

## Disability as a complex cultural identity

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### Abstract

*According to the World Health Organization, disability would concern approximately 10% of the world's population, i.e. 650 million people. This makes it one of the largest minorities in the world. However, disability is still considered as a taboo and is under-represented. Disabled people still have to endure many discriminations. Since 1992, the 3rd of December has been celebrated as the international Day of Persons with Disabilities. This day provides visibility for the rights of people with disabilities, the benefits of their inclusion in society and raises public awareness. This article consists of four distinct parts. It deals with the history of disability through the ages, the culture of disability as a creation of identity, sociological behaviours in reaction to disability and finally provides a comparative study on the situation of disability in France, the United Kingdom and the United States.*



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## Introduction

*“People with disabilities are among the most marginalised groups in the world. They are in poorer health, have lower levels of education, participate less in economic life, and experience higher rates of poverty than people without disabilities.*

***Disability is now seen as a human rights issue. The people concerned are also disabled by society and not just by their bodies.***

*These barriers can be overcome provided that governments, non-governmental organisations, persons with disabilities, and their families work together.”*

World Health Organisation, 2020<sup>1</sup>

On the occasion of the International Day of Persons with Disabilities and World Disability Day, GROW is highlighting people with disabilities to underline the changes that have taken place in the world and to highlight the rights they enjoy today. The aim of this day, and more specifically of this article, is to raise public awareness, sensitize about the rights of people with disabilities, and to inform about the benefits of including people with disabilities in our society<sup>2</sup>.

According to the Larousse dictionary: “Disability is an activity limitation or restriction on participation in society due to an alteration in sensory, physical, mental, cognitive or psychic capacities. Figuratively speaking, disability is defined as a disadvantage that places the person in a state of inferiority”<sup>3</sup>.

This simple definition indicates a negative image and a feeling of inferiority associated with disability through this figurative sense.

To understand how we are going to approach disability, some key terms related to the marginalisation and embarrassment associated with it need to be defined.

“A taboo is a subject that would be improper to evoke, by virtue of social or moral decency.”<sup>4</sup>

“Marginalisation is the act of setting someone apart from society, placing them outside the center of an activity.”<sup>5</sup>

This article will approach different aspects of handicaps. First, it will retrace the history of disability. Then, it will address the matter of culture and identity. Following this, it will analyze handicap from a sociological angle. Finally, in order to illustrate the main point of this article, it will present a

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<sup>1</sup> World Health Organisation. 10 facts on disability. Available at: <https://www.who.int/features/factfiles/disability/fr/> [Accessed 24 Sept. 2020].

<sup>2</sup> French ministry of education. International Day of People with Disabilities. Available at: <https://www.education.gouv.fr/journee-internationale-des-personnes-handicapees-3200> [Accessed 24 Sept. 2020].

<sup>3</sup> Larousse dictionary. Definition of Handicap. Available at: <https://www.larousse.fr/dictionnaires/francais/handicap/38988> [Accessed 24 Sept. 2020].

<sup>4</sup> Larousse dictionary. Definition of a Taboo. Available at: <https://www.larousse.fr/dictionnaires/francais/tabou/76319> [Accessed 24 Sept. 2020].

<sup>5</sup> Larousse dictionary. Definition of Marginalisation. Available at: <https://www.larousse.fr/dictionnaires/francais/marginaliser/49446> [Accessed 24 Sept. 2020].



comparative study on the situation of disability in France, the United Kingdom, and the United States. To conclude, this article will end with some recommendations of associations for disabled people, as well as other cultural recommendations such as films. This part can be read on its own.

## Chapter I : The History of Disabilities

### Antiquity

During this period of time, people with disabilities were excluded from society. They were perceived as impure and as victims of divine curses.

### Middle Ages

During the Middle Ages, people with disabilities were recognized but locked up. It was a common thought to believe that these people had committed a sin in their previous life, meaning that it was God's will to make these people live with a physical disability to punish them. Malformations were therefore seen as sanctions sent by God to punish humans for their sins. This myth was a sort of propaganda that encouraged the able-bodied (term employed to define people without disabilities) to have exemplary behaviour.

Throughout the years, many Hôpital-dieu (former hospitals and social services) emerged. They were intended to welcome the poor, sick people and people with disabilities. This was progress for the time, but still a small step: these people were only partially integrated into society because their disabilities were scaring some people. They were therefore locked up to not "disturb" the rest of the society.

With medical progress and the evolution of popular beliefs, religion was no longer used to explain the existence of people with disabilities, but the accusation turned to the mothers of psychotic children. Handicap would therefore stem from bad education, and would not be linked to a strictly mental disability.

### The 17th Century

The 17th century is synonymous with progress, advances and changes. Disability was interpreted from a medical perspective, allowing the people concerned to be cared for not only from a social, but above all from a medical point of view. Some people were treated and cured. The new movements of this century, particularly the philosophers of the Enlightenment, are gradually including people with disabilities to give them a place in society. Thanks to Voltaire, Montesquieu, or Rousseau, these people are considered in some writings as equal to other human beings: the philosophers cited postulate that they should therefore be treated with the same respect as non-disabled people.

Moreover, Diderot wrote several pieces to sensitize literate people to the situation of people with disabilities. We can notably cite: *Letter on the Deaf and Dumb* or *Letter on the Blind*. He demonstrates the equality of the minds to make education and instruction accessible to people with disabilities.

The Abbé de l'Épée founded the first school for deaf and mute people. He was the pioneer of the concept of sign language, to allow deaf and mute people to communicate and have access to education.

It is only from the 18th Century onwards that we can perceive more integration for disabled people. Philosophers and clerics played a major role in this (very) partial integration defending the fact that people with disabilities should be stimulated with education and instruction to become autonomous.

### The 19th Century

From the 19th century onwards, Victor Hugo, through his novels, wanted "literature to be a mirror of universal life". He then incorporated characters with disabilities into his novels, the best known being the



Hunchback of Notre-Dame, Quasimodo. During this same century, in the medical field, functional prostheses made of boiled leather made their appearance. This was another victory for the inclusion of people with disabilities. The visibility of people with disabilities in the literature has made it possible to consider them more highly and thus to make medical progress for this audience.

