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Physical Disability in Literature: Osteogenesis Imperfecta Representations in Young Adult Romance Novels

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Abstract

Even at this moment in time, at the beginning of the 21st century, the concept of "disability" is regarded as a taboo, as something to be feared and avoided. People that are not directly affected by it pretend it does not concern them. What the vast majority of our society does not realize is that disability can potentially impact everyone. Rejecting it means erasing the years of fights of the disability community for civil rights and the struggles of its members to claim their identity. Moreover, this minority has influenced popular culture more often than people conceive. From literature to films and television, representations of disabled people have been used for generations. It is thought-provoking not only to analyze how stereotypical images have frequently contributed to spreading the misconceptions about this group but also how they have recently been employed to challenge these assumptions. Furthermore, it is noteworthy that depictions of disability have been so frequent that even a rare condition such as Osteogenesis Imperfecta is present in a niche genre like young adult romance novels.

Ancora oggi, agli inizi del ventunesimo secolo, il concetto di "disabilità" è visto come un tabù, come qualcosa di cui avere paura e da evitare. Le persone che non ne sono direttamente interessante fingono che non le riguardi. Ciò che la maggior parte della nostra società non comprende, è che la disabilità può potenzialmente concernere chiunque. Rinnegarla significa cancellare gli anni di lotte delle persone disabili per i diritti civili e gli sforzi dei singoli per affermare la propria identità. Inoltre, questa minoranza ha influenzato la cultura di massa più frequentemente di ciò che la gente realizzi. Dalla letteratura ai film e alla televisione, le rappresentazioni delle persone con disabilità sono state impiegate per generazioni. È interessante non solo analizzare come immagini stereotipate abbiano spesso contribuito alla diffusione di luoghi comuni riguardo a questo gruppo, ma anche come sono state recentemente utilizzate per capovolgere queste congetture. Oltretutto, è degno di nota che ci si sia serviti così ripetutamente di rappresentazioni della disabilità al punto che anche una condizione rara come l'Osteogenesi Imperfetta sia presente in un genere di nicchia come i romanzi romantici per giovani adulti.

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Introduction

This research aims to analyze the representations of the genetic condition of Osteogenesis Imperfecta, vulgarly known as “brittle bone disease”, in young adult romance novels. To do so, two books where one of the principal characters is impaired by this illness are considered. The goal is to identify the recurring topics employed when this condition is depicted and whether these portrayals are stereotypical and spread misconceptions about disability, or if they challenge them.

This work is composed of three chapters. The first one focuses on the fights of the disability community to obtain essential civil rights in the United States. After a brief reference to the situation of disabled people at the time of the Thirteen Colonies, the chapter deals with the 20th and 21st centuries. It is divided into three sections. The first handles the beginning of the battles. To be specific, the attention is centered on the first hardly-obtained legislations that finally guaranteed the disabled population some protection: the 1935 Social Security Act, the 1973 Rehabilitation Act, and the 1977 Section 504. Furthermore, I discuss the role fulfilled by activists like Edward Roberts and Judith E. Heumann and their actions to create the first Independent Living Centers.

The second paragraph concerns the Americans with Disabilities Act of 1990, the most relevant regulation of disability rights in the United States. A pioneer document, it has served as a model for countries all around the world. To begin with, the section considers the actions that led to the act. Successively, an overview of the five titles that composed is provided. Primarily, they forbid discrimination against disabled people in employment and define what measures had to be taken to make cities, buildings, and transportation accessible. Finally, the situation in the 21st century and its most crucial legislation, the ADA Amendments Act approved in 2008, is mentioned.

The concluding paragraph concentrates on what disability studies are and how they developed. It also engages with the various conceptualizations of disability, from how it was considered between the 19th and the 20th centuries to the present day. Until the 50s, disability was exclusively seen through the eugenic and medical models that viewed illnesses as something that had to be erased or cured. In the following years, a change of mentality began, leading to the shift to the social model that, distinguishing between the concepts of “impairment” and “disability”, considered disability merely as a social construct. However, this framework was criticized as well, because of its lack of interest in the lived experiences of single individuals. In the past couple of decades, a “cultural model” has developed, combining aspects from different approaches. The following section illustrates the first theories developed in the field of literary disability studies: the notion of “normalcy” and of “normate” proposed by Davis and Garland-Thomson respectively, the idea of “narrative prosthesis” advanced by Mitchell and Snyder, and the concept of “aesthetic nervousness” suggested by Quayson. To conclude, I offer a brief reflection on why it is essential to engage in disability studies, considering the impressive size of this minority and its potential universality.

The first paragraph of the second chapter examines the struggles of a person with a disability to claim his/her own identity. Every individual shapes their identity from “above”, meaning through the influence of the people that surround them, and from “below”, that is to say through a process of self-definition. As concerns the former, the attention is focused on the concept of “inspiration porn”, which is the consideration of disabled individuals as inspiration by non-disabled. Regarding the latter, I focus on when an individual negatively self-identifies with their impairment as well as when one's consideration of their own disability is viewed in the opposite way. In the first case, the subject adheres to the medical model not accepting or denying their disability. In the second, the person supports the social model. However, despite the fact that having a community and engaging in disability culture help in viewing disability as a positive aspect of identity, it is an extremely intricate process.

The second paragraph focuses on life-writing narratives and how they have been exploited to spread an alternative idea of handicap, in particular from the ‘80s, when parents and then people with disability themselves started to utilize their own voices to report an alternative version of their story for the first time. This is followed by a brief discussion on the typical depictions of disability employed in the genre – the “rhetoric of triumph”, the “rhetoric of horror”, and the “rhetoric of compensation” –, and on the subversive “coming out narrative” to help in the analysis of the autobiography Sono Nato Così, Ma Non Ditelo In Giro. It is a non-fictional 2022 book by Mattia Muratore, an Italian man that was born with Osteogenesis Imperfecta and is a wheelchair user. In it, he talks about everyday life experiences like going to school or on holiday, having friendships and romantic relationships, getting a driving license and playing sports, and how his disease impacted them. Muratore positively self-identifies with his disability, but this does not impede him from being aware of the assumptions and ableist behaviors nondisabled people have and challenging them through irony.

The concluding chapter concerns the principal topic of this work. The first section is dedicated to what Osteogenesis Imperfecta is. To begin with, I discuss why it is conceived as a rare disease and how it is inherited – whether dominantly or recessively. Next, its key symptoms are illustrated and a list of its most frequent forms and their characteristics is provided. The following paragraph focuses on two subjects. The first one is young adult novels. After having provided a definition of this category, it lists its characteristics and dwells on its relationship with disability. The second topic is the romance genre. Its most traditional features are described – initially in general and then specifically in relation to disability. Because sentimental novels are supposed to provoke feelings of happiness and disability is considered as the opposite of joy, tropes that exclude or eliminate it have been extensively employed. Nonetheless, some authors try to use devices and propose narratives that challenge them. The final section is dedicated to the analysis and the comparison of two young adult romance novels that feature a character with Osteogenesis Imperfecta – the Italian *Stringimi piano* by Irene Faranda and the American *When My Heart Joins the Thousand* by A. J. Steiger. After a summary of the two novels, the attention has been centered on observing how OI is portrayed. Themes related to the disease – breaking a bone and its consequences, the fear that it implicates, the desire to challenge fate, the scars, and the impact it has on parents – that the two books have in common have been identified. Lastly, I discuss whether the novels employ stereotypical narratives about disability or innovative ones, and which one of the two proposes a more realistic and effective portrayal of impairment.

1. Disability Rights History and Disability Studies

1.1 From the beginning of the 20th century to the Late 80s: The Disability Civil Rights Movement

1.1.1 The early 20th century and the 30s

The history of the fights of the disability community to acquire civil rights in the United States is extensively addressed in the 2011 updated edition of the book *The Disability Rights Movement* by Doris Zames Fleischer and Frieda Zames, which has been the main source of information for the first two sections of this chapter.

In his article "An Overview Paper on Civil Rights Issues of Handicapped Americans: Public Policy Implications" (1980), Frank Bowe asserted that the discrimination against the disabled population began at the time of the Thirteen Colonies: people with disabilities were often concealed or left to die from their families, and those that were not capable to provide for themselves independently were not allowed to settle in cities. Concomitantly, disabled immigrants were not allowed to enter the country.

At the beginning of the 20th century, because of the development of the eugenic theory, discrimination intensified. Advocating the improvement of humankind from a genetic point of view, disabled people started to be institutionalized and, in 1911, an ordinance that forbade them to be in the public was promulgated in New York City. By 1914, sixteen states had accepted a law proposed by the American Genetic Association that imposed their sterilization to prevent an increase in their number.

A turning point was undoubtedly when impaired veterans returned from the First World War. The 1918 Rehabilitation Legislation recognized for the first time that people with impairments deserved some benefits and that they could contribute to the workforce. Moreover, institutions that until that moment were only a place of confinement, started to provide their patients with an education (quoted in Zames Fleischer – Zames 2011:12-13).

The first activist actions began in the 30s when disability organizations started to be founded. The League of the Physical Handicapped was one of the first, and its goal was to expose discrimination against disabled people in employment. The 1935 Social

Security Act, which guaranteed economic help to unemployed people with impairments, was in force, but the association believed that it was not adequate for those that could be a part of the workforce. From May 29 to June 6, 1935, they organized a protest because they claimed that their physical disabilities were used by employers as a pretext to not hire them, even if they were more qualified than other non-disabled candidates. Moreover, considering that there was broad availability of manual labor jobs and that disabled people could not access the private sector, they insisted that it was a government duty to provide positions for them. Their sit-in produced some results, but they were limited to New York City. In 1936, they decided to travel to Washington to appeal to the President himself. Their requests were a permanent national jobs program and a census of people with physical disabilities, whose goal was to show that many of them were capable of working. Since they were unsuccessful, they returned to Washington in 1937, but they did not achieve better outcomes. Ultimately, most of the members were employed by the civil service in New York City, and the League disbanded. Nevertheless, its activity is noteworthy as it was the first group that, building a coalition of people with a variety of disabilities, did not seek pity, but exploited anger for injustices to fight against discrimination (Zames Fleischer – Zames 2011:5-6).

1.1.2 Independent Living from the late 50s to the early 70s

The process of deinstitutionalization of disability began with two quadriplegic wheelchair users and patients of New York City's Goldwater Memorial Hospital: Ann Emerman and Marilyn Saviola. Emerman was 21 years old when, in 1958, she was selected to participate in the first experiment on independent living for people with disabilities, while Saviola organized a separate ward in the hospital reserved for young people where they lived all together and had fun. Since an elected group of residents defended this section, people created a sense of community and felt empowered. Moreover, Saviola was the first to attend college while still living there. (Zames Fleischer – Zames 2011:33-34).

Another key figure in the process was Edward Roberts, a disabled man because of polio. He had to sue the University of California to be admitted, but in doing so he paved the way for many other paraplegics all around the country. After his grant for disabled students, the Disabled Student Program, was funded, he and his mates formed the Rolling Quads which aimed to make the campus barrier-free. Moreover, they moved out of the Conwell Hospital, where they stayed to confront the problem of accessible housing, and into the Berkley community, creating, in 1972, the first Center for Independent Living. Carr Massi explained in 1977 in the *National Paraplegia Foundation News* that it provided peer counseling together with legal assistance, training in independent living abilities, and job and health services (quoted in Zames Fleischer – Zames 2011:38-39). Even if it was not the first independent living experiment, it served as a model for centers in the other states and it helped to start an actual Independent Living Movement. Furthermore, their presence helped to make the San Francisco Bay Area more wheelchair-friendly. For instance, they were responsible for the first curb cut[1] in the country, as Roberts declared (reported in Zames Fleischer – Zames 2011:40).

1.1.3 1973 Rehabilitation Act and Section 504

After they commenced to live independently, disabled people felt the necessity to have legislations that could guarantee and protect their rights. A pivotal moment was the Rehabilitation Act but coming to its promulgation was not an effortless process. In fact, President Nixon vetoed the initial versions of this law two times, claiming that it was too expensive, and had medical and social welfare purposes that were not coherent with its originally-intended vocational goal. After his first refusal to approve it, Judith E. Heumann and eighty others organized a protest, blocking traffic. The second time, disability activists marched to the Capitol during the annual meeting of the President’s Committee on Employment of the Handicapped. A diluted version of the act was ultimately signed on September 26, 1973 (Zames Fleischer – Zames 2011:49). Because it primarily focused on vocational rehabilitation[2], it applied to people with significant impairments that were not employed, but that could live independently (Zames Fleischer – Zames 2011:34).

Disability activists helped the passage of the Rehabilitation Act, and they contributed to the addition of regulations for Sections 501 to 504 as well. Sections 501

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[1] A curb cut is a ramp cut into a street curb to allow people, especially those with a vehicle like a wheelchair or a stroller, to easily move from the sidewalk to the street and vice versa.

[2] Vocational rehabilitation is a process that helps people with disabilities, from birth or acquired, to enter into or return to the workforce.

and 503 forbade discrimination, based on disability, on employment, and required specific plans to hire qualified people with impairments. Section 502 created the now-called Access Board whose task was to supervise the enforcement of the 1968 Architectural Barriers Act that dealt with barriers and their removal. Section 504 recognized civil rights for disabled people in programs that received federal economic support.

The credit for these regulations belongs to James L. Cherry. After the passage of the Rehabilitation Act, Cherry began to send letters to the Department of Health, Education and Welfare (HEW) requesting their emanation. Unsuccessful, he decided to seek legal help, but this did not lead to better outcomes. After two years, Cherry sued David Mathews, HEW Secretary Director. In July 1976, the court ruled that HEW promulgate the Sections. Due to the beginning of Carter's administration, Joseph Califano was nominated as Secretary Director of HEW and the advancements came to a stop. Disability activists bounded together to ask for their signing, founding the American Coalition of Citizens with Disabilities (Zames Fleischer – Zames 2011:49-53). After 25 days of sit-ins in New York and San Francisco, on April 28, 1977, Califano eventually agreed to ratify the regulations. (Zames Fleischer – Zames 2011:55)[3].

