

INVISIBLE BEINGS: AN OVERVIEW OF PEOPLE WITH DISABILITIES' CIRCUMSTANCES IN JAPAN¹

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Abstract: Despite Japan ratifying the Convention on the Rights of Persons with Disabilities in 2014 and the fact that Tokyo will be the first city in the world to host the Paralympic Games more than once, people with disabilities are usually segregated from society and regarded as invisible. This segregation process starts at childhood and lingers throughout these individuals' lives. This work aims to outline an overview of their living conditions, as well as the Japanese legislation and recent events in the country's history.

Keywords: Disability; Japan; Human rights; Minorities; Paralympics.

1. Introduction

With the Paralympic Games on the way to 2021 in Tokyo, the living conditions of people with disabilities are increasingly in the spotlight of both academia and media coverage locally and worldwide. Dr. Etienne Krug, one of the directors of the World Health Organization (WHO), describes the event as such: *“The Paralympics is one of the world's most prominent events in which people with disabilities demonstrate their tremendous talent and energy...”* yet he notes that

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“too many people with disabilities do not enjoy even the most basic human right.” (KRUG, 2004).

The rights referred by Krug would be, for example, those of free movement (due to inadequate infrastructure), access to education (as a consequence of conventional schools lacking structure for disabled students; special schools either not existing or being financially inaccessible), and the right to their identity (with victims of massacres and sterilization not being identified). Many disabled people are, however, deprived of these rights.

This article aims to explain their living conditions in Japan, a country undergoing a process of social transformation, due to the increase in visibility and rights for those with disabilities. However, recent events, such as the Sagami-hara tragedy and the Eugenics Law, show that there’s still a long way to go, especially regarding the segregation of the disabled. There is still a longstanding tradition of families hiding members with disabilities and, during their upbringing and the start of their work lives, they usually live separately from Japanese society.

The Paralympics will be a new stage in this transformation process, as the games will be an opportunity to show real people with various kinds of disabilities excelling in their respective sports to billions around the world. Japan already has a history with the Paralympics: the country began its participation in 1964 as host to the Summer Olympics and then also to the Winter Paralympics in 1972 (Sapporo) and 1998 (Nagano). With the 2021 Games, Tokyo will once again host the Paralympics.

2. The Disability Plight

People with disabilities account for 15% of the world population, which is equivalent to approximately one billion people. This minority group is distinctive due to two main factors: 1) being the largest population minority in existence (MAIOR, 2016, p.3) and 2) having diversity as one of its most evident characteristics, unlike other social groups that are visibly homogeneous and have shared needs (CARVALHO, 2012).

Persons with disabilities are defined as *“individuals who have their daily and social experiences substantially and continuously limited due to physical, intellectual, or mental impairments”*, according to Article 2 of the Basic Act for Persons with Disabilities⁴, the first Japanese law regarding this population, in 1970 (CABINET OFFICE, 2011, p.1).

In the past, people with disabilities have been viewed as flawed individuals with fearful conditions who are unable to meet social expectations, such as working or having children. The increasing social movements defending human rights, independent living, and self-determination have subverted this model and introduced new values, such as positive identity, dignity, and pride (HEYER, 2000a).

4 障害者基本法: *Shōgaishakihonhō*.

People with disabilities started to be seen as active members of society and as individuals who are able to exercise their own rights (LO, 2012). And disability itself was now seen as a problem external to its bearer, found “*within society, rather than in individuals who just happen to have impairments*” (FRENCH, 1993, p.16, apud STIBBE, 2004, p.22). The solution then became to adjust the social and physical environments in order to properly meet the disabled population’s needs and rights.

The main types of barriers faced by disabled people are: (i) their needs not being taken into account in public policies; (ii) prejudices and misconceptions that hinder social participation; (iii) insufficient services, especially in the health and rehabilitation sector; (iv) inefficient services coordination; (v) inadequate investment; and (vi) lack of accessibility infrastructure-wise, especially in transportation and communication (WHO, 2011).