Although people with motor disabilities were more included in society, people with mental disabilities did not have the same treatment. They were sent to psychiatric asylum with the goal of making them work in the fields depending on their capacities. We can therefore speak of forced labour or even slavery. The largest asylum in Europe, located near Clermont-en-Beauvaisis, will close in 1880.

### **From the 20th Century to the present day**

In the 20th century, laws on people with disabilities and associations were created to defend their rights. It allowed them to be included in a more concrete way in society: this was the purpose of the 1901 law. Thanks to it, associations such as the National Federation for the Inclusion of People with Sensory Disabilities and DYS<sup>6</sup> in France (FISAF), the Federation of the Disabled at Work, the Association of Paralysed People in France (APF) and many others have been able to contribute to the equality of able-bodied people and people with disabilities.

In 1905, the Law on Assistance to the Elderly, Cripples, and Incurable Persons was passed. It made it possible to assist dependent people to integrate them as much as possible into society and allow them to continue to live normally despite their loss of autonomy.

In 1975, the law of orientation in favour of disabled people was passed. “Prevention” and “screening” of disability are privileged, as well as the obligation of access to education and the maintenance of a working and living environment for disabled people.

The law on the obligation to employ handicapped workers, war-disabled and assimilated persons appeared in 1987. It requires that all persons be included in the work environment and that no discrimination be made.

In 2005, the Disability Compensation Benefit (PCH) was introduced: this is a financial aid paid by the department to reimburse certain expenses related to the loss of autonomy. This new law was innovative but unfinished because there is a financial obstacle for the State. The latter does not have the necessary budget to meet the needs of all people with disabilities. In 2016, more than 40 billion euros have been paid for the PCH. Secondly, the benefit does not take into account human assistance: the intervention of a person alongside the person with a disability, who is dependent or in loss of autonomy, who helps him or her to perform certain acts of everyday life (shower, kitchen, etc.). Finally, it should be noted that the benefits are not adapted for children. Indeed, material aids are often not adapted to their size, for example.

In an attempt to propose solutions, it might be necessary to follow the British model, which consists of contributing more for associations, which would then allow them to be better heard and to defend the rights of people with disabilities more effectively. Also, paying more taxes would allow the State to invest in the best way for the people affected by PCH so that they have recourse to the most appropriate aid. In addition, the State would be less indebted and could thus give more to assert the rights of all. But in the current context in France, raising taxes would only worsen the French economy. Revising the distribution of the state budget may be another solution to include all residents of France without asking them for more.

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<sup>6</sup> These are Specific Language and Learning Disorders. DYS disorders include dyslexics, dyspraxics, or dysphasia, ...

Today, many social, political, and medical advances have been proven. But the means made available for the adaptation of public places for people with disabilities are not yet respected everywhere, which proves that there is still a long way to go<sup>7</sup>.

## Chapter II : Disability as a culture and identity

### Problems around the definition of disability

The terms “disability” and “handicapped” cover a wide range of people and realities. If we take, for example, the two emblematic figures of disability, people with Down's syndrome and paraplegics, they are not enough to define the globality and complexity of disability. There is therefore a need to define disability in an adapted manner if we wish to understand the different realities experienced by the people concerned. The Law of February 11, 2005 for the equality of rights and opportunities, participation and citizenship of persons with disabilities gave the first definition of disability, in its Article 2:

*“For the purposes of this law, a disability is defined as any limitation of activity or restriction of participation in society suffered by a person in his or her environment as a result of a substantial, lasting or permanent impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling disorder.”*

However, as psychiatrist and occupational physician Claude Veil points out: “people with disabilities are a social group with imprecise contours”. According to a Handicap-Incapacity-Dependence survey, between 3 and 15% of French people aged 17 to 59 declare themselves to be more or less disabled<sup>8</sup>. Disability is therefore a subjective issue since it represents a feeling and experience that depends on the individuals concerned. This new way of thinking about disability is taken into account by the International Classification of Functioning, Disability and Health, which insists on a vision of disability that integrates the reduction or aggravation of different types of disability, as well as contextual and environmental factors. This vision enables treatments and aids to be adapted to changes in disability.

### Where does the term “disability” come from?

The term “disability” was first used in a 1957<sup>9</sup> law on the employment of persons with disabilities. With the law of 30 June 1975 on the orientation of disabled persons, the aim was to use a less discriminatory vocabulary than certain terms previously used, such as infirm, maladjusted, invalid, etc. The term “handicap” was used for the first time in a 1957 law on the employment of disabled persons. Through this new name, society abolishes negative or stigmatising connotations, but it also shows a step towards a new approach and management of disability.

<sup>7</sup> N.D. (2013). *L'histoire du handicap*. handicap.fr. Available at: <https://informations.handicap.fr/a-histoire-handicap-6026.php> [Accessed 24 Sept. 2020].

BALDON, L. (2018). *Handicap : 40 milliards d'euros de dépenses... ciblées ?* ifrap.org. Available at: <https://www.ifrap.org/emploi-et-politiques-sociales/handicap-40-milliards-deuros-de-depenses-ciblees> [Accessed 24 Sept. 2020].

<sup>8</sup> FRONTEAU, A. & LE QUÉAU, P. (2003). Le handicap : du problème personnel à la reconnaissance sociale. *Credoc consommation et mode de vie*, n° 163. Available at: <https://www.credoc.fr/publications/le-handicap-du-probleme-personnel-a-la-reconnaissance-sociale-de-220-000-a-4-millions-de-personnes-selon-les-definitions> [Accessed 24 Sept. 2020].

<sup>9</sup> Loi n° 57-1223 (23 nov 1957). Article 13. Available at: [https://www.unea.fr/sites/default/files/loi\\_57-1223\\_du\\_23\\_novembre\\_1957\\_sur\\_le\\_reclassement\\_professionnel\\_des\\_travailleurs\\_handicapes\\_o.pdf](https://www.unea.fr/sites/default/files/loi_57-1223_du_23_novembre_1957_sur_le_reclassement_professionnel_des_travailleurs_handicapes_o.pdf) [Accessed 24 Sept. 2020].