1.1.4 The late 70s and the 80s: the peak of the disability rights movement

Accessible transportation, presumably because it was fundamental to participate in social life, represented the first goal after Section 504 came into effect. The 1976 Transbus lawsuit was the first to regard this issue. A coalition of disability organizations sued three federal transport agencies requesting the federal government constrain them to produce only the Transbus, a low-floor bus with wide doors and ramps. In May 1977, President Carter's first Secretary of Transportation, Brock Adams, decreed in favor of the disability community. However, because of the pressure from the American Public Transport Association, especially from its member General Motors which promoted its

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[3] The history of the disability civil rights movement, and in particular of the 25-day long sit-in in San Francisco, is narrated in the documentary *Crip Camp: A Disability Revolution* (USA: Higher Ground Production, 2020).

accessible bus, which was lift-equipped and had a separate door for people who could not mount steps, Congress reevaluated the mandate. (Zames-Fleischer – Zames 2011:56-57)

In 1981, the U.S. Department of Transportation wrote new Section 504 regulations concerning transportation. They defined that transit agencies had simply to plan and design mass transportation facilities and services so that they could be utilized by disabled people, and that each one of them was allowed to choose if they wanted to acquire buses with lifts, institute only a paratransit service[4] or establish a hybrid system. To avoid spending money on drastically changing their vehicles, many of them preferred the second option stating that it could be equivalent to the service for the public, but it was immediately evident that it could not be the same. In 1982, the Surface Transportation Assistance Act established new and national minimum criteria for lift-equipped buses and paratransit services (Zames Fleischer – Zames 2011:66-67).

Among the cities that more rapidly developed an accessible transportation system, there are Seattle and the San Francisco[5] metropolitan area, whereas New York City took longer.

From 1976 to 1980, the disability community collaborated with the Metropolitan Transportation Authority of New York to develop a plan to implement accessibility and provide the “reasonable accommodations”[6] dictated by Section 504. When the MTA refused to submit the plan, they formed a coalition called Mobility Through Access and launched a sit-in at MTA headquarters in January 1981. Thereupon, MTA stated that on September 30, 1981, accessible buses would be available on some routes. Disability activists Denise McQuade and Anne Emerman tried to board the buses that day, but the driver did not have the key to start the lift. At that point, the two women blocked the vehicles. Because lift-equipped buses were unpublicized and many people did not know of their presence, it was believed that MTA intended to deter the use of the buses by

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[4] Transportation system that complements fixed-route mass transit by providing individualized rides without fixed routes or timetables to people that cannot use public transport, because of their impairments.

[5] The Bay Area Rapid Transit, responsible for trains and subways, has operated for the disabled population correctly in the Berkeley/San Francisco region since the 60s, because of wheelchair-user Harold Wilson’s activism. As concerns public transportation, even before the signing of Section 504, California laws established that transit agencies had to purchase at least a certain number of accessible buses. (Zames Fleischer - Zames 2011:63-64).

[6] Adaptations to guarantee access to disabled people that do not necessitate a considerable cost or require considerable adjustments.

wheelchair users so that they could affirm that making transportation accessible was unworthy as they were a small number of consumers. Mobility Through Access launched “Ride The Bus Day” to capture the attention of the media to the subject. In 1984, the New York State Handicapped Transportation Act was signed. The law established the making of the most crucial subway stations wheelchair-friendly, the obligation for 65 percent of the buses to be accessible[7], and the formation of the Transportation Disabled Committee, an eleven-member group in charge to develop a plan to implement the paratransit system, known as Access-A-Ride (Zames-Fleischer – Zames 2011:57-63).

The disability community would not have accomplished any achievement if it were not for the organizations that fought for its civil rights. One of the first was Disabled in Action. It was founded by paraplegic wheelchair user Judith E. Heumann, after her 1970 lawsuit, which ended in her favor, against the New York City Board of Education, which refused to grant her a teaching license because of her impairment. The organization’s goal is to eliminate discrimination against people with all kinds of disabilities. (Zames Fleischer – Zames 2011:71-72). To do so, it launched its own newspaper *DIA Activist*, and it sought the attention of the media. It also participated in demonstrations like protesting for the passage of the 1973 Rehabilitation Act or blocking the buses that refused access to disabled people. The fact that most of its members were unemployed allowed the association to benefit from the attorneys from the federally funded Legal Service Corporation for people with limited resources, and pro bono services from private law firms. Because the lawyers received fixed salaries their only incentive was to win remarkable cases. Consequently, DIA triumphed in most of its lawsuits. One of the most significant was the one concerning making voting polls wheelchair-friendly. Despite the existence of the New York State Election Law providing that all polling places had to have at least one accessible entrance, the law was being ignored so DIA decided to sue. The case was settled only in 1994 when only five voting locations were not adapted.

Another organization that fought to establish and protect disability rights was the Disability Rights Education and Defense Fund in Berkeley and the ADAPT. The former

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[7] Eventually MTA recognized the importance of all the buses being accessible and engaged in equipping the totality of their mass vehicles.

created the Disability Clinical Legal Education Program to train law students in disability rights law. Moreover, in 1988, they helped with the passage of the Civil Rights Restoration Act[8], (Zames Fleischer – Zames 2011:74-79) and the Fair Housing Amendment Act[9] (Zames Fleischer – Zames 2011:45-46). The latter was founded by Wade Blake with the help of the Atlantis Community, an independent living center in Denver with 120 clients. From its foundation, in 1983, to 1990 its acronym meant American Disabled for Accessible Public Transit, while later it became The American Disabled for Attendant Programs Today. Their activism began with a demonstration supporting lift-equipped buses (Zames Fleischer – Zames 2011:82-83).

1.2 From the 90's to the present day

1.2.1 The 90's: The Americans with Disabilities Act

Activism and the hardly achieved victories together with the empowerment and the sense of community triggered people with disabilities to demand legislation dedicated to their civil rights.

The struggles that led to the Americans with Disabilities Act began in 1982 when the National Council on Disability recommended to Congress to edit a civil rights law to prevent disability discrimination. In 1984, the Council, which originally was an advisory body under the Department of Education, became an independent federal agency. At that point, it was authorized to propose a first document that required accessible transportation and the elimination of employment disincentives from social security. However, disability leaders were skeptical about the approval of this type of legislation considering Section 504 was still scarcely enforced, and funds for disability services were rarely granted. The next step took place in 1988 when a report called *Toward Independence* set the basis for an early version of the ADA. Made up of thirteen pages, it was completely unrealistic. For instance, it established that all buildings had to be made accessible in two years. That same year, the Task Force on the Rights and Empowerment of Americans with Disabilities, whose function was to advise

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[8] It established that if a court ruled against a division of an institution in a civil rights lawsuit the whole of it had to meet Section 504 regulations.

[9] It forbade housing discrimination, and it required certain access characteristics in newly built structures as well as their addition, if needed, to existing construction.

Congress on the ADA, was founded. Activist Justin Dart was nominated as its co-chair, and he organized a cross-disabilities force consisting of leaders and organizations from all over the country to promote its passage. In 1990, President George Bush eventually signed the more specific fifty-two-page bill, which established the rights of people with disabilities at a federal level (Zames Fleischer – Zames 2011:89-93).

The definite law consists of an introduction and five titles. In the introductory section, the concept of "disability" is described. The definition provided is "a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment". It is immediately specified that "major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working" (www.access-board.gov/law/ada.html).

The first title of the document deals with job employment. While Section 504 referred to entities receiving federal funds, ADA applies to both public and private sectors. It prohibits discrimination against a qualified person exclusively because of his/her impairment, and it also forbids the employer to ask candidates in advance if they have a disability. It also establishes that delivering "reasonable accommodations" is mandatory. Title I became effective in July 1992 for employers with more than twenty-five workers. In July 1994, the threshold has been lowered to fifteen (Zames Fleischer – Zames 2011:93-95).

Title II, which became effective on January 26, 1992, is responsible for public transportation and public service[10]. This section establishes that nobody can be excluded from participating in them or denied their benefits. In addition, it mandates "program accessibility", which implies that they must be usable by people with impairments in the most integrated way. This includes making necessary structural changes, like multiplying curb cuts. However, since the cities of Philadelphia and New York refused to implement them, Disabled In Action of Pennsylvania and the Eastern Paralyzed Veterans Association divisions of Philadelphia and New York City had to sue the local Departments of Transportation. Given that curb cuts are relevant nationwide, the

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[10] Any program or activity delivered by public entities of any state or local government (Zames Fleischer – Zames 2011:275).

decisions of these cases had an impact everywhere. Moreover, the 1995 lawsuit *Helen L. vs Didario* marked a turning point regarding institutionalization. Because this title decrees that home attendant services[11] must be provided in the most integrated setting, the court supported Helen L.'s claim that this environment was her own home. The court's decision determined that the nursing home was a segregated solution, and that unnecessary seclusion of people with disabilities is itself a type of discrimination. As regards transportation, all new or renovated facilities must be barrier-free, vehicles must be usable by people in wheelchairs, and public entities that ensure fixed routes have to guarantee an equivalent paratransit system if it is not unreasonably expensive (Zames Fleischer – Zames 2011:98-101).

Title III bars discrimination in public accommodations[12] and determines that adjustments for disabled people must be offered in the most integrated way. Moreover, it tackles two types of private transportation. The first regards private bus lines, taxicabs, and limousines: newly purchased buses must be accessible together with taxicabs using vans. The second concerns services incidental to the essential scope of a business, like hotel vans from and to the airport. Depending on the seating size of the vehicle, they must be adapted for disabled people or guarantee an "equivalent service"[13]. Furthermore, Title III requires all structures constructed or renovated after January 1993 to be accessible to wheelchair users. Concerning existing edifices, architectural and communication impediments had to be removed, if "readily achievable"[14]. If this is not attainable, alternative "readily achievable" methods had to be conceived to provide those goods and services. Title III became valid on the same day as Title II. The following day, Disabled In Action of Metropolitan New York and Barrier Free Living[15] sat in against the inaccessibility of the observation tower of the Empire State Building. The affected parties reached an agreement imposing that the tower had to be accessible by June 1994. Regrettably, this is just one example of the

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[11] It refers to the (physical) assistance provided by a trained individual to a person with a disability to accomplish the daily life activities that he/she cannot fulfill because of his/her impairment.

[12] It refers to public or private entities that provide a service to society. Places of public accommodations are, for example, stores, restaurants, offices, hotels, etc., and sites operated privately like schools, senior citizens centers, etc.

[13] In this framework, it means for example that not all hotel vans have to be accessible to wheelchair users, but at least a sufficient number.

[14] That is to say easily and without expense.

[15] Agency that oversees transitional housing for people with disabilities.

countless demonstrations and lawsuits that had to be performed to enforce this section (Zames Fleischer – Zames 2011:95-98).

Title IV mandates a relay service, a telephone service that allows people with speech or hearing impairments to communicate with those who use voice phones. It must be intrastate and interstate, work all day every day, and cost the same as the "normal" telecommunication system. The operators cannot change, record, or share the subject of the conversation, or limit its duration. This section also dictates that federally funded public service announcements must include closed captioning, at least partially.

Title V clarifies the role of the ADA. In the first place, it explains that the law cannot undermine what is established in the 1973 Rehabilitation Act and its Section 501 to 504. Next, it specifies that states are subjected to the document, which, however, does not invalidate local laws that ensure similar or broader civil rights. Lastly, it establishes that the triumphant party in an ADA case, other than the U.S. government, may be granted the attorney fees and the litigation costs.

The first ADA case took place in 1998 and concerned whether asymptomatic HIV is included in the definition of "disability" described by the law. The lawsuit ended in favor of the disabled person (Zames Fleischer – Zames 2011:101-102).

1.2.2 The 21st century

More than thirty years later, the ADA is still considered the most meaningful legislation concerning disability civil rights, and celebrations continue to be organized on its anniversary. However, the disability community did not settle for it and has endured in fighting for equality.

In 1992, for instance, some amendments were implemented to the 1973 Rehabilitation Act. They imposed the investment of more federal resources on the Independent Living Centers and the establishment of a Statewide Independent Living Council in each state whose task was to prepare and supervise a three-year implementation plan for independent living services (Zames Fleischer – Zames 2011:45-46).

On the contrary, despite ADAPT efforts[16], the 1997 Medicaid Community Attendant Act (MiCasa), which would have guaranteed integration in the community rather than institutionalization, was rejected. As Senator Harkin explained, its goal was to reform the federal laws that required states to pay for nursing home care in their Medicaid[17] programs, without imposing a similar obligation regarding attendant services (quoted in Zames Fleischer – Zames 2011:221). However, in 2010, a provision called Community First Choice Option was eventually established. It encouraged, but did not force, states to provide community-based services in the home by increasing the federal allowance of Medicaid payments to the states that choose the option (Zames Fleischer – Zames 2011:221-222).

Protests and lawsuits were often unavoidable even to enforce the ADA, and the courts' ruling against it meant overturning the progress so hardly achieved. Three litigations about employment, in 1999, are extremely relevant. Supporting the employers, the Supreme Court limited the definition of disability claiming that the ADA does not apply to people that have an impairment that can be corrected by medications or other measures. Alarmingly, in the following years, cases of this kind were always more frequent (Zames Fleischer – Zames 2011:104-105).