The rights of people with disabilities as a theme only achieved international scope thanks to the United Nations (UN), with their inauguration of the International Year of Disabled Persons in 1981 (HEYER, 2000b). But the main change occurred in 2006, with the creation of the Convention on the Rights of Persons with Disabilities (CRPD): the first comprehensive multilateral treaty on disabilities; in other words, a paradigm shift occurred. Its signatories committed to many responsibilities, such as: to prohibit discrimination, provide rehabilitation and vocational training services, promote jobs in both the public and private sectors, as well as to ensure “reasonable accommodation” in the workplace (UN, 2006, apud LO, 2012).

Japan signed the Convention in 2007, but only ratified it in 2014, becoming the 140th country to do so, after China and South Korea (SHIRASAWA, 2014). The reason for that delay was due to the Japanese government not putting forward sufficiently effective policies in accordance with the Convention. Japan was accepted after establishing the Act for Eliminating Discrimination against Persons with Disabilities⁵ in 2013 and creating an amendment in 2014 to the 1970 Law (NAGASE, 2013).

Even though the first law was created in the ‘70s, progress on disability rights still took decades. Before the 1990s, according to Stibbe (2004), people with disabilities were invisible on television, as well as in society. They sometimes appeared in documentaries and educational programs, but never during prime time.

The introduction of a disabled character first occurred in 1993 with the *dorama*⁶ *Hitotsu Yane no Shita*⁷, in which a side character was a wheelchair user. But, it was only with *Hoshi no Kinka*⁸ – in which the protagonist was a deaf nurse – that disabled characters (mainly hearing impaired) took center stage and became part of popular

5 障害を理由とする差別の解消の推進に関する法律: *Shōgai wo riyū to suru sabetsu no kaishō no suishin ni kansuru hōritsu*.

6 ドラマ: from the English “drama”, it’s a popular term used for Japanese dramas or TV series.

7 ひとつ屋根の下. Official English title: Under One Roof.

8 星の金貨. Official English title: Heavens’ Coin.

culture. Sugimoto (2001, apud STIBBE, 2004) explains that these *doramas* have had a significant impact on Japanese society, introducing concepts such as *bariafuri*⁹ and causing a boom in demand for sign language courses.

Since then, there's been an increase in series that deal with disabilities, including animations, whether in fantastic ways (through transmutation in *Fullmetal Alchemist*¹⁰ or demon contracts in Tezuka's classic *Dororo*¹¹) or in realistic ways (the loss of an arm due to bombing in during World War II in *Kono Sekai no Katasumi ni*¹² or deafness as a congenital condition in *Koe no Katachi*¹³). In all these examples, the disabled are the heroes and the series are not afraid to show the difficulties of their daily lives (O'REILLY, 2018).

Since in Japan people with disabilities usually live in separate environments from the rest of society and are even hidden by their families at times, the only contact most people have with disability is through its fictional representation (STIBBE, 2004). The media then ends up with the role of making society aware of disability.

This invisibility turns even data collection and research into a challenge. Officially, Japan has approximately 7.8 million people with disabilities, or 6% of its total population (CABINET OFFICE, 2015). This amount is significantly lower than other countries; for example, the United Kingdom has 27.2% and Finland, 32.2% (MATSUI, 2009, p.1). There are several reasons for this, such as 1) the desire by the individual or their family members to hide the condition; 2) data collection without frequency and lack of a universal methodology; 3) the absence of an agency responsible for data collection. Until 1973, such endeavors were carried out by means of home visits with questionnaires and interviews, but these were abolished for infringing on the right to citizens' privacy. The new method to collect data then relied on regional hospitals and thus lacked a national scale scope (OKUNO, 1998; HEYER, 2000b; OI, 2009). Therefore, even current data does not necessarily reflect the reality of disability data in Japan.

Japan officially recognizes three types of disability identification: (i) physical disability, (ii) intellectual disability, and (iii) psychological disability. The first type includes cases of physical impairment such as visual and hearing impairment. The second deals with delayed learning, limitations in communication, personal care, and social skills. And the third deals with psychological abnormalities, such as schizophrenia (SUZUKI, 2009; LO, 2012; MAIOR, 2016). The last survey conducted by the government – at the time of this work's publication – was in 2015, and it stated

9 バリアフリー from the English barrier-free.