The term “disability” is linked to the field of health, because of its individual and subjective dimension, but it is also linked to the legislative field since it is the law that defines who can have the status of a disabled person or not. This competence is reserved for the Commission for the Rights and Autonomy of Disabled Persons<sup>10</sup>, which is the only body that can designate a person's rate of disability and can therefore award him/her the benefit of his/her compensation in terms of work or education. This enables the disabled person to access this status of beneficiary and the compensation provided for by the Law of 11 February 2005, Article 2: “*right to national solidarity which guarantees access to the fundamental rights recognised for all citizens as well as the full exercise of their citizenship*”.

The word “disability” represents both people with impairments or disabilities in the medical field and the level of constraint, difficulty, or disadvantage in the social field. As regards the latter, instead of normalising disability and its representation, society presents them as abnormal and marginal.

Thus, the term “disability” is defined in a constant confrontation between the medical and social fields, but also between notions of what is normal and what is pathological.

Our way of thinking about disability is therefore not limited to the ways of thinking created by institutions and different organisations, but must also be created in a relationship between people with and without disabilities<sup>11</sup>.

### **The objectification of singular experiences to create a collective identity**

As people with disabilities cannot gather around their experience, which is subjective, they gather around the social experience they all share: exclusion from society. Transforming a unique experience into a common experience can be done in two stages: first by socialisation and politicisation, then by objectification of this experience. Objectification marks a difference between the subjectivity of the unique experience and the common experience. Thanks to this objectification, disability is detached from the individual to represent a social, political, and objective reality. It is no longer the inability of the individual to adapt to society, but the inability of society to include him/her. It enables people with disabilities to free themselves from the responsibility of their disability and become political actors with the aspiration to change society<sup>12</sup>.

### **Handicapped by society**

Society has an influence on the creation of a disability identity. People with disabilities are poorly included both morally and materially. They suffer from discrimination but also from the lack of infrastructures adapted to their situation.

According to a European Commission study<sup>13</sup>, 85% of European public opinion thinks that access to public transport for people with physical disabilities is difficult and 59% of respondents think that access to schools and universities for blind people is difficult. Faced with this type of exclusions, movements are born with the aim of making society more inclusive, such as the Disabled in Action - Disability in action

<sup>10</sup> Loi n° 2005-102 (11 fév 2005). Pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, Article 66. Available at: <https://www.legifrance.gouv.fr/loda/id/JORFTEXT000000809647/2020-09-25/> [Accessed 24 Sept. 2020].

<sup>11</sup> COMPTE, R. (2008). De l'acceptation à la reconnaissance de la personne handicapée en France : un long et difficile processus d'intégration. *Empan*, (n° 70), p. 115-122. Available at: <https://www.cairn.info/revue-empan-2008-2-page-115.htm> [Accessed 24 Sept. 2020].

<sup>12</sup> OLIVIER, M. & BARNES, C. (2010). Disabled People and Social Policy: From Exclusion to Inclusion, op. cit., p. 73. Available at: <https://www.cairn.info/revue-les-cahiers-du-centre-georges-canguilhem-2010-1-page-69.htm> [Accessed 24 Sept. 2020].

<sup>13</sup> THE EUROPEAN OPINION RESEARCH GROUP (EORG) pour la Direction Générale de l'Éducation et de la Culture. Les européens face aux handicaps eurobaromètre 54.2. Available at: [https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs\\_149\\_fr.pdf](https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_149_fr.pdf) [Accessed 24 Sept. 2020].



(DIA) in the United States or the Union of Physically Disabled Against Segregation (UPIAS) in Great Britain.

The British prefer the term “socially disabled people” rather than simply talking about “disabled people”, meaning that disability is created by society and not by those living with that disability. People with disabilities transform a created negative image into a positive identity through the reversal of stigma. Exclusion from society has implications for them in terms of education, careers and community life. This affects their self-esteem and can cause them to have a bad self-image, whereas a person with a physical disability may have the same academic potential and the same intellectual capacities as a person without a disability.

### **Disability Identity Denial: Denial and “Loss of Self”?**

However, some people with disabilities do not consider themselves disabled. There are two possible explanations for this situation. The first is the consequence of a conformity that can be qualified as standardization. People with disabilities try to live like able-bodied people. To integrate into society, they negotiate their lives to be as normal as possible in order to be accepted. But research on identity, ego and disability characterizes this normalization as a “loss of self”<sup>14</sup>. This denial would be oppressive and would take away from the person their true identity<sup>15</sup>.

The second explanation could be an acceptance of disability as a characteristic that does not cover the whole personality of the person. This would be the best position to adopt as it would allow an adequate distinction to be made between handicap and impairment. With this reasoning, disability cannot justify the exclusion of someone or the diminishment of someone's humanity. The choice to integrate disability as an integral part of identity is consistent with the idea that objective social experience must be enriched by subjective experience. For Sally French and Liz Crow<sup>16</sup>, this subjective experience must be re-introduced into the social model. This is necessary in order not to exclude certain people from the movement, as well as to give an adequate response to the intrinsic expectations of disability. Moreover, according to them: “knowing yourself and your disability is the first step towards empowerment”<sup>17</sup>.

People with disabilities have succeeded in creating a disability identity by coming together around an objective social experience of exclusion from society enriched by a subjective experience. This positive identity is created against the negative idea of society, which sometimes leads to a denial of disability for some people. To be more inclusive, society must view disability as a characteristic and not as a global identity.

<sup>14</sup> SHAKESPEARE, T. (2010). "Disability, Identity and Difference" in G. Barnes & G. Mercer (eds), *Exploring the Divide: Illness and Disability*. Leeds: Disability Press. [online] 2010. Available at: [http://thedigitalcommons.org/docs/shakespeare\\_social-model-of-disability.pdf](http://thedigitalcommons.org/docs/shakespeare_social-model-of-disability.pdf) [Accessed 24 Sept. 2020].

<sup>15</sup> MURUGAMI, M. W. (2002). Disability and Identity. *Disability studies Quarterly the first journal in the field of disability studies*. Available at: <https://dsq-sds.org/article/view/979/1173> [Accessed 24 Sept. 2020].