In 2008, the ADA Amendments Act was ultimately approved by Congress. It establishes that medicaments and other expedients soothing the effects of a disability cannot represent elements in determining whether an individual is disabled. Once again, its passage was the result of activism by disability leaders and organizations, like "The Road to Freedom". An eighteen-month 120-stop bus tour, it left in November 2006 from Washington D.C. and traveled around the country to promote the ADA Restoration Act, an earlier version of the ADAAA. The planner was Jim Ward, president and founder of ADA Watch and National Coalition for Disability Rights, whose goal was to take back the ADA to what it was originally (Zames Fleischer – Zames 2011:218-219).

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[16] After its focus on accessible transportation, ADAPT became The American Disabled for Attendant Programs Today, in 1990. In its second phase, it fought because 25 percent of the federal money allocated to nursing homes would be directed to a national attendant services program. In 1997, in addition to the support of the MiCasa Bill, they organized forty protests against the refusal of Greyhound Bus Company to provide accessible vehicles. DIA joined the New York City sit-in. In 1999, Greyhound agreed to shift to lift-equipped buses in two years (Zames Fleischer – Zames 2011:82-85).

[17] Medicaid provides health coverage to millions of Americans, including eligible low-income people and people with disabilities. Medicaid is administered by states, respecting federal laws. The program is funded by states and the federal government (www.medicaid.gov/medicaid/index.html).

The disability community accomplished a lot, but there is nevertheless a long way to go. The upcoming issue to address will undoubtedly be health care. In fact, neither the ADA nor the previous regulations cover the accessibility of disabled people to health care facilities and services (Zames Fleischer – Zames 2011:244). Additionally, with the advancement of technology and the possibility to undergo genetic tests to control the presence of diseases in the embryo, disability leader Andrew Imparato wondered in an interview in 2009 whether health care would be denied to parents that decide not to abort (quoted in Zames Fleischer – Zames 2011:248-249).

1.3 The emergence and relevance of disability studies

1.3.1 From the medical to the cultural model of disability

The term "disability studies" refers to the discipline that deals with the social, medical, and cultural constructions of disability. (Wohlmann-Rana 2019:4). This field developed in the 70s and, in 1980, the first issue of the foremost interdisciplinary journal concerning disability studies, *The Disability Newsletter*, was published[18]. Subsequently, in 1995, the first US disability studies program was launched at Syracuse University (Barker-Murray 2017:xiv-xv).

Different models have been adopted to study the concept of disability. The first is the "eugenic model", which asserts that disability is a flaw that must be extirpated from humanity (Hagood 2010:387). It is based on the idea developed between the 19th and the 20th centuries by Sir Francis Galton, half-cousin of Charles Darwin, that society's moral duty is to improve humankind by regulating reproduction and eliminating "imperfect" individuals. The procedures carried out by eugenicists at the time included selective reproduction, sterilization and euthanasia of children born with any kind of impairments (Davidson 2017:75). Regrettably, this approach to disability is still present. Because of the advancement of technology, prenatal tests are available for an always-increasing number of conditions, leading to an augmentation of abortion rates and the risk that disabled people would be directly prevented from existing in the future (Zames Fleischer – Zames 2011:228-229).

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[18] In 1985 it became the *Disability Studies Quarterly*.

When the discipline developed, the so-called “medical model” was the prominent framework through which disability was conceptualized. Disability was regarded as something undesirable and, consequently, that had to be cured. The core and agent of the disability, the non-normative body, must be aligned with the norm, while disabled people are only defined as patients (Wohlmann-Rana 2019:4-5). A hardly distinct version of this theory is the “rehabilitation model” that considers disability as something to be repaired or concealed (L.J. Davis 1999:506).

With the beginning of the fights for civil rights and independent living, disability began to be understood from a sociological point of view as well (Barker-Murray 2017:3). The primary idea of the “social model” was the distinction between the concepts of “impairment” and “disability”, first asserted in 1975 in the United Kingdom. The Union of the Physically Impaired Against Segregation published its *Fundamental Principles of Disability* (Barker-Murray 2017:xiii), claiming that while “impairment” refers to the reality, the actual diminution of mobility, sight, hearing, etc., it becomes a “disability” exclusively because of society’s treatment. Therefore, disability started to be seen as a social construct, and barriers, negative attitudes, and exclusion are what make impairments into disabilities. Instead of finding a way to eradicate disability, its goal was to identify a strategy for social change.

However, even this model has been criticized. While the medical model focuses excessively on the body, the social one eliminates the corporeal element from its analysis, negating a fundamental aspect of one person’s identity. Consequently, a synthesis between the two, named the “cultural model”, has been conceived. It combines the historical and social dimensions of disability with embodied and individual experiences (Wohlmann-Rana 2019:4-6). In fact, according to cultural anthropology, culture is: “the totality of “things” created and employed by a particular people or a society, be they material or immaterial” (Waldschmidt 2018:71). Understanding this concept in a so general way allows taking into consideration not only the “things” in themselves but also the impact they have on single individuals and in the shaping of their identity (Waldschmidt 2018:71). To go back to the cultural model of disability, it is based on four premises. First, it asserts the ideas of “impairment”, “disability” and “normality” are categories described by the context, specifically by the media, academic discourses, and everyday situations, and that, as a result, they are likely to change again over the years. Second, it asserts that disability is not a natural fact, but a naturalized difference, that is to say, "that disability exists only and insofar as certain […] differences can be distinguished and thought of as "relevant for health" within a given cultural and historical order of knowledge" (Waldschmidt 2018:75). Next, it maintains that if, as it has been said, the concepts of "dis/ability" are influenced by context, factors like experiences, identity, history and culture, power, and stigmatization need to be considered when analyzing them. Consequently, disability and ability are interdependent, and it is crucial not only to examine the lives of disabled subjects but to compare them with those of nondisabled individuals. To conclude, it invites investigating "normality" and how society has come to problematize health-related issues, how "norm" and "deviance" have been defined, how institutions favor practices of inclusion and exclusion, and how identities are forged (Waldschmidt 2018:75-76). With all of this in mind, it is easily understandable why disability studies have started to investigate cultural aspects, including literature.

1.3.2 Disability studies and literature

While in Germany, disability studies remained confined to the field of pedagogy and sociology, in the United Kingdom and the United States they have expanded to the cultural area. (Wohlmann-Rana 2019:3). Literary disability studies emerged in the 90s when scholars start to interrogate themselves on the relationships between disability and literature. The first two texts that helped in developing the field are Lennard J. Davis' *Enforcing Normalcy* (1995) and Rosemarie Garland-Thomson's *Extraordinary Bodies* (1997). Both authors started from the assumption that if disability is regarded as a negative difference, the "norm"[19] is what it deviates from. Nonetheless, the two asserted the "norm" is a random ideological construction that denies everything that does not satisfy certain criteria. According to Davis (1995), one characteristic of "normalcy", is to implicate that the majority of the population must adhere to it. Consequently, every individual who does not correspond to these standards is marked as anomalous, and that is what happens when disability is considered. Davis (1995) concluded that "the 'problem' is not the person with disabilities: the problem is the way that normalcy is

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[19] The "norm" is defined as "normalcy" in Davis and "the normate" in Garland-Thomson.

constructed to create the ‘problem’ of the disabled person” (quoted in Barker-Murray 2017:3). As concerns Garland-Thomson (1997), she noted that a notion that by its definition should be found everywhere is actually impossible to encounter. She explained that the “normate” is the identity of those who because of their body features and their capital could theoretically assume a position of authority and power. However, what arises when trying to identify the required characteristics is a narrow profile that represents a minority of people. To terminate, Garland-Thomson (1997) observed that “disability is not so much a property of bodies as a product of cultural rules about what bodies should be or do” (quoted in Barker-Murray 2017:4). Applying their notions to literature, Davis and Garland-Thomson have remarked that most literary representations of disability are based on the idea that disability is described by what it is not, and it is not conceived as one way of being.

Another pivotal work in literary disability studies is David Mitchell and Sharon Snyder’s *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000) which defined the concept of “narrative prosthesis” (Barker-Murray 2017:4). Mitchell and Snyder argued that characters with impairments function as a prosthesis for writers that want to compose “open-ended” texts, the most efficient type to handle social issues. Authors that desire to challenge the hierarchy and overturn social constructs employ personages with disabilities because they represent disruptiveness. Consequently, these characters act as crutches on which writers and texts rely to accomplish their goals. If on one hand, this role is empowering, on the other it is also limiting, as it exploits stereotypical depictions of disability.

The last crucial contribution is Ato Quayson’s *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007). In his book, Quayson introduced the concept of “aesthetic nervousness”. The idea is that when an able-bodied subject enters an interaction, normally he/she exploits “normal” life experiences to participate in it. However, when he/she is faced with a person with a disability, he/she is uncertain about how to behave because the formalities he would use are usually not adapted, and this provokes a feeling of uneasiness in him/her. Quayson analyzed this reaction in literary contexts, but the idea can be efficiently expanded in real social relations (Hagood 2010:389-390). However, these last two theories concerning literature and disability have not been employed in this research, as they were not extremely relevant for the analysis of the two young adult romance novels investigated. Nonetheless, Mitchell and Snyder (2000) have been the first to divide literary representations of disability into two categories: the ones that offer stereotypical portrayals of impairment called “normalcy narratives”, and the ones that challenge it, known as “disability counternarratives”. In a way, they have paved the way for the analyses that have followed, including the one conducted in this research.

The critical works concerning literary disability studies are not limited to the few cited above and their number is continuously increasing. In 2007, for instance, the Journal of Literary and Cultural Disability Studies[20] was founded. Published in the United Kingdom by Liverpool University Press, it was the first journal dedicated to humanities-centered disability research.

1.3.3 The importance of disability studies

In 2021, to celebrate the XVI edition of the Paralympic Games held in Tokyo, the campaign *#WeThe15* was launched. It was organized by a coalition of organizations such as the International Paralympic Committee, the Special Olympics, the International Disability Alliance, UNESCO, United Nations Human Rights, and the European Commission, as well as many others. Its goal is to promote a global movement that can bring together all disabled people to fight against discrimination and promote inclusion, along with spreading awareness about the social constructivist model of disability.

The title of this campaign is the best way to adequately explain why engaging in disability studies is important. Its name refers to the fact that 15 percent of the global population has a disability, which means around 1.2 billion people, making the disability community the largest minority (www.wethe15.org)[21].

There are three more fundamental reasons why more people should get interested in disability studies. Firstly, despite the distance that most people put between themselves and disability, disability is a potentially universal condition. In point of fact, everyone can become disabled because of an accident or due to the advancement of age.

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[20] Originally it was called the *Journal of Literary Disability*.

[21] According to data collected in 1994-1995, in the United States, the percentage increases to 20%, concerning 54 million individuals (Zames-Zames Fleischer 2011:xx).

It is noteworthy that sometimes non-disabled persons are referred to by leading scholars as Temporary Able-Bodied (TAB) (L.J. Davis 1999:502).

Moreover, according to Wohlmann and Rana (2019), the distinction between disability and non-disability is not a binary one. They are a part of a continuum of what humans' bodies and minds can or cannot do. Defining someone as disabled means marking a neat line between individuals, in spite of its not being always so clear-cut. With this in mind, it is easy to understand why disability studies should appeal to a broader audience.

Furthermore, if the social model of disability is taken into account, and it is consequently believed that the "impairment" is the actual reality and that "disability" is "exclusively" a social construct, it is conceivable that if everyone researches and learns how this happens, in the foreseeable future there will be a less disabling society (Wohlmann-Rana 2019:5).

2. Identity and Disability

2.1 Claiming Identity for People with Disability

2.1.1 Identity from above and from below

Each human being has their personal identity, which is different from all the others. It is precisely what makes humans, humans. According to disability study scholar Tom Shakespeare (1996), "identity" can be used in two different ways when related to disability, a concept that can easily be applied to human identity in general. He asserts that "identifying" can be regarded as an active verb and as a reflexive verb. With the expression "active verb", he refers to the process by one non-disabled person of recognizing and acknowledging someone as disabled. With "reflexive verb", he indicates the path that causes an impaired individual to comprehend him/herself and assert belonging to the disability community. The duality in the procedure of defining one's identity described above can equally be found in the thought of Michael Foucault. He claimed that everyone is made into a subject from above, that is to say, through the people that surround them and the entities that exercise control over them; and from below, intending the process through which people self-define their identity and share it with others, "speaking the truth about themselves" (quoted in Shakespeare 1996:94).

Furthermore, Shakespeare believes that the recent accomplishments of the disability community offer them new alternatives to forge their identity, and to illustrate this phenomenon, he employs the metaphor of storytelling. Affirming that "identity is an aspect of the stories we tell ourselves and to others", he explains that, in the past, people with disabilities had a limited spectrum of stories available to them, but now new narratives about disability are being told by able-bodied people and by the community itself. He believes that this can be the opportunity to share a more positive and happier image of living with impairments. (Shakespeare 1996:94). Moreover, the metaphor of the storytelling and the fact that narratives put together characters and plot, causality, and conflicts, allow considering identity as a mix of elements, including context and embodiment (Shakespeare 1996:99). The following sessions will discuss the definition of identity for a person with a disability from below and from above.

2.1.2 Identification as disabled by other people

In identifying someone as disabled, people ground on internalized assumptions and prejudices. They notice someone that can fall into the undifferentiated category of "disability" and automatically positions them in it, without even trying to understand their distinguishing characteristics and look at the single individual, the person behind the impairment. As it has been formerly illustrated, most of the time, belonging to this group is perceived as something negative and to absolutely avoid.

In his essay, Shakespeare explicates that there are two dominant ways to identify disabled people as a collective – one based on the medical model and the other, slightly more positive one, on the social model (Shakespeare 1996:95)[22].