10 While that's the official English title, the Japanese title differs a bit: 鋼の錬金術師, *Hagane no Renkinjutsushi* (lit. *Steel Alchemist*).

11 どろろ.

12 この世界の片隅に. Official English translation: In This Corner of the World.

13 聲の形 (lit. Shape of a Voice). The Official English translation is A Silent Voice.

that there were 3,937,000 people with physical disabilities (31% of the disabled population), 741,000 people with intellectual disabilities (6%), and 3,201,000 people with psychological disabilities (which accounts for 25%) (CABINET OFFICE, 2015).

In order for a person with disability to be legally recognized as such, he or she must carry an identification document, as well as a disability guide, which lists the name, type, and severity of the condition. It is not obligatory to carry the document at all times, but that is what makes it possible to receive economic benefits¹⁴ and discounts on social and medical services. Only individuals with this document are counted for disability quotas. Activist groups heavily criticize this choice due to the stigma and shame attached to this type of identification (HEYER, 2000a).

In Japan, there is also a deep stigma against those who are unable to work (ADAMS, 2016). Employment is a key symbol of – particularly male – status and the inability to be able to perform this role invokes a sense of failure, especially for disabled men (TAKAGI, 2016). Disabled women, however, face even more vulnerability than men. For them, the opportunity for independence may be virtually non-existent. They are less likely to marry, and in the case of women who acquired a disability after marriage, there is a greater likelihood of divorce (GILL; CAROL, 1996 apud LEE, 1998).

There is a sense of shame in having “abnormal” relatives, and it is considered the duty of the family – mainly women – to not only care for, but even hide them from society (STEVENS, 2007 apud TAKAGI, 2016).

This stigma is evident in the Sagami-hara tragedy in 2016, the largest mass extermination in Japan since World War II. The attack happened at the *Tsukui Yamayuri En*¹⁵ clinic in Kanagawa, which specializes in caring for patients with mental disabilities. 19 people were killed and 26 were injured there. The perpetrator of the massacre was a former employee, Satoshi Uematsu, who defended the act “*in the name of Japan and world peace*” (HERNON, 2017, p.1), claiming that disabled people should disappear.

Unlike in the West, the police doesn’t usually reveal the victims’ identities to the media. This decision was intended to focus on protecting the victims’ families. This action intensified the debate regarding the existing prejudice against people with disabilities. According to Suzanne Kamata (HERNON, 2017, p.1), “*Not showing their names and faces is like denying their humanity. The incident did not receive the same level of attention as other tragedies, there were no hashtags on Twitter, and the subject died quickly.*” The lack of information about the victims hinders the development of empathy towards them (ADAMS, 2016; HA; SIEG, 2016; HERNON, 2017).

14 These economic benefits include: tax reduction and exemption from some taxes, subsidies when purchasing mechanical or electronic aid items, and discounts on public transportation. Adults with severe conditions who receive an annual salary of less than 3.4 million yen (the equivalent of \$34,000) can receive 26,800 yen per month. Families with disabled children are entitled to 33,000 to 50,000 yen per month depending on the degree of the disability, and an additional 14,000 yen if the children require constant care (HEYER, 2000b; PENKETH, 2015).

15 津久井井やまゆり園

Another issue that has been majorly discussed and criticized is the Eugenics Protection Act¹⁶ of 1948, which legally authorized the sterilization – with or without consent – of those with disabilities and hereditary mental illnesses to “*prevent the birth of inferior offspring (...), protect the life and health of the mother (...), improve the quality of the nation*” (HURST, 2018, p.2). Even individuals who consented to the procedure often did so under threat from doctors and family members. This law lasted for nearly five decades, and was only repealed in 1996 (HURST, 2018; McCURRY, 2018).

The Eugenics Protection Act still generates repercussions to this day. Between 1948 and 1996, approximately 25,000 people were sterilized, of which 16,500 underwent forced sterilization. Concerning the latter, 70% of the procedures involved women, with the youngest patients being only 10 years old at the time of her sterilization (HURST, 2018).