<sup>16</sup> FRENCH, S. (1993). Disability, impairment or something in between? in J. Swain, V. Finkelstein, S. French & M. Oliver (éd.), *Disabling Barriers – Enabling Environments*. Londres, Sage, p. 17-25.

CROW, L. (1996). Including all of our lives: renewing the social model of disability. in C. Barnes & G. Mercer (éd.). *Exploring the Divide*, Leeds. Disability Press. p. 55-72.

<sup>17</sup> WINANCE, M. RAVAUD, J-F. (2010). Le handicap, positionnement politique et identité subjective. Le cas des pays anglo-saxons. *Les Cahiers du Centre Georges Canguilhem*. (N° 4), pp.69-86. Available at: <https://www.cairn-int.info/revue-les-cahiers-du-centre-georges-canguilhem-2010-1-page-69.htm> [Accessed 24 Sept. 2020].



## Chapter III: Disability and sociological behaviour

### Guilt and pity

If we go back to the Middle Ages, deformities and deformities were seen as punishments from God, a punishment for the sins committed by people with deformities. The handicap of these people would then allow them to “redeem their faults”. While people with disabilities initially repent of a feeling of guilt towards themselves and their “faults”, this guilt will gradually trickle down to their parents. The mother giving birth to a disabled child finds herself held responsible for the pathology of her child according to the medical profession. But what about this guilt these days? Has this feeling really disappeared? Some road safety campaigns would try to tell us no.

In 2015, a road safety campaign titled “How Long”<sup>18</sup> showed the difficulties of the “post-accident” for victims of serious road accidents. This spot divided the disabled community. Indeed, some people find in this film hope concerning life after the tragedy and a good awareness of the dangers of the road: “Being one of the victims of one of these accidents, I find this campaign great”, testifies Bertille Baudino on Facebook.

However, some see it as a degrading message vis-à-vis disability and people with disabilities such as Elena Chamorro, member of the collective Non au report (No to postponement), who, in an article declares: “*How long will we continue to believe that the handicap can only be tragedy? (...) Life after the accident, with a disability, would be a broken life, unrepairable as opposed to the happy life of a valid, the only “valid”, that before the accident*”<sup>19</sup>. Associating disability with road accidents perpetuates an image of disability as a tragedy to be feared or pitied. However, disability is not limited to tragic accidents, it is most often present from birth. Systematically associating it with accidents therefore makes people with disabilities feel guilty. Looking at this spot we are tempted to say to ourselves “I’ll be careful on the road, I don’t want to end up like them”. A thought that Yann Beauson, APF communications director, shares: “*This spot is irresponsible. He uses people with disabilities as a scarecrow: “This is what you absolutely must not become.” To defend a noble cause, the decrease in the number of road accidents, it degrades the image of people with disabilities. I also wonder about the consistency of the government’s communication policy. Road Safety, a public body, airs this spot using people with disabilities as a foil when other ministries trumpet that they are fit to work, to go to school ...*”. Presenting people with disabilities as a foil perpetuates the feeling of pity, guilt and the marginalization of people with disabilities presented as at fault.<sup>20</sup>

### Saviour syndrome

Saviour Syndrome is a psychological disorder that results in excessive empathy for others and a need to help under all circumstances. Although often the “saviour” has altruistic intentions, this syndrome often hides a constant need for gratitude that does not really benefit the “victim”. We speak of saviour syndrome when this need to help conditions the relationship with a person. Here, we will talk about people with disabilities as “victims” of this syndrome. How dangerous is this syndrome behind this altruistic facade?

<sup>18</sup> Sécurité routière. (2020). « Combien de temps » - Rendre la #routeplussure ne dépend que de nous. Available at: [https://www.youtube.com/watch?time\\_continue=3&v=HYsafTywB9U&feature=emb\\_title](https://www.youtube.com/watch?time_continue=3&v=HYsafTywB9U&feature=emb_title) [Accessed 24 Sept. 2020].

<sup>19</sup> CHAMORRO, E. (2015). Combien de temps allons-nous croire que le handicap ne peut être qu’une tragédie ? *Auxmarchesdupalais*. [online] Available at: <https://auxmarchesdupalais.wordpress.com/2015/03/01/combien-de-temps-allons-nous-croire-que-le-handicap-ne-peut-etre-que-tragedie-1/> [Accessed 24 Sept. 2020].

<sup>20</sup> SEURET, F. (2015). Sécurité routière, le spot qui dérange. *Faire-face.fr*. [online] Available at: <https://www.faire-face.fr/2015/03/10/securite-routiere-spot-personnes-handicapees/> [Accessed 24 Sept. 2020].



Although this desire for rescue makes the person concerned optimistic and enterprising, they mistakenly idealize the ability of the person with a disability to overcome their difficulties, but also the effectiveness of the help they provide. This attitude involves two risks. The first risk is that the “saviour” idealizes his or her understanding of the difficulties linked to disability and does not take the time necessary to listen to the person with a disability. The second risk is more serious than the first. This is the risk of devaluing all the aids or actions that have already been provided for people with disabilities. The saviour syndrome often leads the individuals concerned to consider that the actions and assistance given to people with disabilities so far are insufficient or inappropriate. Falling into this attitude adds to indignation the ease of “there is only”: “there is only to arrange public transport and elevators”, “there is only to create more specialized institutions”, “just hire more nurses or increase the allowance for disabled people”, and so on.

The permanent actions of these “saviours” are in reality ineffective because they are the only beneficiaries. This attitude gives them the feeling and the impression of being righteous and good. In reality, this fantasy of reparation, like the feeling of pity and charity that we have just spoken of, comforts only the one who feels it and not the “victim”.

### **The addiction paradox.**

The final obstacle to empathizing with people with disabilities is the problem of the assumed dependence of some of them. There is a paradox about addiction which is that we subconsciously wish to be addicted, but forbid ourselves. This prohibition of dependency is intended by our society which idealizes and advocates autonomy. But why are we afraid of addiction?

We are afraid of addiction because we were addicted children. Over time, our relationship to addiction changes:

During childhood, we are constantly dependent on someone else: we depend on our parents to eat, move around, learn to speak, etc. In early childhood, we seek to prolong the addiction that we had as a baby by asking our parents to carry us so as not to have to walk for example.