However, it is noteworthy to mention that these two conceptions are not the only ones. Another of the most frequent ways non-disabled people typically consider impaired individuals is as an inspiration. This is an evident symptom of the low expectations society has about disabled people, who are only considered a way for able-bodied to feel better about themselves. Consequently, impaired people are not taken seriously, and this provokes anger and frustration in them as they feel that their worth is not properly valued. When the phenomenon of considering people with disabilities is taken to the extremes, it is called "inspiration porn". The choice of dealing with this notion is dictated by two reasons. The first is that considering people with disabilities as inspirations is one of the major ways able-bodied perceive them. Moreover, the fact that this idea had been so adequately illustrated by Stella Young, an advocate with Osteogenesis Imperfecta, makes it more relevant for this research, whose primary focus is on this rare condition.

Stella Young was born in Stawell, Western Victoria, Australia, in 1982, and began her activism at the age of 14 when she fought for the accessibility of shops on the principal street in her hometown. In addition to being a member of the Victorian Disability Advisory Council, and working with the Youth Disability Advocacy Service, she conducted eight seasons of Australia's first disability culture program, *No Limits*. She died at the age of 32 on December 8th, 2014 (www.ted.com/speakers/stella_young).

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[22] This paragraph will not go into detail about these perceptions, as they have been addressed in the concluding section of the previous chapter.

In April 2014, she participated in the TedxSydney event where she delivered her memorable speech *I'm not your inspiration, thank you very much*. She began by recalling two episodes of her life. The first dated back to when she was 15 years old, and the mayor of her town proposed to give her the Community Achievement Award, even if she had not accomplished anything and she was an ordinary teenager if her physical condition was not taken into account. The second event took place when she was a teacher in a high school. Twenty minutes later after the beginning of her first lesson, one of her students asked her when she was going to start her motivational speech. Young explained that these happenings occurred because people with disabilities are often regarded not as individuals but as objects of inspiration, a phenomenon that she called "inspiration porn". As Young explained, she used the word "porn" deliberately, because this discriminatory attitude objectifies a specific group (people with disabilities) to benefit another (able-bodied individuals), that in this way feels better about themselves by thinking, "however bad my life is, it could be worse, I could be that person". In Young's opinion, society has been told a lie, that is that disability is an undesirable thing and that living with it makes you exceptional. It is incontestable that disabled people constantly overcome obstacles, but that they are not what society thinks they are, as they are not impediments produced by their impairments but, adhering to the social model, by society itself. Moreover, she specified that the issue is not being inspired per se. She admitted she learned from other disabled people all the time, but not in relation to their degree of disability, but about the way they deal with a "world that exceptionalizes and objectifies us" (www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much).

2.1.3 Negative self-identification as disabled

When an individual considers their disability as a negative identity, it is typically an outcome of their applying to themselves the medical approach to disability. The subject focuses exclusively on the impairment, which is seen as a tragedy and is not accepted. Consequently, he/she experiences sufferance, grief, and loss. Being an individualized occurrence, the context is not questioned and no alternatives to the medical diagnosis are taken into account. Their disability becomes a rational explanation for their failures, as the person presumes that it plays a fundamental part in their incapacity to accomplish their goals.

An alternative to this vision consists of employing various forms of denial. The first is the subject affirming to be completely normal and attempting to reduce the importance of their disability through various actions like trying to conceal it. As a result, interactions are difficult to manage and provoke emotional stress. A similar tactic is considering the impairment in a religious way – it is regarded either as wanted by God and thus tolerated, or decided by fate and therefore the unique solution is to resign. Either way, the designated "victim" bears the sufferance of their disability, in the hope of recompense in the afterlife. The last one is traditionally employed by men, essaying to comply with their gender expectations, and it consists of searching for a way to overcome the handicap. They refuse to accept reality and try to reverse it by engaging in superhuman activities, such as extreme sports.

These coping strategies are not effective or healthy. They are all the result of the influence on the subject of the external disempowering definitions of disability, which the individual is not capable to reject or dissociate themselves from. Every so often the concerned person attempts to fabricate a compromised identity, including more positive self-esteem as well, but it is temporary and extremely fragile, and it has a considerable emotional and psychological cost (Shakespeare 1996:98-100).

These theoretical principles are actualized in Ph.D. student Eliza Chandler's article "Sidewalk Stories: The Troubling Task of Identification" (2010)[23]. She asserts that it is undeniable that the assumptions about what it means to be disabled change from time to time and from culture to culture, but in the context in which she was born, in the 80s and in a white middle-class family in Nova Scotia, having Cerebral Palsy was regarded under the medical model lens. To demonstrate the influence that other persons' consideration of her disability has on her life, she recounts the emotions she experiences when she falls. She explains that when there are cracks in the sidewalk, and she crashes to the ground, she fulfills other people's expectancy that she represents a living problem, that this problem is within her, and that the disabled body is unpredictable.

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[23] It is interesting how Chandler narrates the episode of the sidewalk naming it "a story", recurring to the metaphor of storytelling to define identity, as Shakespeare (1996) did. In her article, she claims that "I have many stories of disability (…) that collectively bring sense to my being in the world as disabled" and that these stories are what form the chronicle of how disability became significant to her (Chandler 2010:2-3).

Recognizing this and identifying in this way is immensely painful for Chandler, who also adds that, as it has already been said, is an individualized experience. The people around note her only to avoid her and her impairment because they do not want to have anything to do with disability, leaving her alone to deal with her struggles. Noteworthy is additionally her focus on the body, which is the device that causes her to enter this type of situation and interaction. She admits to having undergone the phase of denial as well, believing that if she were attentive not to identify as disabled, the idea of disability as a problem would be something separate from her (Chandler 2010:1-3)[24].

2.1.4 Positive self-identification as disabled

People with disabilities that tend to self-identify more confidently are generally those that reject the medical model and its negative assumptions and concentrate on the social model and the exclusion and injustices toward disabled people. Ordinarily, what happens is the individual transitioning between these two visions. This process is described as "coming out", and it causes the individual to reject the external definition of who they are and to claim their subjectivity. Even if it can be the result of personal development, it predominately occurs in a collective context. In fact, belonging to a group prompts a process of self-identification in its members, especially if they all have one aspect in common. Furthermore, there is a correlation between self-organization and the development of a political movement, like the one fighting for civil rights in the 70s, and direct actions are another element that helps people in the shaping of their own identity. In addition, the disability movement overturned the idea that people with disabilities are incapable, resigned, and powerless, providing a new paradigm of identification to the members of the community. Moreover, it established new ways of describing disability that, being conceived by the interested party, are viewed as the most appropriate ones. Thereupon, disabled people began to be considered the most experts in disability issues, taking the place of professionals.

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[24] Quoting Rod Michaklo's book *The Difference That Disability Makes* (2002), in her article Chandler also underlines that there is a considerable difference between being diagnosed with a disability and identifying as disabled and clarifies that they do not necessarily occur at the same time.

Another collective aspect that prompts a process of identification in single individuals is disability arts[25]. In fact, it has been observed that there is a deep connection between culture and identity. Disability arts offer the opportunity for the community to gather, discuss, challenge the status quo, and attain unity, and at the same time, they give each of its members the possibility to become active agents for social change.

However, the process of positive identification is incredibly complicated, and it is not a once-for-all, but an unceasing work in progress. It is remarkable to highlight that people born with impairments and people becoming disabled go through different paths when it comes to identity. While the former have viewed themselves as deficient all their lives and they have not experienced any alternative, the latter have to shift from an able-bodied identity to an identity as "other". Moreover, some people engage in political activities to avoid focusing on personal psychological issues, like non-acceptance and self-hatred, leaving them with a feeling of stress and frustration (Shakespeare 1996:100-104).

There are two significant difficulties in regarding disability as a positive aspect of identity. To begin with, as it has been evidenced by Chandler's article (2010), people with disabilities are influenced by society to see themselves under the medical model lens. Able-bodied subjects view being different as being inferior, and people with disabilities tend to internalize this definition. This so-called internalized oppression is supported by the absence of positive cultural representations and role models, and by the discrimination that frequently results in segregated environments.

In the second place, people with disabilities are isolated and separated from each other and they are surrounded by able-bodied individuals. Because it is reasonably probable that they are the only member of their family that has an impairment, they cannot identify even with their closest ones. On top of all that, their parents are likely to feel guilt and shame toward their child's condition, which makes it even harder for disabled individuals to "come out" and comprehend there is nothing wrong with their difference. Subsequently, when they experience injustices, they must deal with them by

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[25] Activist Allan Sutherland has defined "disability arts" as "art made by disabled people that reflect the experience of disability". In this context, disability is not viewed as an obstacle but as a potent subject for artistic works. Disability arts does not have a therapeutical purpose and does not fold to other people's assumptions. It is primarily addressed to people with disability. (disabilityartsonline.org.uk/what-is-disability-arts).

themselves, and cannot readily rely on someone who can comprehend and fight with them.

Therefore, it is evident why it is so effortful for disabled people to recognize and dissociate from the negative judgments other people have to forge a more positive identity for themselves (Shakespeare 1996:104-105). To go back to Chandler (2010), she affirms that people with disability can undoubtedly succeed in feeling proud about their condition, but this is not going to eliminate the pain, frustration, and discrimination they typically experience because of the assumptions that able-bodied individuals have about them. Having the disability community provides people with a protected space to verbalize their stories, but it would not cancel the sufferance either. To conclude, Chandler believes that a complete transition between the vision of the medical model and the one of the social model is unobtainable and undesirable, and the only possibility is accepting the togetherness of pride and shame in identifying as disabled and that the community is what makes this ambivalence endurable (Chandler 2010:4).

2.2 Affirming Identity through Life-Writing Narratives

2.2.1 Life-writing and disability

Life-writing is a genre that concerns life. It can narrate one person's existence from birth to death or recount single everyday life events, without excluding the presence of fictional elements. It is mistakenly considered limited to autobiography and biography, but it actually includes memoirs, letters, diaries, journals, non-written sources such as biopics, plays, and musical performances, as well as more modern ways of sharing one's life like social media (oclw.web.ox.ac.uk/what-life-writing). Nonetheless, for the purpose of this paper, the primary focus is going to be on life-writing as a literary genre.

Life-writing began to be employed by marginalized and oppressed people, including disabled individuals, already in the 18th century, but it is only since the 50s that it has been used consistently to provide a voice to those who have been silent and silenced (Wohlmann-Rana 2019:11). It has been observed that there is a direct correlation between the political and literary: the civil rights movements expanded the public for memoirs, while life-writing narratives were one of the devices activists used to support their critiques and demands (Couser 2017:201-202). Therefore, disability life-writing specifically has been ceaselessly increasing since the 80s and has helped to constitute a community, share valuable experiences and advice, protest, and challenge the traditional stories of the past about having a disability (Wohlmann-Rana 2019:11). However, before the current memoir boom, it was the memoir authored by the parents of a disabled child that prevailed. Their purpose was honorable – they wanted to raise awareness about their child's condition, and to recount a life enjoyed despite the unfavorable event – but they repeatedly resulted in depicting having a child with a disability as the nightmare of any parent (Couser 2017:208).

Echoing Lorraine Adams' distinction between "somebody memoirs" and "nobody memoirs"[26], Couser coins the term "*some body* memoir"[27] to refer to life-writing non-fictional narrations of living with an anomalous body. He claims they can be divided into two categories. The first one concerns a few conditions that have been the subject of many narratives. Contrary to widespread belief, however, these are neither the more fatal or dangerous ones nor the more common ones. Couser explains that other factors dictated by culture and context are involved. The second category is made up of countless diseases, some relatively rare, that are the center of an exiguous number of memoirs. Today as never before in the United States book market having a rare disability is considered enough to publish a full-length (auto)biography. The decreased cost and increased reputability of self-publishing have helped, together with the expanding prominence of the internet, an ideal platform for self-representation thanks to blogs and social media (Couser 2017:202-203).

2.2.2 Common rhetorical motifs in life-writing disability narratives

As it has been asserted above, life-writing disability narratives represent a practical tool to alter the current popular opinion on disability. Not only do they make

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[26] Adams explains these concepts in her article "Almost Famous: The Rise of the 'Nobody' Memoir" published in the *Washington Monthly* on April 2, 2002. "Somebody's memoirs" are those written by celebrities. They benefit from an already existing public and their realization is a consequence of their writers' fame. "Nobody memoirs", instead, are authored by subjects that were not notorious before publishing their work, and whose celebrity depends exclusively on their story (quoted by Couser 2017:202).

[27] Nonetheless, he specifies that the technical term for this type of chronicles would be "autosomatographies" (Couser 2017:202).

people with disability feel less isolated and more empowered, they also provide society with a distinct point of view promoting social change. However, this is not uncomplicated. As it has been previously demonstrated, people with disabilities tend to internalize prejudices and assumptions able-bodied subjects have about them, and if they do not properly challenge them in their works, they risk contributing to their spread. Couser reports the rhetorical patterns in life-writing disability accounts that do that[28], which he had identified in his book *Signifying Bodies* (2009).

Couser begins with what he terms the "rhetoric of triumph", which is the most prevailing and valued one, and perfectly adheres to the concept of "inspiration porn" discussed above. It is particularly present in the narratives of overcoming, which feature a protagonist that is a so-called "supercrip"[29], a comic plot, and a happy ending where the disabled individual accomplishes unforeseen outcomes despite their misfortune. However, these accounts are deceiving – they misrepresent reality, in which impaired people continuously struggle with unemployment and poverty, and they imply that society does not have such a significant part in disabling individuals to the point that a person cannot triumph through perseverance. Contrary to what it may be thought, these narrations are produced to reassure the able-bodied public – the disabled audience knows perfectly well the actuality is different from the one represented in the memoirs. Nonetheless, because a more positive perspective is offered to them, the nondisabled feel reassured, at least temporarily, from their fear of disability.