In 2016, the UN Committee on the Elimination of Discrimination against Women (CEDAW) called on the Japanese government to adopt “*measures aimed at providing access to legalized remedies, compensation, and rehabilitation services to all victims of forced sterilization*” (McCURRY, 2018, p.2). But, it was not until 2018 that discussions about compensation began. The victims are the ones leading the lawsuit and they argue that the The Eugenics Protection Act is both unconstitutional and that it infringed on their bodily autonomy rights. The victims seek compensation of 11 million yen, the equivalent of \$100,000 (ASAHI SHIMBUN, 2018a). The government showed interest in talking with the victims, but claimed that it had no plans to provide compensation for all of them since it had no legal responsibility to do so (McCURRY, 2018; ASAHI SHIMBUN, 2018a).

Other countries that have carried out similar procedures, such as Germany and Sweden, have publicly apologized to the victims and provided them with financial compensation, while the Japanese government has not compensated any victims to date¹⁷ (McCURRY, 2018; ASAHI SHIMBUN, 2018a). Recently, there have been signs of possible evolution. There are plans to conduct fact-finding missions in conjunction with local authorities, which could be a possible precedent for public apologies (HURST, 2018).

For Hurst (2018), although forced sterilizations were abolished in 1996, the discriminatory attitudes that existed behind the law are still present in today’s Japanese society. Nowadays, Japan has a sophisticated Welfare State, with good rehabilitation institutions aimed at disabled people, but that comes at the expense of equality and integration since these institutions are separate from the rest of society. And despite improvements in infrastructure with the creation of “barrier-free” areas in the past decades, people with disabilities are systematically treated as invisible by Japanese society (OTAKE, 2006).

16 優生保護法: *Yūsei Hogo Hō*.

17 At the time of this article’s publication (in 2020).

The institutionalization of people with disabilities is still a common tradition in Japan. Children with disabilities usually study in special schools¹⁸, each dedicated exclusively to a specific type of disability. Upon graduation, these young adults either live in rehabilitation centers (public or private)¹⁹, work in remote warehouses²⁰ or in welfare factories for the physically disabled²¹. The isolation and segregation from mainstream society that start during their childhood remain throughout their lives (ADAMS, 2016).

In 2006, the Fundamental Law of Education²² led to education reform in Japan (VISLIE, 2003 apud MITHOUT, 2016). This reform had as its principle the idea of “education for all”. That meant that schools would have an obligation to meet the demands of all children, regardless of particularities in abilities, knowledge of the Japanese language, as well as ethnic, social, or family background. According to Mithout (2016), this is was provided financial relief to parents since special schools are expensive due to their low student-teacher ratio (of up to six students per teacher).

However, this reform’s success varied heavily depending on the disability type. Children with visual and hearing impairments continued to encounter major obstacles in taking entrance exams to non-special schools, while the physically disabled struggled with lack of accessibility in school grounds. On the other hand, autistic children and children with developmental disabilities in general had higher rates of success fitting in (MITHOUT, 2016). Increasing the amount of students with “invisible disabilities” in mainstream schools may increase their social recognition, but it is not a fix-all solution, as children with other types of disabilities continue to have limited – or complete lack of – access to these schools (DISABLED WORLD, 2010; HEYER, 2000a).

The attitudes of teachers, school administrators, other children, and even family members are also barriers to these children’s inclusion in mainstream education (WHO, 2011). The tradition of hiding disabled children, bullying, abuse and authorities’ lack of attention or attitude are obstacles that haven’t been solved. Segregation in childhood becomes one of the biggest obstacles to their future. Children with disabilities grow up in a bubble, unprepared to deal with the real world and, in most cases, this bubble permanently limits their chances of entering society. When they reach adulthood, they tend to live either with their parents, in institutions or in group homes, which makes it difficult or even impossible for them to adjust to Japanese social norms and long working hours (KUDO, 2010).

18 養護学校: *Yōgo gakkō*.

19 These centers not only don’t protect worker’s rights but they also pay wages under 30,000 yen per month, which makes it impossible for a person with disability to live independently (OTAKE, 2006).

20 授産施設: *Jusan shisetsu*.

21 身体障害者福祉工場: *Shintaishōgaisha fukushi kōjō*.

22 教育基本法: *Kyōiku kihonhō*.