As we go through puberty and adolescence, we begin to seek some independence. From that moment we fall into the idea that we must no longer “regress”.

While in adulthood we have this injunction to always “progress”. When we become adults we feel this need to become more and more independent, until we achieve absolute independence. We feel a fear of becoming passive or manipulable, fear which in reality hides a desire to let go of the burden of freedom and responsibility.

How does this fear of dependence impact society's view of disability? Disability often implies dependence on financial, material or even human assistance. This ideology of independence leads people with disabilities who manage to be independent “despite” their disability to be regarded as heroines.

The English psychoanalyst Mikaël Balint<sup>21</sup> had already undertaken this challenge of independence as an absolute value. He does not associate maturity with independence, but rather with the acceptance of our dependence on what makes us happy.

In order to be mature, we should therefore accept not only dependence on our peers but also on all kinds of machines and types of material that surround us and aim to facilitate our existence. Prostheses allow people with disabilities who require them to improve their daily lives, to move around, to eat or to make

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<sup>21</sup> BALINT, M. (1960). *Le médecin, son malade et la maladie*, Paris, Payot.

themselves understood. This invaluable help that they bring demonstrates the aberration of being afraid of a dependence on these objects and machines.

These reflections legitimize the fight towards the acceptance of the desire for dependence which must be done in two ways. As a first step we must learn to recognize the anxieties that disability causes. Secondly, we must make the equipment that will put an end to the marginalization of people with disabilities on a daily basis more accessible and visible<sup>22</sup>.

## Chapter IV: Comparative study: the perception of disability in France, the United Kingdom and the United States

Now we will take a more holistic approach to disability. Indeed, the French approach is one among others: in each country, disability is received in different ways and numerous laws and arrangements exist to include the people concerned. We have chosen to compare the functioning of France, the United Kingdom and the United States based on the articles of the United Nations Charter. We will talk about the care of people with disabilities in transport, the different possible education choices, as well as medical care. We will also analyse the expectations and reality of the inclusion policy and end with welcoming people with disabilities into the workplace.

### **The perception of people with disabilities**

In France, the mentality is intended as such: there are many views on the person said to be different from the norm. If she doesn't walk like this or if she doesn't speak like that, she will be perceived as different and therefore less accepted by the French. This is the case for people with visible disabilities. In the street, they receive insistent looks from people who are curious and question their behaviour and appearance. But at the same time, these people have the will to help, without quite knowing how to do it: one of the limits of the desire for inclusion.

Compare with England. People with disabilities are better perceived: the English are more willing to help a blind person in transport, for example. When a blind person is on the train or plane, they are taken care of by an agent from the transport company in question whose role is to take care of people in a situation of handicap. An agent takes care of one person at a time and makes sure they are comfortable: they won't comment on their differences and will strike up a conversation. By taking him to the requested point, he will ensure that the person is not lost on the rest of their way and will not hesitate to show them the route to follow. In France, we can find this observation, but with some operating differences. First of all, it may happen that one of the transport agents takes care of several people upon their arrival at the station or at the airport. He or she usually doesn't make an effort to create a link and just drops them off at the point indicated.

Unfortunately, the French fear confrontation with people with disabilities. As mentioned in the first part of the article, in the past, these people were said to have received a curse in their former life. Even today, these beliefs have remained anchored: the fear of people with disabilities tends to hide them from society. The French therefore tend to hide the different forms of disability: this is called the culture of disability, that is to say the progressive transformation of the representation that society has of discrimination, segregation and discrimination. Exclusion, whoever is the ones who pay the price. They therefore tend to minimize the problems of people with disabilities so that they appear as "normal" as possible. Thus, since the latter are not widely recognized in French society, there are not enough

<sup>22</sup> TISSERON, S. (2011). L'empathie à l'épreuve de Elephant Man. *Enfances & Psy.* (n° 51), p. 59-67. [online] Available at: <https://www.cairn-int.info/revue-enfances-et-psy-2011-2-page-59.htm> [Accessed 24 Sept. 2020].



structures adapted to their disability in public spaces. They do not have the chance to gradually become autonomous and are excluded. There is therefore a strong inequality of opportunity. Finally, all these consequences stem from the ignorance and lack of information of people not affected by a disability<sup>23</sup>.

### **Education, a key moment in the lives of all children**

So now let's talk about education, a key area for the social inclusion of people with disabilities. In 1945, the Charter of the United Nations mentions in its article 24-1 that “*States Parties recognize the right of persons with disabilities to education. With a view to ensuring the exercise of this right without discrimination and on the basis of equal opportunities, the States Parties shall ensure that the education system provides for school integration at all levels and offers, throughout of life, educational opportunities*”. Added to this, in 1975 in France (and 1970 in Great Britain), the law of orientation of the handicapped people which affirms that “the handicapped children and adolescents are subjected to the educational obligation”.

In schools, there are two courses for people with disabilities. First, the specialized environment for children with disabilities. Having a program and a rhythm adapted to their capacities, the children feel in their element. In the United Kingdom, the choice of this course is not encouraged: the English consider that the fact of putting disabled children in specialized classes tends towards segregation because these children will not have the opportunity to be in contact with non-disabled children, and therefore integrate with them.

The traditional school path is the second possible path: the main advantage is the mix between the children. From a social point of view, this is an asset for non-disabled children because, unlike the first course, they get used to children with disabilities. Later in their adult life, they will have no problem communicating with themselves. In addition, since non-disabled children are in contact with children with disabilities, they become more responsible and, as a result, acquire their autonomy more quickly. The mix between these two types of people is a real asset for these two populations.

Finally, education has a key role to play in the inclusion of people with disabilities. If they are, from an early age, integrated into society through, for example, a traditional class, then they have the opportunity to reach their maximum potential and may find it easier to find a job for example<sup>24</sup>.

### **Medical aids for a person with a disability**

Article 25 of the Convention on the Rights of Persons with Disabilities informs that “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”.