The second pattern is that of Gothic fiction, commonly known as horror. The author describes the impairment[30] as a source of dreadfulness, only because it belongs to the past and has been surmounted. Employing comic plots as well, it deliberately exploits the fear of disability, only to soothe it considering the narrator has escaped from it. However, the repulsion and the pity toward the impaired protagonist remain because even if he/she is blessed to have recovered totally, the stigma associated with the condition abides. This narrative strategy is strictly connected with the rhetoric "of

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[28] These patterns are strictly connected with the theme of disability identity discussed in the previous section. If innumerable disabled writers recur to them, it means that they are typical ways able-bodied individuals view people with disabilities, who internalized them.

[29] As Couser clarifies, "supercrip" is a denigrative word that refers to people with disabilities who overcompensate for their supposed deficiencies, achieving something that was thought to be impossible for someone with their condition. In addition to being extremely hurtful and damaging, it puts considerable pressure on the person, who feels ashamed if they are not capable to fulfill the expectations (Couser 2017:203-204).

[30] In the case of this narrative, the impairment has been acquired during the lifetime (Couser 2017:204).

restitution”, in which the impairment is corrected or cured. Nevertheless, in this case, the hero is not the narrator, who has not contributed substantially to this conclusion, but the medical professional, whose knowledge and skills have produced this outcome. Both patterns, it is worth underlining, interpret disability through the medical model.

Lastly, Couser deals with the “rhetoric of compensation”, which supposes that people that suffer from a chronic or progressive illness that seems to exclude the comic plot and the happy ending are recompensed on the spiritual and religious levels. In this type of account, the narrator frequently feels to be a special servant designated by God. If one on hand it may seem that this pattern is subversive because it overturns the connotation of immorality typically attached to the disabled body, on the other, it persists in propagating the idea that having an impairment needs a reward.

Nonetheless, Couser claims that some subversive accounts have developed in the last decades. The most prominent one is the story of coming out, that is to say, the narration of owning and claiming one’s identity as a disabled person, encouraging others to do the same. Appropriated from gay and lesbian chronicles, it is especially utilized by individuals with an invisible or an effortlessly concealable disability. Another counter-discursive pattern is the narrative of emancipation, in which the coming out is literal. The narrator is liberated from, for example, institutionalization, and requests equality asserting that the impairment does not justify discrimination.

In his chapter, Couser dwells as well on the complicacies of life-writing for disabled people. He explains that the act of writing in itself can be immensely complicated for them precisely because of their impairment. Many authors must resort to the help of assistive technology and to the collaboration of other persons to finalize their work. Still, Couser affirms that if the writer can approve the text, then it should be considered valuable. Moreover, even non-disabled celebrities turn to ghostwriters for their memoirs, and this does not decrease their worth and popularity.

To conclude, Couser explains that when the social model developed, this type of life-writing narrative was considered too individualized and in conflict with the goal of the model of demonstrating the oppression of disabled people as a group. In the last years, however, the awareness of its limits and the increasing sophistication of memoirs have made sure that disabled life-writing narratives are more appreciated. Furthermore, considering the denigrating assumptions of living with an impairment and the augmentation of practices, like prenatal tests and assisted suicide, that threaten the existence of people with disability, Couser asserts the necessity of what he defines as "quality-of-life writing" – shreds of evidence that having a disability is respectable (Couser 2017:203-210).

2.2.3 *Sono nato così, ma non ditelo in giro* by Mattia Muratore

Mattia Muratore was born in Monza, Italy, in 1984, where he has lived all his life in the municipality of Arcore. He was born with Osteogenesis Imperfecta, a rare genetic condition that caused him numerous fractures and made him a wheelchair user. He graduated in Law, and he is currently working at the University of Milano-Bicocca. Not only Muratore is an advocate for the paralympic sports, but he has also been part of an electric wheelchair hockey team, the Sharks Monza, for 25 years, for whom he is now the president and captain. In 2018, he won the world championship with the Italian national team. In 2022, he authored his first autobiography*, Sono nato così, ma non ditelo in giro*, published by Chiarelettere (www.chiarelettere.it/autore/mattia-muratore.html).

Muratore's work is undoubtedly one of the examples of "quality-of-life writing" Couser referred to, and that is the reason why it has been chosen as a case study for this research[31]. The pattern Mattia employs is counter-discursive but in an innovative way. It is not an actual "coming out" story, because Mattia does not recount his process from denial and non-acceptance to claiming and owning his disability. Mattia does feel proud to be disabled, but he apparently always has, or, at least, his previous relationship with his disease is not essential. In his work, he "merely" recounts his life, with all its ups and downs, including but not solely those because of and thanks to his illness.

His contentment with his own being is evident from the very introduction of his autobiography, "Intro: i disabili e i loro innegabili vantaggi", when Mattia ironically lists the advantages of being disabled, like skipping the queue to enter the museums. To conclude, he claims:

> Allora, dicevamo, conviene o no [essere disabili]? C'è chi questa cosa non la capisce. C'è chi la capisce, ma non l'accetta. […] E poi ci sono quelli come me. Quelli che ce l'hanno fatta e ne

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[31] Moreover, as it has already been stated, Muratore has Osteogenesis Imperfecta, the condition that is the primary focus of this work.

> vanno fieri. Quelli che, anziché nascere con la camicia, sono nati con la carrozzina. Che poi, a voler essere pignoli, sono nato senza. Me l'hanno comprata dopo. (Muratore 2022:5-6)

Another example of this can be observed when he is recounting a date that he had with a woman, and he admits having declared her at some point: "Ok, dai, va bene. Hai avuto il coraggio di uscire con me e quindi, in fondo, te lo meriti. Ti dichiaro ufficialmente, in via definitiva e solenne, che sono felicemente handicappato. Da sempre" (Muratore 2022:148)[32].

In addition to demonstrating that Muratore is proud of who he is, these quotes are important for two reasons. Primarily, they highlight that the author is completely aware that not all people with disabilities are at peace with their situation like he is. Second, they are examples of irony, an attitude that characterizes all his work. The fact that he laughs about his being disabled not only is one of the umpteenth demonstrations he is perfectly at ease with his impairment but it also allows him to challenge the assumptions abled individuals have, without being too severe.

In fact, his being proud to be disabled does not have to be mistaken with Muratore not being aware of the preconceptions that surround the concept of "disability". In the chapter "Non accettate caramelle dagli handicappati", Mattia provides a fictional context to put together some of the most widespread prejudices. The section is set in a high school in Milan, and it is narrated by Attilio, a rebel adolescent boy[33] who, along with his classmates, attends a conference delivered by Ennio Bevilacqua, a man with a serious physical disability, who is going to talk about his charitable organization. For the whole chapter, Bevilacqua's words are interposed with Attilio's thoughts and reactions to the man's appearance and lecture. When Bevilacqua enters the room and introduces himself, Attilio instantly thinks: "Ma come si fa a mandare in giro certa gente? […] Quelli come te andrebbero eliminati subito, da piccoli. Altro che farti andare in giro a parlare in pubblico" (Muratore 2022:26-27). When the speaker claims that, despite a significant disability and its challenges, it is possible to live a fulfilling life, Attilio does not believe it: "Tutte palle. La verità è che non ti sei ancora sparato un colpo in bocca soltanto perché da solo non ci riesci" (Muratore 2022:27), while when he admits he is married and he has some children, Attilio's first reaction is in line with the

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[32] The use of the word handicappato, which in Italian has a negative meaning, is provocative.

[33] The choice of a young boy as the protagonist for this chapter it is not casual. It underlines that even if things for the disability community are slowly changing, younger generations are still growing up with stereotyped ideas about what it means to have a disability.

belief that disabled people cannot have a sincere romantic relationship, and that the people that are with them are not their partners, but their caregivers: “Si, certo. Una compagna. Te al massimo ti sarai trovato una badante extracomunitaria disposta a fare qualsiasi cosa pur di avere due lire e il permesso di soggiorno. […] E poi? Figli? Siamo proprio sicuri che siano tuoi?” (Muratore 2022:28). Attilio’s responses are obviously taken to the extremes, but it is done intentionally. The readers initially are shocked and angered by the student’s convictions, but it is reasonably probable that they will come to realize that at least once they have thought like Attilio. Furthermore, when Bevilacqua ends his speech, everyone is crying and looking at him with admiration. His speech was intended to persuade the students to recognize the silver lining in every moment of their lives because if he can do it, they can as well (Muratore 2022:29-31). Muratore is aware of the concept of “inspiration porn”, and he uses Attilio’s reaction to challenge it highlighting that even this other approach to disability is wrong.

Besides being aware of the misconceptions surrounding disability, Muratore is able to recognize ableist[34] behaviors and condemn them too. Narrating some episodes that happened to him, he indirectly invites the readers to avoid behaving in these ways. To begin with, Muratore talks about when people move wheelchair users without demanding their permission. He relates that one day when he was younger, he was struggling to push his wheelchair up a steep ascent when suddenly he began to proceed without any effort. After a few seconds of bewilderment, he realized:

> Molto semplicemente, alle mie spalle si era materializzato un inquietante tizio grande, grosso e pelato che, afferrati i manici sullo schienale della mia carrozzina, aveva pensato bene di spingermi. Così, per aiutarmi un po’. Per carità, gesto nobilissimo, nulla da dire. Ma […] avvertimi, no? Almeno dimmelo! Ti pare che io, mentre vado in giro e vedo un vecchietto che si muove a passo di lumaca, gli piazzo le mani sul culo e gli do uno spintone? (Muratore 2022:39)

The second example he proposes is that frequently the first thing that non-disabled individuals inquire about a disabled person is their diagnosis. They are so curious, and probably so driven by the fear that the same “misfortune” could happen to them, that sometimes they stall them on the street. The writer recounts a time when he was eating in a restaurant and an old woman he did not know asked him this question out of nowhere. Nonetheless, even in this case, Muratore employs the irony that characterizes him to answer: “Eh, sa signora, da piccolo mi hanno fatto fare tutte le vaccinazioni

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[34] Ableism is the discrimination or social prejudice against people with a disability.

tranne quella per evitare di diventare handicappati. Se la son dimenticata, quei maledetti" (Muratore 2022:159).

Ultimately, Muratore remarks that when a person with an impairment is with someone else, other people have the tendency to speak to the abled individual. He explains that one night he was in a club with some friends when a man tripped in his wheelchair. The guy immediately apologized to Mattia surprising him: "Rendendosi conto dell'inconveniente, si girò e chiese scusa. A me. Mai successo prima, mai più successo dopo. Da che mondo è mondo, le scuse indirizzate a un disabile, vengono sempre rivolte a chi lo accompagna […] quasi il disabile stesso fosse un soggetto incapace di riceverle o di comprenderle" (Muratore 2022:239).

Despite his awareness of ableist prejudices and behaviors, as I have already mentioned, Muratore feels proud of his condition. One of the arguments that can explain it is his adherence to the social model which, as it has been discussed in the previous section, promotes a process of positive identification. The author indeed dedicates an entire chapter[35] to Osteogenesis Imperfecta explaining through a metaphor what it is and the process of recovering from a fracture, but the rest of his autobiography is centered on everyday life situations made more complicated by society rather than by his impairment. From attending school and university to going to a concert or the stadium, from looking for a job to going on holiday, from having friends to engaging in a romantic relationship, Muratore deals with the most ordinary events in a person's life to accentuate all the struggles disabled subjects must face to enjoy life like everyone else. Three situations are going to be examined further as they are the most relevant and crucial ones. Primarily there is a physiological and basic need of every human being – going to the bathroom. The writer goes back to this topic multiple times in his work. The first time, he chronicles that he was waiting for a concert to start when he realized he had to use the toilet. However, it was not possible, there were too many people, and he would have not been able to pass through and reach it (Muratore 2022:78-79). After some pages, he explains that having an accessible bathroom is mandatory by Italian law. However, many places decide to use it as a storage room, obliging the disabled person to wait until the person in charge has moved the objects that were inside (Muratore 2022:87-88), or to close it with a key to prevent other persons from getting it dirty,

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[35] Chapter one "Vita da matita", pages 7-11.

forcing the impaired subject to ask the authorization to utilize it (Muratore 2022:170). The second example concerns reserving a table at a restaurant. The author reports a conversation he had by phone with the owner, who admitted that there were some steps to go inside. Initially, the man treats them as not a problem adding that they would lift him. After having kindly remarked that it was his decision if the steps were or not an impediment, Mattia lied about being very heavy and using an electric wheelchair, at which point, the owner gave up. The writer did so to accentuate that finding an offhand solution for an individual does not make a place accessible and that the issue should be avoided in the first place. The ultimate illustration regards driving. Muratore explains that obtaining a driver's license is extremely crucial for a disabled person because it allows him/her to go around independently, especially considering they habitually cannot benefit from the transportation system due to its inaccessibility (Muratore 2022:186). Furthermore, it is one of the few contexts in which they are treated in the same way as everyone else: "Quando siamo alla guida delle nostre auto, come per una misteriosa magia, la nostra condizione di poveri handicappati viene meno. O meglio, non è più visibile a occhio nudo. Improvvisamente, visti da lontano, anche solo dall'esterno dell'abitacolo, siamo uguali agli altri" (Muratore 2022:193). The author lists the innumerable difficulties that driving implies, like reaching the toll booth (Muratore 2022:186-187), loading and unloading the wheelchair (Muratore 2022:190-191), refueling (Muratore 2022:192), and above all abled people that use the handicapped parking spots (Muratore 2022:116-117; 163-164; 194-195).

Regardless of covering it with irony to be more effective so as not to result too tedious, the frustration with the disabling attitude of society is palpable in the entirety of his autobiography. Notwithstanding, it is only toward the end of the book[36] that Mattia lets himself go to a direct criticism of society. He pretends to write a letter to his "mister" – another word for "coach" – in which he asks him why still nowadays not all the public facilities are accessible and why it is so complex to be more attentive to the needs of the disabled population. He dares to wonder how beautiful it must be to live freely:

> senza vincoli, senza barriere, senza quello che ti guarda come se fossi appena sceso da Saturno, senza dover sempre, in qualche modo, sentirti in dovere di dimostrare che non sei un perfetto

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[36] Chapter "Lettera al Mister", pages 249-256.