The quota system introduced with the Promotion of the Employment of Persons with Disabilities Law²³ in 1960 aimed to ease the work inclusion issue by establishing that at least 2.2% of total vacancies in the private sector²⁴ and 2.5% in the public sector had to be filled by people with disabilities (INAGAKI, 2018). In case of non-compliance, a fine of 50,000 yen (\$454) must be paid. The law also requires the employer to create “reasonable accommodations” so that workers don’t face undeserved hardships (YES, 2018; ASAHI SHIMBUN, 2018b; LO, 2012).

However, the quotas were never filled. The increase in employability only occurred after the names of companies that did not fill the quota were published. The media criticism and pressure from public opinion forced these companies to change their behavior. For Mori and Sakamoto (2018), social norms appear to be one of the main factors in encouraging the employability of disabled people, even when no fines are paid.

The Japanese quota system is one of the most complex in the world, but reliability in the system is shaken after learning that even the government, a body that should be an example to society as well as responsible for regulating and punishing the private sector, has manipulated data to appear more inclusive than it actually is (SHIMAMOTO and MURAKOSHI, 2018; SIRIPALA, 2018; YES, 2018).

The lack of a national institution focused on people with disabilities with no ties to the government hampers both social mobilization and data collection, plus its verification. The soft law characteristic of most Japanese laws is yet another challenge due to its lack of punitive character. There is a legal tradition of providing only the “duty to compromise”, born from the fear that mandatory laws would threaten Japanese society’s harmony (PECKITT, 2016; NAKAGAWA, 2010). Kristof (1996) argues that such “harmony” is acquired by excluding all those who do not fit in. This exclusion means that people with disabilities are often discouraged from getting married, working, or even going out for leisure purposes (such as going to movie theaters and restaurants). In other words, they’re discouraged from living in society as citizens.

Conclusion

A transformation is taking place in Japan due to the increased awareness of rights for people with disabilities coupled with the creation and implementation of laws as tools for social change (HEYER, 2000b), especially with the Paralympic Games on the way. However, there are still stigmas based on prejudiced conceptions, as well as a lack of interest and proactivity by the government, to which activist groups and victims publicly demand change.

23 障害者の雇用の促進等に関する法律: *Shōgai-sha no koyō no sokushin-tō ni kansuru hōritsu*. At first, this law only included people with physical disabilities. In 1987, people with mental disabilities were included, although their employment was not yet mandatory.

24 This applied to companies that had at least 45 workers (INAGAKI, 2018).

The Paralympics offer not only an opportunity to bring to reality a topic that for many is abstract or unknown, but they are also a way to test the host country's infrastructure. Both in China and Russia, after their respective Paralympic Games, there was significantly more awareness and discussion about disabled people's conditions. Nowadays, 200 Russian cities use Sochi as a model. The same occurred with Barcelona back in 1992 and is now one of the most accessible cities in Europe (CRAVEN, 2016).

Craven (2016) emphasizes the importance of the Paralympics' role in empowering individuals through social inclusion. For Blauwet (2005), there is no doubt that the passion shown in Paralympic athletes' effort and ability will translate into awareness and advocacy for endeavors in other areas, such as study and work.

However, Marshall (1998, apud STIBBE, 2002) points out that there is a difference in treatment between disabled people who overcome their barriers with sports and "ordinary" disabled people. Athletes' narratives focus on the individual's ability to overcome their individual tragedy. Society appears to not have a role. Van Der Veere (2020) points out that this is problematic because these stories individualize disability, rather than dealing with the social problems that people with disabilities face in their everyday lives. It becomes important to "*appreciate people with all kinds of disabilities, regardless of whether or not they can ski down a mountain*" (MARSHALL, 1998, apud STIBBE, 2002, p.15).

Therefore, even if society may view Paralympians in a positive light, there can still be a lack of understanding – and a negative view – of disability in general. The Paralympic Games can help shed visibility and increase acceptance of those with disabilities, but they are only a part of the process. Society, government and the private sector must not forget their roles' importance in this topic. In Japan, people with disabilities are still relegated to the condition of invisible beings even as Tokyo prepares to host the Paralympic Games for a second time.

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