The French system is one of the most advanced in the world in terms of medical care. However, today, showing one's disability card is not enough: people with disabilities must prove their disability in order to be able to benefit from the rights they should spontaneously enjoy. This is the case for several stages of life: the inability to work, the fact of being given a third time at exams, benefiting from parking spaces for people with disabilities... Furthermore, the file may be difficult or even impossible to fill in for some

<sup>23</sup> JOACHIM, S. (2018), Londres en avance sur la question du handicap ? La France doit-elle changer sa culture et ses mentalités pour évoluer ? *France-handicap-info.com*. [online] Available at: <https://france-handicap-info.com/france/accessibilite-dependance-societe-emploi-economie/83-societe/4950-londres-en-avance-sur-la-question-du-handicap-la-france-doit-elle-changer-sa-culture-et-ces-mentalites-pour-evoluer> [Accessed 24 Sept. 2020].

<sup>24</sup> ADEVEILLE, M.H. (2007). Mixité sociale : les handicapés dans la société britannique. *Journals.openedition.org*. [online] Available at: <https://journals.openedition.org/mimmoc/340> [Accessed 24 Sept. 2020].



people with disabilities: some are unable to write or read and need a third person. Finally, claiming one's rights in France today is becoming a necessity, whereas the State should offer these rights spontaneously.

### **Inclusion policy is advocated in the UK and the US, but what is it really all about?**

Judicial institutions play a key role in the lives of people with disabilities. When a new law is passed, their lives can be completely turned upside down. It is therefore important for each country to think carefully about the implementation of these laws concerning people with disabilities.

The United Kingdom and the United States claim to follow a policy of non-discrimination. In the United States, there is a highly structured federal policy: it raises all benefits for persons with disabilities in that country, and each state is free to add additional support. This public is seen as completely legitimate in the eyes of the American State and it is important for this country to help and adapt to it as much as possible.

In 1990 the ADA was set up: *Americans with Disability Act*. The objective is “to eliminate all discrimination against persons with disabilities by establishing obligations and standards applicable in all federal states in the areas of employment, access to public services, transport, telecommunications and accessibility for all places open to the public. It outlaws all discrimination against persons with disabilities and provides them with protection, particularly in the area of employment”.

In the United Kingdom, the terms used to refer to people with disabilities are very important. The terms “mental deficiency” or “mental subnormality” are not well perceived by the English people to refer to a person with a mental disability. This highlights the fact that she would be “less intelligent” than the others. Yet the IQ test is based on a child's cognitive functioning, not on emotional intelligence. Once again, the person with a disability is not highlighted in his or her qualities.

In 1991, the British Minister of Health, Stephen Dorrel, used the term “learning disability”. By mentioning this term, he did not characterize these people as mentally retarded, but rather as having a slow pace of learning (but they are capable of learning many more things than is commonly believed!).

Also in the United Kingdom, in 1997, Tony Blair (Prime Minister of the United Kingdom from 1997 to 2007) set up the Disability Rights Task Force. It takes stock of the problems faced by people with disabilities and then takes them back to the government for action to make the legislation effective.

In 2001, the Department of Health published the book *Valuing People: A New Strategy for Learning Disability for the 21st Century*. The aim is to improve the lives of people with learning disabilities using 4 principles.

The first is the “recognition of the rights of the disabled (proper education, the right to vote, the right to marry and found a family, to express one's opinion, with help if necessary)”. The second concerns the “principle of independence (public services must help the person and in order to achieve this independence, the person can be helped)”. In third place is the fact that the person has a “choice about what he or she wants or does not want to do (work, choice of place to live)”. Finally, the “principle of inclusion, of belonging to the environment in everyday life (work, transport, medical care)” is mentioned.

Through these four main principles, we would have the right to a better inclusion of people with disabilities. But to implement them, there is a huge financial need. To achieve this ideal goal, in 2001, the British government created a fund called the Learning Disability Development Fund. Its purpose is to fund these four main principles.

In support of individual countries' decisions at the international level, Article 26 of the Convention on the Rights of Persons with Disabilities states that “States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain

maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.

Through these different implementations, we can consider that no discrimination would be made in any context, but we will see later on that, in the work context for example, these principles are not respected. Unfortunately, we tend to observe that laws are only respected when it suits the country.

### **The working environment, a field that is sometimes inaccessible to people with disabilities**

After having talked at length about the place of the person with a disability in society, we can move on to the subject of the employment of this group. The Convention on the Rights of Persons with Disabilities has written an article on labour law, which is an important area for people with disabilities. It is Article 27: “States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities”. In France, the United Kingdom, and the United States, there are different laws to include people with disabilities in the world of work. These people, therefore, have the right to work, but we will see that these laws are not always applied.

In France and the United States, since 1987 and 1990 respectively, from the moment a company employs at least 20 employees in France and at least 15 employees in the United States, it must recruit at least 6% of people with disabilities. This law is often not complied with for financial and economic reasons: it is cheaper for the company to pay the financial compensation in the event of non-compliance than to hire people who supposedly do not have sufficient production for the proper functioning of the company. For example, hiring a disabled person in France is more expensive than hiring an able-bodied person because, depending on the type of disability, it is sometimes necessary to make resources available and to be more patient, as this person may need more time to assimilate new knowledge and more support in adapting to his or her role, but also in adapting to a new environment (new people, new buildings, new work tools, etc.).