> idiota. Ma soprattutto, non sai quanto mi piacerebbe vivere anche un solo giorno della mia vita senza dover chiedere. Neanche una domanda, neanche un favore, niente di niente. […] Un giorno senza dover lottare per un sacrosanto diritto qualunque […]. Noi handicappati siamo obbligati a vivere come se fossimo agli arresti domiciliari. Dobbiamo chiedere il permesso per tutto. (Muratore 2022 252-253)[37] [38]

He then goes on to say that people with disability deserve to live in a civil world where they can secure the job they are qualified for. Where there is an accessible entrance everywhere, that is the same for everyone. Where they can use public transportation without struggling, and where accessibility is taken for granted. He concludes by inviting society not to allow the fear of what it does not know to block it, and to change its mentality (Muratore 2022:253-254).

Surrounding himself with people with disabilities is another explanation for the author's acceptance of his disease. Muratore talks about some of the individuals that had a significant impact on his life in his book. There are all his wheelchair hockey teammates. There is the 50-year-old man, nicknamed "Il Pirata", that helped him and his friend Francesco to navigate their first time to the stadium (Muratore 2022:15-17). There is Ivan, the handbiker that Mattia met at the gym, and that became like a coach to him (Muratore 2022:125-129). There are Marco and Gimmy, two guys that hung out in the same pub as he, and that were at the center of attention one evening because of their desperate attempts to make a good impression on a girl (Muratore 2022:175-183). But most importantly there is Niko. Their friendship began during the years of middle school, and the author dedicates one entire chapter[39] to recounting their Saturdays spent going around their hometown, Niko in front and Mattia attached to Niko's electric wheelchair. In spite of all the difficulties that implicate living in an ancient and inaccessible city, those afternoons were life-changing as they represented the chance for them to be free and independent for the first time and to understand that, despite their impairments, they could be so all their life:

> I nostri sabato pomeriggio erano meravigliosi. […] Parlavamo di tutto, ci confidavamo, ci scambiavamo impressioni su questa o su quella tipa, ridevamo della nostra condizione di pover handicappati. […] Eravamo talmente orgogliosi di noi stessi, della nostra libertà, del fatto di

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[37] In a previous chapter, the author had already remarked that asking for help is a survival strategy for disabled people (Muratore 2022:44).

[38] He also had already stated the necessity to continue to fight: "Arriverà, forse, il giorno in cui si potrà vivere in un paese dove i disabili avranno gli stessi diritti (e naturalmente anche gli stessi doveri) di chiunque altro. […] Ma fino a quel giorno bisognerà lottare con le unghie e con i denti per ogni cosa, anche per il più piccolo diritto apparentemente scontato (Muratore 2022:72).

[39] Chapter "I disabili a passeggio", pages 33-48.

> cavarcela da soli, del non aver bisogno di nessuno per prenderci la vita che volevamo. (Muratore 2022:37).
>
> Tornavamo alla base, ci salutavamo e ci davamo appuntamento al sabato successivo. A un altro di quei sabati […] che ci hanno aiutati a diventare ciò che siamo ora. Che ci hanno aiutato a capire che sì, eravamo anche disabili, ma non per questo non potevamo essere liberi. (Muratore 2022:48).

To conclude, Mattia Muratore's life-writing account is without any doubt one example of "quality-of-life writing". The author presents a new counter-discursive pattern, one that includes everyday life issues of having a disability but also a narrator that has always been proud of his condition. Evidently, his adhesion to the social model and his community have contributed to shaping his positive identification, but there is one simpler reason that led Muratore to enjoy life as he does – he loves living.

> Negli anni tanta gente mi ha chiesto come sia possibile che io, nella mia situazione (*poverino!*), abbia sempre affrontato con una (a detta loro) inspiegabile positività tutto ciò che mi è capitato […] Poi, crescendo, sono arrivato a una conclusione tanto forte quanto banale: amo la vita. […] E alla fine chi se ne frega che io sia qui in piedi, sui trampoli, a cavallo o in carrozzina. Il benessere di una boccata di sole in piena faccia, la goduria di una birra ghiacciata sotto le stelle, il calore di un pranzo in famiglia davanti al camino, be', saranno sempre gli stessi. (Muratore 2022:227-228).

3. Osteogenesis Imperfecta in Young Adult Romantic Novels

3.1 What is Osteogenesis Imperfecta

3.1.1 How Osteogenesis Imperfecta is inherited

Before dwelling on the representations of Osteogenesis Imperfecta in young adult romantic novels it is appropriate to explain what this condition is about.

According to the Osteogenesis Imperfecta Federation Europe[40], at present, 500667 people in the world have OI (oife.org/), and less than 50000 are in the United States. OI is universally considered a rare disease, even if there is no unique definition for this concept. In the U.S., for instance, an illness is deemed to be rare if it affects less than 200000 individuals (rarediseases.info.nih.gov/diseases/1017/osteogenesis-imperfecta/living).

Osteogenesis Imperfecta is caused by a mutation in a gene. Genes are what convey the information that determines the features that parents pass to their children. Happening equally among males and females, in 90 percent of the cases, people have OI because of a mutation in the gene that causes the production of type 1 collagen, responsible for bone formation, bone strength, and the composition of numerous tissues. A flaw in the gene reduces either the quality or the amount of type 1 collagen. The other 10 percent of the cases are produced by a mutation in another gene (Bober 2013:5-7). People with OI can have inherited the defective gene from one or both parents, who do not need to suffer from the disease to transmit it. Every so often neither parent passes it, the gene solely stops working properly before birth.

Human beings possess two copies of every gene, one that is inherited from the mother, and one from the father. The majority of individuals have a dominant form of Osteogenesis Imperfecta, that is to say, they have got one ordinary copy of the concerned gene and one that is flawed. The defective gene is stronger or "dominant" and prevails over the standard one. This results in the person developing the condition.

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[40] Founded in 1993, OIFE is an umbrella organization that gathers all the European national organizations for OI, including the Italian As.It.O.I. (Associazione Italiana Osteogenesi Imperfetta) established in Padua in 1984 (www.asitoi.org/). The US organization – OIF (Osteogenesis Imperfecta Foundation), created in 1970 – is one of the associate members (oif.org/about-us/mission/).

Subjects that possess a dominant form have a 50-percent chance to transfer it to their children.

Other people have a recessive form instead. Their parents do not have OI, but they both possess an anomalous or “recessive” gene that provokes the disease. When this is the case, parents have a probability of 25 percent per pregnancy that the child is going to have the illness. Their unaffected children have a two-thirds chance of possessing the atypical gene and becoming a carrier of the disease. If one person suffers from a recessive form of Osteogenesis, all his/her children will carry the gene, but they will not automatically have it (www.niams.nih.gov/health-topics/osteogenesis-imperfecta).

3.1.2 OI’s characteristics and its various forms

Osteogenesis Imperfecta prevalently implicates a fragile skeleton, but many other organs are concerned as well. Fractures are its prominent symptom. They are extremely frequent from birth to puberty; they then decrease in young adult years to augment again with old age. Other characteristics include hearing loss, brittle teeth[41] – both present in more than 50% of people with OI – vision problems, blue sclerae, loose joints, ligament laxity, muscle weakness, and cardiac issues.

OI is an incredibly differentiated disease. Not only are there numerous types that vary from one another, but there are differences also within the same type. The most severe forms can cause premature death, while the milder ones may have no visible features. Since the ‘70s, a list of numbered types has been employed to describe OI’s form, and eight have been identified as the most significant ones:

- Type I: is the most typical and mildest type. Symptoms are few and not obvious and the subject has an average or near-average height.
- Type II: is the most severe. Newborns can die within weeks due to heart or respiratory complications. At birth, the baby already presents numerous fractures and serious bone deformities, in addition to underdeveloped lungs, small stature, and low birth weight.
- Type III: is severe, but habitually it is not mortal. It is defined by numerous broken bones at birth, while healed fractures that occurred anteriorly may be

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[41] Also called dentinogenesis imperfecta or DI.

observable through x-rays. It is characterized by a progressive bone deformity, especially of the rib cage, short height, and scoliosis.

- Type IV: is moderate and between type I and III as concerns stature and seriousness. Scoliosis and bone deformity, including of the rib cage, are its symptoms.
- Type V and VI: are similar to type V. However, the mutation does not concern the protein of collagen. The former is a dominant-inherited form, while the latter is recessive.
- Type VII is severe and recessive.
- Type VIII is similar to type II but is produced by recessive inheritance (Bober 2013:5-7).

3.2 Disability in young adult romantic novels

3.2.1 Characteristics of novels for young adults

To better focus on the key novels examined in the following section of my work, it is proper to elucidate also what young adult novels are and what their relationship with disability is, together with the frequent patterns employed in romantic books that include an impaired character.

The label "young adult" refers to a category of literary works based on readers' age. To be specific, it traditionally includes books composed for adolescents between 12 and 18 years old, and it ideally constitutes an intermediate step between middle-grade fiction and the adult one. It does not constitute a separate literary genre, but its narratives can belong to various genres (www.tckpublishing.com/young-adult-fiction/). The attention of the publishing industry to this market share is a recent phenomenon, with the term coined only in the 1960s (Wilcox 2019:1). Because they deal with protagonists that are entering adulthood and experiencing change in their identity, they are also defined as "coming-of-age" stories. (www.tckpublishing.com/young-adult-fiction/).

However, it has been discovered that they are not appreciated exclusively by teenagers. As Wilcox reports from Caroline Kitchener's article "Why So Many Adults

Love Young-Adult Literature" (2017), statistics show that about 55 percent of YA readers are adults. Wilcox relates that in her article "The Value of Young-Adult Fiction" Catherine Addington (2014) affirms that adults' interest in these novels is a consequence of today's obsession with youth. However, Wilcox proposes another explanation – she maintains that because every human being has experienced childhood, everyone can identify with some aspects of YA fiction (Wilcox 2019:1-2). Moreover, another reason can be the increasingly deeper themes confronted. In the past few years, YA books have started to handle issues like racism, sexism, and even ableism, to the point that a study has demonstrated that they can help prevent prejudices, according to Melanie Ramdarshan Bold's article "The Eight Percent Problem: Authors of Colour in the British Young Adult Market (2006-2016)" (quoted in Wilcox 2019:7). Nonetheless, fiction for young adults has been profoundly criticized. It has been accused among others flaws of being simplistic, addressed solely to children, not of enough literary quality to be taught in schools, and authored by amateur writers (Stephens 2007:34).

If typically, the focus to explain the concept of "young adult literature" is on the target readers, Stephens concentrates on its characteristics to define the category, while defending it at the same time as valuable literature. He declares that: "as I see it, the label 'Young Adult' refers to a story that tackles the difficult, and oftentimes adult, issues that arise during an adolescent's journey toward identity, a journey told through a distinctly teen voice that holds the same potential for literary value as its 'Grownup' peers" (Stephens 2007:40-41).

A more exhaustive list of the fundamental characteristics of young adult fiction includes the following:

1) Its protagonists are predominantly teenagers. There may be some adult characters that perform a key role, but the adolescent is the one that the readers follow. It is even more so if it is a first-person narrative because he/she represents the person that they are inside the mind of.
2) A teen voice is exploited. More often than in adult novels, a first-person narrator is employed, who is the adolescent protagonist. The language adopted is modern and the rhythm is rapid, to mirror the way of speaking of younger generations. (Stephens 2007:42).

3) It is the present tense to be primarily utilized because it conveys a sense of immediacy, and it reflects teenagers' tendency to consider the present as what matters most.
4) The crucial topic is the protagonist's journey toward the definition of his/her identity. While in adult fiction characters are constrained by certain limits and learn how to live within them, characters in YA novels, in the effort of defining who they are, recognize the existing boundaries and try to overcome them (www.tckpublishing.com/young-adult-fiction/).
5) The issues that the characters handle are adult ones like suicide, kidnapping and murder, racism, homosexuality and homophobia, physical or mental disabilities and ableism, etc (Stephens 2007:42).

As regards disability, Curwood (2013) reports in her article a statistic from Koss and Teale's article "What's Happening in YA Literature? Trends in Books for Adolescents" (2009) that demonstrated that 25 percent of young adult works included an impaired character. As the author reports, according to Mitchell and Snyder's *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), books that present subjects with a disability can be divided into two distinct categories: "normalcy narratives" and "disability counternarratives"[42]. This distinction can be applied to YA fiction as well. Novels that belong to the former typically include negative, oppressive, and restrictive representations of the disabled character, who by the end must be either normalized or withdrawn (Curwood 2013:21). Curwood adds that scholars have underlined that in these novels disabled characters were part of the story merely because they represented a necessary instrument in the moral development of other characters. Fictions that pertain to the latter category offer new possibilities instead. Habitually, these involve high expectations for the disabled characters, who contribute to society as everyone else, make their own choices, and establish relationships (Turnball et al., Exceptional Lives: Special Education in Today's Schools, quoted in Curwood 2013:17). As Dyches and Prater (2000) highlighted in *Developmental Disability in Children's Literature: Issues and Annotated Bibliography*, in the beginning, the first type of narrative prevailed, while in the past couple of decades writers tried to produce more counter-discursive chronicles (quoted in Curwood 2013:17).

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[42] In this categorization a striking similarity with Couser's distinction between unrevolutionary and subversive rhetorical patterns in life-writing narratives can be remarked.

To conclude, echoing *Martha Nussbaum's Cultivating Humanity: A Classical Defense of Reform in Liberal Education* (1997), the author explains that when readers stumble upon a person with an impairment in a novel they apprehend "sameness and difference". Identifying "sameness"[43] aids to comprehend others' experiences and constructs a profound sense of community, while remarking on "difference" propel people to question social constructions of normalcy and disability, avoiding the "othering" of disabled individuals, and preventing prejudices and social injustice (Curwood 2013:19).

