabilitation centres or Centres of specialized education) so that they constitute real gateways to regular schooling. Eventually the education system should be reformed towards the abolition of the associations and the full integration of PWDs into the regular education system.
- The Tunisian government should consider creating an interministerial/steering committee in charge of the development and implementation of disability-related policies, as preconized by the UN CRPD. The constituted committee should include civil society organizations operating towards the promotion of PWDs rights.
- The Tunisian government should mobilize the necessary financial resources in order to guarantee an autonomous life to PWDs.

**The donor community and international NGOs should**

- The donor community and international NGOs should support the government in developing an effective, up to date, transparent, integrated disability registry ensuring that the latter is based on the definition of disability contained in the CRPD ratified by the Tunisian government in 2008.
- The donor community and international NGOs should allocate disability-related funds to the Tunisian government under the conditionality that PWDs and PWDs-led civil society organizations are integrated in the decision-making process of disability-related legislations and policies.
- The donor community and international NGOs should support the Tunisian government in developing specific, life-cycle social assistance programmes dedicated to PWDs.

**Civil Society should**

- Civil society should advocate for the participation of PWDs and PWDs-led civil society organizations in all reform processes of the legislative disability framework and PWDs-related public policies in Tunisia.
- Civil society should advocate for the development of a steering committee/inter-ministerial committee in charge of the development and implementation of disability-related policies that includes PWDs and civil society organizations operating towards the promotion of PWDs rights.
- Civil society should advocate for the systematic integration of PWDs into the political representative institutions.
- Civil society should advocate for the development of clear, reliable data on the prevalence of disability in Tunisia to be based upon the definition of disability contained in the CRPD as a prerequisite for the development of disability-related policies.

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