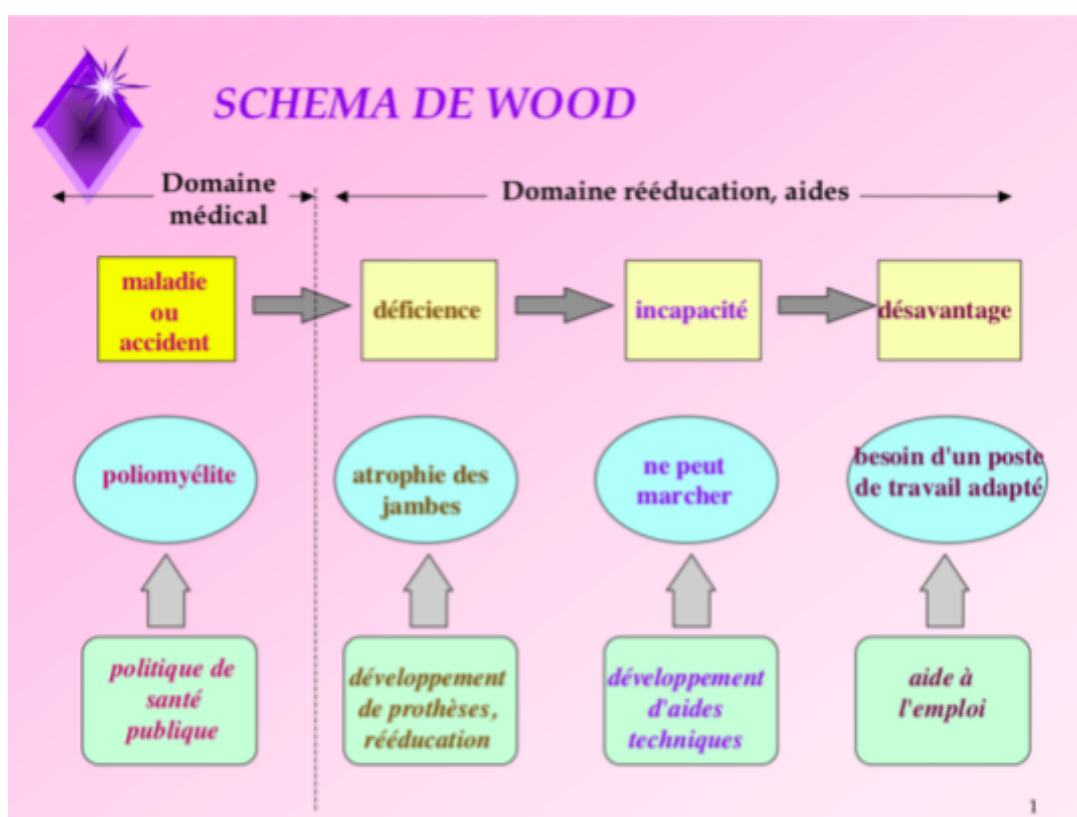
In the three countries studied, the policy is intended to be non-discriminatory. In the United States, it is the draft Americans with Disability Act (ADA) enacted in 1990. The objective is to “eliminate discrimination against persons with disabilities by establishing obligations and standards applicable in all states in the field of employment (...)”. To this end, two types of aid have been introduced: SSDI (Social Security Disability Insurance), for those who have been able to work and contribute sufficiently to Social Security (this aid is intended more for those who have become disabled as a result of an accident), and SSI (Supply Security Income), for those who are unable to work for the rest of their lives (people born blind, deaf, paralysed, certain autistic people, etc.). Once the beneficiaries of one of these two aids, there is an integration programme: the Ticket to Work. Set up in 1999, it offers people receiving SSDI or SSI reintegration or vocational rehabilitation programmes. To this end, a range of services is offered to the disabled person. If he or she wishes, he or she can be helped by these different services for his or her reintegration, and thus find a job once the rehabilitation has been completed.

This programme can be seen as a miracle solution, but unfortunately it is not working that well. For example, in 2007, 12 million tickets were sent by the Social Security administration. Out of these 12 million, only 144,000 people registered for the program. And of these 144,000 people, only 0.01% of them found a job. This defeat would be due to the fact that, when one wants to enrol in the programme, one must first of all prove one's total incapacity to work (whereas, as a reminder, they are already beneficiaries of the SSDI or the SSI, therefore considered as disabled persons for these two aids) in order to finally obtain the disability benefit, which takes a particularly long time to obtain and often requires numerous appeals.

In the United Kingdom, there are also two aids available for people with disabilities. Firstly, the New Deal for Young People, which promotes the employment of 18-24 year olds who have been on unemployment benefit for more than 6 months. Then, the New Deal for Disabled People, created for adults with disabilities, except for those between 18 and 24 years old. It provides assistance to adults who are unable to work because of their disability. The problem is that this allowance encourages them to refuse any job offer, even if they are offered a job, for fear of losing this financial assistance. This has negative consequences for people with disabilities: they become apathetic, bored and live in precariousness or even poverty. As a result, they can more easily develop health problems. It is therefore important for people with disabilities to have a job, not for an economic reason but for a reasonable living comfort<sup>25</sup>.

In conclusion from the comparison of these three countries, judicial institutions often tend to agree with the employer in order not to jeopardize their business. Here we find an operation that advocates the economy, being ready to dehumanize the most vulnerable people.

In order to illustrate the above, we can take the example of Wood's diagram. This explains the fact that people with disabilities have a disability that results in an inability to do something. They are therefore at a disadvantage compared to non-disabled people, but thanks to employment assistance, an adapted workplace can change their pace of life and enable them to be included in society again and maximise their autonomy.



(Illustration) INSTITUT FÉDÉRATIF DE RECHERCHE SUR LE HANDICAP (2010), *Schéma de Wood*. ifrhandicap.ined.fr. Available at [http://ifrhandicap.ined.fr/hid/hid\\_ftp/presentation/wood2.pdf](http://ifrhandicap.ined.fr/hid/hid_ftp/presentation/wood2.pdf) [Accessed 24 Sept. 2020].

<sup>25</sup> COHU, S. (2010). Les politiques en faveur des personnes handicapées aux États-Unis et au Canada. *Cairn.info*. [online] Available at: <https://www.cairn.info/revue-francaise-des-affaires-sociales-2008-4-page-91.htm> [Accessed 24 Sept. 2020]. "loi ADA"; "SSI"; "SSDI"; "Ticket to work"

People with disabilities are, from a legislative point of view, fully included in society, but in terms of what is applied, much progress still needs to be made in different areas. Is the Convention on the Rights of Persons with Disabilities a beacon of hope or a utopian text for the inclusion of people with disabilities?

## Association recommendations

### **APF (Association des Paralysés de France)**

A major French organisation created in 1933, recognised as being of public utility, defending and representing people with disabilities and their families. This association is a national movement for the defence and representation of people with motor disabilities with or without associated disorders and their families. It brings together 30,000 volunteers and more than 14,000 employees<sup>26</sup>.