3.2.2 Sentimental novels and disability

Each genre has its own rules, conventions, plots, and themes that differentiate it from the others. Consequently, every genre tends to allow particular types of disability narratives, which influence not only how disabled characters are represented, and how their representations are interpreted, but also the frequency by which they are employed, the condition they have, and the role they perform (Cheyne 2017:185-186).

Romances are fundamentally characterized by two elements – a central love story and an optimistic and emotionally gratifying ending. Being the outcome foreseeable, the focus is on the struggles the protagonists must confront to be together and to insure the happily-ever-after (HEA) conclusion, which habitually consists of their marriage and/or the arrival of their children.

Sentimental novels involve an immersive reading process. Readers are expected to empathize, identify, and be transported by feelings of joyfulness and hope for the future. The success of this type of narratives depends on their ability to produce the anticipated affective experience. The representation of the two lovers fighting to reach their goals results in the public's involvement while promising them that the characters will obtain what they deserve, and that love triumphs over any impediment.

When disabled characters perform secondary or minor roles in romances, the most typical figure they interpret is the needy impaired child. Traditionally he/she is the

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[43] As it has already been affirmed in the previous chapter, representations of impaired characters in literary works and in the media are useful to people with disability as well, as they contribute to the process of definition of their own identity. Negative images conduce to a pessimistic identification, but they can also trigger resistance, while positive depictions among others make them feel that their experiences are as valid as everyone else's encouraging an affirmative consideration of their condition.

son/daughter of the male protagonist, who encounters and spends time with the central female character because she becomes the caregiver, the nurse, or the therapist of his child. In these cases, the HEA is even more satisfying because not only the leading couple can finally be together, but also because the child has acquired a new parent. Frequently, the needy impaired child assumes the “yardstick role”[44] as well. In sentimental novels, impersonating this part means helping to establish whether characters are worthy or not of love. Working for or with a disabled person or merely recognizing that he/she is human is evidence of their virtuousness.

However, when the impaired character represents one-half of the central couple, the relationship between disability and romance becomes more complicated. As it has previously been affirmed, the HEA[45] is a key element of romance, making this genre future-oriented. For the conclusion to be satisfying, the foreseen future needs to be the one the protagonists wanted, the one that the readers hoped for them, and one where sensual desire itself is preeminent. The issue is that current prejudices and assumptions make considering futures that include disability as the direct opposite of HEA (Cheyne 2019:135-140), producing:

> a misfit between naturalized feelings about disability and the way that the text requires the readers to feel for its affects to be secured. The resulting discomfort can be resolved or eased in multiple ways, but one of them is a shift in the way the reader thinks (and feels) about disability – a shift that may affect behaviors and feelings in all kinds of disability encounters. (Cheyne 2019:152).

The shift Cheyne talks about involves entering “into an imaginative engagement with a world in which disabled people are not only worthy and desiring of love, but succeed in securing it” (Cheyne 2019:139). Moreover, authors themselves must try to propose “disability counter-narratives”. While some manage to do it, others do not.

Writers that adhere to the idea that a future with a disability is contrary to the HEA traditionally recur to two tropes. The first one includes an abled character that rejects the idea of sex – and the children that might result – with the impaired protagonist, who is perceived as someone that cannot desire an intimate relationship. In this context, the nondisabled subject takes the role of protector, while the disabled individual assumes the yardstick one. The novel ends with the abled person marrying

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[44] In her book Yardsticks: Retarded Characters and their Role in Fiction (1995), Patricia M. Puccinelli defined “yardstick quality” as “the capacity to act as or provide a measure against which other characters in the narrative are assessed” (quoted in Cheyne 2019:138).

[45] Nonetheless, the futures are rarely shown or depicted in detail, as they frequently are exclusively imagined by the readers (Cheyne 2019:139).

the nondisabled heroine, producing even more blissful feelings in the readers, because of the horrendous conclusion that has been prevented. The second recurrent plot comprehends the cure, or at least the amelioration, of the impairment[46]. Not only does it promote the idea that a nondisabled body-mind is essential for the HEA, but it also implies that someone who cannot be mended cannot be romantically fulfilled. This trope typically includes three elements. To begin with, there is the cure itself, which comes at the end of the story to reinforce the happily-ever-after (Cheyne 2019:140-143). An alternative to the concluding cure trope is the pseudo-cure narrative. It portrays something that seems and serves as a cure, but it does not implicate a change in the bodily state of the protagonist (Cheyne 2019:147). An illustration of this can be a wheelchair user that, while their condition has remained the same, can walk using crutches at the end of the novel, thanks to physical therapy. Secondarily, whether directly or indirectly, the merit for the cure is of the nondisabled partner. For instance, in some cases, it is the fact of falling in love that propels the disabled person to pursue treatment or therapy. This supports the opinion that disabled individuals are passive and confers the agency to the nondisabled subject (Cheyne 2019:143). Lastly, the impaired personage feels they do not deserve or will represent a burden to, their partner due to their disability-related issues, like internalized oppression (Cheyne 2017:193). This sentiment, which emerges after an event that sparks the realization, is the fundamental barrier[47] to the HEA. At this point, the concerned character tends to conclude the relationship, as an act of self-sacrifice[48]. Even though the barrier is always surmounted, this aspect positions disability as a problem, and the love of a non-disabled person as the solution (Cheyne 2019:144-145).

However, some devices can be employed to problematize this trope. Customarily, the HEA implicates that either disability is erased or ameliorated, and the couple ends together, or disability persists, and the lovers separate. If the abled partner insists that

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[46] In her book *Feminist, Queer, Crip* (2013), Alison Kafer defined this trope "the curative imaginary", implicating "an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention" (quoted in Cheyne 2019:147).

[47] Pamela Regis in *A Natural History of the Romance Novel* (2003) has described "the barrier" as one of the prime elements of romances and that depictions of barriers that are especially complex are necessary for attaining the emotional experience expected from the genre when they are overcome (quoted in Cheyne 2019:143).

[48] Cheyne affirms that, according to Regis (2003), another key aspect of romances is what she called the "point of ritual death", that is to say, the moment in which the HEA seems totally unattainable (Cheyne 2017:193).

he/she does not care about the protagonist's disability, a third option is offered to the readers – one that includes disability and a happily-ever-after. Moreover, it is true that in the case of pseudo-cure narratives the impairment is improved, but the character secures love while remaining disabled (Cheyne 2019:149-150).

Some representations can explicitly challenge "normalcy narratives". Primarily, authors can position nondisabled protagonists as lacking, making them realize that their perception of disability is influenced by socially-constructed definitions of normality. Successively, they can concentrate all disablist prejudices in one character that stands out from the others because of his/her attitude towards impairment, conveying the idea that this way of thinking is unacceptable. Next, writers can portray disabled individuals as potential romantic partners. Lastly, they can take advantage of the affective engagement of the readers. In *Making Meaning in Popular Romance Fiction: An Epistemology* (2014), Kamblé asserts that one of the crucial pleasures of romances is "sentophilia", the "pleasure in thinking and feeling another's thoughts and feelings" (quoted in Cheyne 2019:155). This relates to Feagin's notion, proposed in *Reading with Feeling: The Aesthetic of Appreciation* (1996), of "affective imaginings" that suppose readers not only imagine someone experiencing a certain emotion, but also acknowledge what it is like to feel it (quoted in Cheyne 2019:155-156). Authors can exploit this connection not only to challenge assumptions about disability but to make readers experience them. For instance, depicting a character's reaction to impairment and the effects that it has on the disabled individual can lead readers to think about how they would have responded in the protagonist's place, how they feel in disability encounters, and about the consequences of their behaviors, encouraging changes in their attitude (Cheyne 2019:153-158).

3.3 Osteogenesis Imperfecta in young adult romance novels

3.3.1 *Stringimi piano* by Irene Faranda

Stringimi piano is a young adult sentimental novel written in 2018 by Irene Faranda, set in 1999 near Bologna. The protagonist is Arianna, a 19-year-old girl with Osteogenesis Imperfecta, who finds herself in a private hospital to recover from a car accident that caused her various vertebral fractures. One day, in a card box packed with books that her parents brought her, Arianna notices a journal with her name on it. It is revealed that is her mother's and that she composed it when she was pregnant with her[49]. Arianna cannot stop herself from reading it, but she eventually forgets it on the food tray losing it. Meantime, Arianna encounters Leon, a basketball player injured in a match who is the only other adolescent patient in the hospital. The two rapidly become friends and Arianna convinces him to help her to find the journal and a woman called Natascia, whom she thinks has OI as well because the nurses have frequently compared them. By the end, Arianna finally retrieves the journal and meets Natascia that, to her disappointment, does not have OI, but haphephobia, the terror of being touched. By that time, Leon has completely recovered, and he has been offered a contract to play in Canada. The night before his discharge, he visits Arianna in her room, where they say goodbye. Leon donates her some soap bubbles. During one of their chats, in fact, Arianna had confessed that when she was little, she wanted to play with soap bubbles, but her mother forbade it because she was fearful Arianna would have fallen, fracturing a bone. Before definitely leaving, Leon encourages Arianna, who has fallen in love with him, to play with the bubbles to overcome her fears. In the epilogue, the readers find out that, twenty years later, the protagonists are still in touch.

3.3.2 *When My Heart Joins the Thousand* by A. J. Steiger

When My Heart Joins the Thousand by A. J. Steiger is a young adult romance novel published in 2018. The story is set in Illinois and the protagonist is Alvie, a 17-year-old girl affected by autism, who goes to the park every afternoon to observe "the boy with the cane". One day, she witnesses him throwing his cell phone into the lake. Intrigued, Alvie collects it and notices his name, Stanley Finkel, and his mail address written on the back. That same evening, she decides to message him. They chat online for two weeks until Stanley asks her to meet in person. Once Alvie gets there, she admits she accepted merely to propose to him to have sex with her. Stanley reluctantly consents, but he is not capable to actualize it because he wants to court her first. Alvie refuses, but Stanley ultimately convinces her to go on a date. From that moment, they

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[49] All throughout the book, before Arianna discovers it and after she has mislaid it, the chapters are alternated with extracts from the diary. Therefore, the readers simultaneously follow Arianna's story and her mother's pregnancy journey from when she found out to be pregnant, to when she was informed that her baby was going to have OI, to when she goes to the hospital to give birth.

start spending all their time together. One day, the two face a bully, and, in the fight, Stanley fractures his arm. It is only at this point that he confesses to Alvie that he has Osteogenesis Imperfecta. After some weeks, Alvie suffers from a mental meltdown and punches Stanley in the face. Fearful of becoming a danger to him, Alvie breaks up with him. Some days later, Alvie appears in front of a judge that grants her request for emancipation, because she has demonstrated to have been able to live independently. However, the following day, Alvie loses her job and is evicted from her home, obliging her to sleep in her car. Casually, she reads in a newspaper that Stanley is in the hospital due to another confrontation with the bully and she rushes to see him. Initially, Stanley rejects her, but when she admits she is living in her car, he agrees to let her stay in his house. "Forced" to spend time together, Stanley and Alvie reconcile, and he also aids her to apply for jobs. Alvie understands that for them to have a chance to engage in a romantic relationship, she must be honest with him. She then confesses to him that her mother committed suicide some years before because she could not bear having a daughter with autism. However, Stanley does not distance himself from her as she expected. On the contrary, he convinces Alvie that it is not her fault and that she deserves to be loved. In the end, the two decide to move in together in a new home.

3.3.3 A comparison between the two novels

Before engaging in a close analysis and comparison between the two novels, it is noteworthy explaining why a rare disease like Osteogenesis Imperfecta is employed in numerous novels and movies. In their article, Beauchamp, Chung, and Molinger (2014) reiterate that authors' intent is to induce readers to react to what they are reading. The reaction is supposed to be driven by emotions, and disability is especially adept for it. Nonetheless, some conditions provoke more feelings than others, and OI is one of these. In a speech at the University of California (2003), Mason explained: "aboulia isn't a major player while just-as-rare Osteogenesis Imperfecta is the core of a major motion picture. It is not fun to have a character who does nothing, but someone who can't even be born without shattering into pieces evokes emotion simply in its description" (quoted in Beauchamp-Chung-Molinger 2014:8)[50].

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[50] The film Mason is referring to is *Unbreakable* (2000), directed by M. Night Shyamalan and starring Bruce Willis and Samuel L. Jackson. In the movie, the character of Elijah Price, played by Jackson, has

To return to the novels by Faranda and Steiger, some themes in common can be identified[51]. To begin with, evidently, they both depict Osteogenesis Imperfecta. Arianna and Stanley are both affected by it and shatter some bones during the story. As it has been mentioned, Arianna is in the hospital because she needs to recover from an accident that caused her numerous vertebral fractures (Faranda 2018:13-14). Stanley instead breaks his fibula falling in class (Steiger 2018:41-42), then breaks his arm fighting the first time with the bully (Steiger 2018:151-153) and ultimately suffers from seventeen breaks the second time they confront each other (Steiger 2018:267).

In addition to focusing on the condition, both novels narrate the side effects that it implicates. For instance, they dwell on the loss of independence that results from possessing a bone in pieces. Arianna explicates that only when she will have completely recovered, she will be capable to transfer from her wheelchair to the bed by herself, but that until that moment she must wait for the nurses (Faranda 2018:61), while Steiger employs various pages to relate how Alvie must assist Stanley to take a shower and get dressed when he is discharged from the hospital (Steiger 2018:271-276). Moreover, each of the novels is particularly focused on describing one specific aspect of OI. As regards *Stringimi piano* (2018), Arianna comments multiple times on being short and on being consequently mistaken for a child repeatedly (Faranda 2018:29; 70; 82; 142; 246), while Steiger's novel concentrates on the blue sclerae[52]. In fact, it is the first thing Alvie notices when she meets Stanley: "For the first time, I meet his gaze. And I can't stop staring. His eyes are blue. Not just the irises. The sclerae – the whites – are tinted a misty blue gray" (Steiger 2018:57). This distinctive trait recurs several times (Steiger 2018:95; 101; 169) to the point that, even if Alvie does not know yet that Stanley is affected by OI, she is suspicious that there can be a reason behind the color of his eyes, and she researches online about the possible causes (Steiger 2018:102).