### **Handicap international**

An international solidarity NGO that operates in some 60 countries. The association intervenes in situations of poverty and exclusion, conflicts and disasters alongside people with disabilities and vulnerable populations in order to improve their living conditions and promote respect for their dignity and fundamental rights, and to act and testify so that their basic needs are properly covered.

There are therefore a multitude of types of disability and this is why each of these associations is specialised in a specific field of disability: APF in motor disability, Handicap International has a humanitarian dimension and campaigns for the rights of people with disabilities in general, and Vent du Large targets people with mental or intellectual disabilities.

## Cultural recommendations

Disability suffers from a lack of representation. We rarely see television personalities with disabilities. The non-representation of a minority contributes to its marginalisation. Cinema provides a high level of visibility and makes it possible to address many societal issues, and disability is no exception to the rule.

If you like cinema and would like to learn more about disability, these films are sure to appeal to you<sup>27</sup>:

### ***Champions (2018)***

Directed by Javier Fesser with Javier Gutiérrez, Alberto Nieto Fernández, Daniel Freire

### ***Elephant Man (1980)***

Directed by David Lynch with Anthony Hopkins, John Hurt and Anne Bancroft.

### ***Forrest Gump (1994)***

Directed by Robert Zemeckis with Tom Hanks, Gary Sinise and Robin Wright.

### ***Freaks - La Monstrueuse Parade (1932)***

Directed by Tod Browning with Wallace Ford, Leila Hyams and Olga Baclanova.

### ***Gilbert Grape (1994)***

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<sup>26</sup> APF France. Présentations courtes. Available at: [présentation d'APF France handicapwww.apf-francehandicap.org > sites > default > files > p...](http://présentation.d'APF France handicapwww.apf-francehandicap.org > sites > default > files > p...) [Accessed 24 Sept. 2020].

<sup>27</sup> Sens critique. (2020). Top des meilleurs films traitant du handicap. *Senscritique.com*. [online] Available at: [https://www.senscritique.com/top/resultats/Les\\_meilleurs\\_films\\_traitant\\_du\\_handicap/535174](https://www.senscritique.com/top/resultats/Les_meilleurs_films_traitant_du_handicap/535174) [Accessed 24 Sept. 2020].



Directed by Lasse Hallstrom with Johnny Depp, Leonardo DiCaprio and Juliette Lewis.

***The Intouchables (2011)***

Directed by Olivier Nakache and Eric Toledano with François Cluzet, Omar Sy and Anne le Ny.

***La famille Bélier (2014)***

Directed by Éric Lartigau with Louane Emera, Karin Viard, Françoise Damiens and Éric Elmosnino.

***The Eight Day (1996)***

Directed by Jaco van Dormael with Daniel Auteuil, Pascal Duquenne and Miou-Miou.

***Patients (2017)***

Directed by Fabien Marsaud, known as Grand Corps Malade and Mehdi Idir with Pablo Pauly, Soufiane Guerrab, Moussa Mansaly, Alban Ivanov, Yannick Renier and Franck Falise.

***Red like the Sky (2006)***

Directed by Cristiano Bortone with Luca Capriotti, Marco Cocci and Simone Colombari.

***The Theory of Everything (2014)***

Directed by James Marsh with Eddie Redmayne, Felicity Jones and Charlie Cox.

***One Flew Over the Cuckoo's Nest (1975)***

Directed by Milos Forman with Jack Nicholson, Louise Fletcher and Will Sampson.

If you like music, here are three songs about disability<sup>28</sup>:

“**Ça ne tient pas debout**” (1990) by Michel Berger<sup>29</sup>.

“**Why**” (2020) by the group Anadjoh<sup>30</sup>.

“**6ème sens**” (2006) by Grand Corps Malade<sup>31</sup>.

Of course there are many other films and a lot of other music that talk about disability and contribute to bringing visibility to this cause.

## Conclusion

Throughout the ages, disability has always been taboo and misunderstood. People with disabilities have often been blamed, discriminated against and excluded from society. Much progress has been made in both the scientific and social fields. However, disability is still a factor of exclusion and the aids or laws proposed are unfortunately still insufficient.

Disability can be associated with a complex identity, a policy of recognition that brings together people with a wide range of singular and subjective experiences. Yet these people find themselves united around a common experience of society: they share a situation of exclusion from it. This exclusion could be the

<sup>28</sup> Enfant Différent. (2020). Chansons et Handicap. *Enfant-different.org*. [online] Available at: <https://www.enfant-different.org/outils-de-sensibilisation/chansons-et-handicap> [Accessed 24 Sept. 2020].

<sup>29</sup> Mickparis. (2007) Ca ne tient pas debout - Michel Berger. *Youtube*. [online] Available at: <http://www.youtube.com/watch?v=1csKg6Hg-oE> [Accessed 24 Sept. 2020].

<sup>30</sup> Anadjoh. (2020). Anadjoh WHY (confinement clip) Home made. *Youtube*. [online] Available at: <https://youtu.be/ITqjvi55TOo> [Accessed 24 Sept. 2020].

<sup>31</sup> Musical Journey. (2010). Grand corps malade 6ème sens. *Youtube*. [online] Available at: <https://www.youtube.com/watch?v=96RKHanO778> [Accessed 24 Sept. 2020].

key to a step towards the objectification of disability as a community despite the heterogeneity of its members.

A better understanding and inclusion of disability is not a job to be done only by people with disabilities but also by people without disabilities. These people need to better understand the different feelings that disability provokes in them, as understanding these feelings and reactions is a first step towards a more tolerant and healthy relationship between non-disabled people and people with disabilities. Finally, it would be a question of society including disability through education, bringing more visibility in order to raise awareness and abolish this taboo around disability. By comparing France, the United Kingdom and the United States on the management of disability, we can see that policies have been implemented on the subject of disability in order to put an end to discrimination of all kinds. However, we have also seen that these policies are not always respected, particularly in the world of work. Unfortunately, we tend to say that laws are only respected when it suits the country.

We can all contribute to improving the place of disability in society. Today, it is a question of making our behaviour more tolerant towards people with disabilities, but also for companies to ensure that the principles of non-discrimination and financial and social aid are respected. Culture remains an effective means of giving visibility to all kinds of causes, which is why we recommend various films and some music about disability.

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