However, it is noteworthy that there are also some differences in how the disease is narrated. In the Italian story, OI is introduced in the third chapter (Faranda 2018:19),

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OI. The scene where Price is falling from a flight of stairs and images of him are alternated with the ones of glass shattering into pieces, while the noise of it breaking is played in the background (*Unbreakable*. USA: Touchstone Pictures, 2000), is evidence of Mason's theory that OI is extremely emotion-invoking. Evidently, his opinion on the reason why OI is so frequently employed is valid for novels as well.

[51] It is remarkable that both novels have been published in 2018, and that the characters affected by OI, Arianna and Stanley, are both 19 years old.

[52] Steiger's choice of focusing on the eyes is not casual. As it has been stated, Alvie (and the readers) finds out about OI at about half of the novel. Talking about the eyes allows the author to inform that there is something "abnormal" about Stanley, without using the main symptom of the disease.

and some clues are given even before that time, like when Arianna thinks: "di ossa me ne sono rotte, in passato, ma mai le vertebre e mai cinque tutte insieme" (Faranda 2018:19) and when she overhears that the nurses are fearful of transferring her from the gurney to the bed (Faranda 2018:14-15). On the contrary, in *When My Heart Joins the Thousand* (2018), Stanley confesses he has OI only later in the novel (Steiger 2018:157-160)[53]. Another diversity is the point of view by which OI is presented to the reader. In Faranda (2018), Arianna is the narrator of the novel, and the readers are narrated her first-person experience of the condition. In Steiger (2018), the narrator is Alvie, meaning that the disease is presented through her eyes and through what Stanly decides to explicitly impart to her.

The second theme that recurs in both stories is fear: because it is so simple for people with OI to hurt themselves, they are often terrified by what to others may seem harmless. For instance, in *When My Heart Joins the Thousand* (2018), Stanley admits that when he was a child, he was frightened of carousels[54] (Steiger 2018:174). In Faranda (2018), this topic is even more developed, and it is introduced when Arianna and Leon go to the hospital kitchen one night to look for the journal. While searching for it, Leon drops a bottle of oil, and Arianna has a panic attack. Even if she is using a wheelchair, seeing the oil on the ground terrifies her, because it reminds her that, if she was standing, she could have slipped on it, shattering a bone. Without saying anything, she abandons Leon, who gets angry with her (Faranda 2018:110-112). Some days later, the two meet, and Arianna tries to explain to him what happened in her mind through a metaphor. She tells him that her life is like constantly being on the cornice of a skyscraper from where she can potentially fall at any moment (Faranda 2018:121-124). When Leon signals that the oil would not have been dangerous because she was sitting, Arianna replies: "una pistola è una pistola. Anche quando ha la sicura inserita" (Faranda 2018:123).

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[53] However, after he and Alvie have tried to have sex in the motel, but he could not follow through, he asks Alvie to stare at him, hoping that she would notice that he has OI. After having looked at him for a few seconds, Alvie replies: "'I see you' I say. 'I see Stanley Finkel.' […] I have a feeling that wasn't the answer he was looking for, but I don't know what else to say." (Steiger 2018:80-81).

[54] Stanley tells this to Alvie after she has almost had a mental breakdown due to having stayed close to a big aquarium. Alvie says that she has not told Stanley she was afraid of water when he proposed the dolphin exhibit as the place where they could have lunch together because it is a stupid fear. It could be argued that Stanley saying that he was afraid of carousels, at that point where the readers and Alvie do not know yet he has OI, can be a way to comfort Alvie and retort to her low self-esteem due to autism.

The next recurring theme is individuals with OI's desire of challenging fate, which leads them to engage in actions that can be extremely unsafe and is a consequence of their living with constant attention. In *Stringimi piano* (2018), this topic is present from the prologue, where an episode that occurred when Arianna was a child is narrated. She recounts that one day she took advantage of her mother leaving her alone at home to play with some soap bubbles because she knew her mother would not have allowed her to do so as it was dangerous for her. In Steiger's novel, this subject is observable when Stanley asks Alvie to go ice skating with him. Alvie at first is reluctant: "He told me he used to skate when he was a child, until he broke his scapula. Does this have something to do with that? Probably. Even so, this seems like a foolish way of confronting his demons" (Steiger 2018:177). Realizing what Alvie is thinking about his idea, Stanley immediately says: "I haven't gone crazy, honest. I just want to go out and stand on the ice for a few minutes. I don't really know how to explain this. It's just something I need" (Steiger 2018:177). Even if Stanley does fall and hurt himself (Steiger 2018:178-181), Alvie recognizes that it was important to Stanley: "He overexerted himself today, but I know better than to say anything about it. This was something he needed to do" (Steiger 2018:181)[55]. Furthermore, this matter can be identified when Stanley confronts the bully for the second time. While the first time they opposed each other it was the bully, named TJ, with two other friends that attacked Stanley and Alvie, the second time it is Stanley who provoked him. Stanley and TJ casually meet in the park and as Stanley recounts: "he was going to walk away, but I started shouting at him […]. He kept telling me to shut up, but I wouldn't. Not even when he knocked me down" (Steiger 2018:267). There is no reason why Stanley may have wanted a physical confrontation with TJ, especially considering that the previous time ended with him fracturing his arm, if it were not to demonstrate to himself that he could challenge him.

Evidently, an individual affected by OI necessitates numerous surgeries in their life to fix their broken bones. Consequently, a topic strictly connected with this condition and that is detectable in both stories is the presence of scars and the role they assume in the disabled character's self-confidence. One time Arianna is spending time

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[55] The fact that Alvie understands that this was fundamental for Stanley, can be considered a signal that she accepts every part of him, including his disease and its consequence, and that she will stay by his side no matter what.

with Leon, she is looking at herself in the mirror staring at the two slight signs that the halo[56] has left. She complains that every time she looks at herself, she will remember the procedure she had to undergo. Leon tries to resassure her, asserting that they will disappear with time. When Arianna admits to being disgusted by the scar on Leon's knee, he insists that she touch it. At the start, she refuses, but ultimately she surrenders, and, guided by Leon's hand, she caresses it with her fingertips. Switching to *When My Heart Joins the Thousand* (2018), scars make Stanley extremely vulnerable: "You remember before, I told you I felt like Frankenstein's monster? It wasn't really a joke" (Steiger 2018:162). He does not go swimming because of them (Steiger 2018:193), and when Alvie aids him to take a shower, he demands her to keep her eyes closed (Steiger 2018:272). Most importantly, scars constitute the reason why Stanley is so reluctant to have sex with Alvie. She informs him she does not care multiple times: "They're just scars" (Steiger 2018:162), but she accepts to wait for him to be ready, acknowledging that Stanley himself must come to terms with them first: "I want to tell him that his scars don't matter, but I know that words won't make a difference" (Steiger 2018:272). When Stanley lets Alvie see him without a t-shirt, he grips her hand allowing her to touch them, and to convince him they do not matter to her, Alvie kisses them[57] (Steiger 2018:328-330).

Lastly, both novels focus on the role of parents and the impact the disability of their child had on them. In *Stringimi piano* (2018), the readers get in touch with Arianna's mother's journal from when she was pregnant, while both Alvie and Stanley provide details and memories about their parents. Moreover, both authors depict a negative parental reaction to and consideration of impairment. As Arianna's mother recounted in her journal, when she and her husband discovered their baby would have Osteogenesis Imperfecta, they found themselves hoping for their baby to not survive. Relating a conversation they had where the father implicitly alleged this, Arianna's mom wrote: "non lo odiavo per averlo detto. Odiavo me stessa, perché la pensavo anche

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[56] Halo-gravity traction is a procedure employed to stretch and straighten the spine. It represents the first step in correcting scoliosis and spine deformities. It consists of surgically attaching a lightweight metal ring (halo) to the person's skull utilizing some pins – which leave small scars on the forehead. Once the halo is positioned, the doctor connects it to a pulley system to which weight is periodically added to slowly straighten the spine. When it has reached the best possible position, the subject will have surgery to stabilize it permanently (www.childrenshospital.org/treatments/halo-gravity-traction).

[57] Cheyne claims that the act of kissing a scar is an extremely exploited trope in romance novels, and, as it can be evicted from Steiger's novel, it symbolizes the acceptance of the disabled partner's imperfect body (Cheyne 2017:193).

io così" (Faranda 2018:180-181). As regards *When My Heart Joins the Thousand* (2018), Alvie's mother took her own life, while trying to kill Alvie too, drugging her and then diving them both into the lake with the car. The reason why Alvie's mother decided to commit suicide is that she did not accept the fact that Alvie had autism and she did not know how to properly support her, as can be evinced by Alvie's words to Stanley: "Mama never knew how to deal with me. She wanted a normal little girl, one she could cuddle and talk to and dress up, and instead she got this silent, broken thing who recoiled from touch" (Steiger 2018:306). It can be argued that Alvie blames herself for her mother's decision unreasonably, and that there are other explanations of what pushed her mom to kill herself. Nonetheless, Alvie's mom confessed to her daughter her struggles:

> I'm trying, but I don't know how to help you. Tell me what you need. Tell me how I can make this stop. […] You were such a happy baby. […] You were perfectly normal. And then you started school, and suddenly there were all these… problems, […] I miss the real you. […] I know you're still in there, though. […] Just … underneath … everything. (Steiger 2018:135-138)

In addition to portraying a negative parental reaction to the disability of their children, the two novels also narrate how it affects the parents' conjugal life. As concerns Faranda's book, even if it is not explicitly stated, Arianna's parents do not get along since when Arianna's mom was pregnant with her. Through her journal, it is revealed that she did not inform her husband when the doctor first noticed there was something wrong with the baby, and when she ultimately decided to confess it to him everything changed. Arianna's father has not been capable of forgiving his wife for having kept it secret, and he is convinced that if she had told him before, they could have asked for a consultation with a specialized doctor, which potentially could have resolved the situation. Almost twenty years later, their relationship is still hostile to the point that while they are visiting Arianna in the hospital, they start to accuse each other of the accident (Faranda 2018:25). A similar situation is narrated by Stanley to Alvie, in *When My Heat Joins the Thousand* (2018). He recounts that his father would forget how strong it was when he drank and that this resulted in him breaking Stanley's arm while they were playing together one day. It was a terrible fracture, for which Stanley required surgery. His mother never forgave her husband for this, and they divorced when Stanley was nine (Steiger 2018:121-122). Ultimately, the two stories deal with overprotective parents. As concerns *Stringimi piano* (2018), this aspect can be seen in the episode of the soap bubbles. Arianna relates that when her mom returned and saw her playing with the bubbles, she overreacted: "'Arianna, sei impazzita?' La voce di Mìmola mi riportò a casa. Da quanto era tornata? In un attimo corse al mio fianco. Mi strappò il tubetto dalle mani, si fletté sulle gambe per guardarmi negli occhi. Chiudere i miei non servì. 'Ormai dovresti saperlo' disse. 'Questi non sono giochi per te.'" (Faranda 2018:8). Whereas, in Steiger's novel, Stanley's mother did not allow him to have an ordinary life out of fear, particularly after she separated from Stanley's father:

> She'd always been protective – and once Dad was gone, I was all she had. I wasn't allowed to play outside with other kids. If I tried to sneak out, she would lock me in my room for days. I missed so much school anyway, because of fractures and surgery, no one really thought it was strange when I didn't show up. Eventually she just pulled me out altogether. […] I felt like I was suffocating. When I told her I wanted to go away to college she freaked out. (Steiger 2018:313-314)

Therefore, it can be asserted that the fear that people with OI have, is – at least partially – influenced by their parents' attitude. Repeatedly, parents forbid their children something because they are terrified they could injure themselves, without realizing that in this way they are limiting them from conducting a normal life. This does not mean that people with Osteogenesis Imperfecta can and should be allowed to do everything, but it means that a way to combine safety and a typical life should be found.

After having identified the recurrent topics in young adult romance novels including a character with Osteogenesis Imperfecta, the current intent is to analyze whether these two books offer "normalcy narratives" or "disability counternarratives". To begin with, it is noteworthy how the central couple of the two stories meet. In *Stringimi piano* (2018), Faranda reiterates the "normalcy narratives" that nondisabled individuals would not notice and consider the disabled person as a potential romantic partner if they were in an ordinary context. In fact, Arianna and Leon encounter each other in the hospital, when Leon is recovering from an injury that causes him to be temporarily disabled placing him on the same level as Arianna. The idea that Leon would not have approached Arianna if they were in an everyday life setting is confirmed when Arianna and Leon confront each other: "Fingi pure che siamo uguali, se ti fa piacere. Ma la verità è […] che non mi avresti mai rivolto la parola, fuori di qui" (Faranda 2018:215), at which point Leon stays silent. Furthermore, the night they say goodbye, he admits he does not know how he would have behaved if they had known each other outside the clinic (Faranda 2018:241)[58]. While it can be disputed that Steiger (2018) echoed the “normalcy narrative” that disabled people can merely couple with each other, considering Alvie has autism and Stanley has OI, what the author actually achieved was overturning it. When Alvie and Stanley first get in contact, in fact, they are unaware of the disability of the other. It is true that Stanley understands almost straightaway that Alvie has Asperger’s, but when she emails him the first time, he starts to chat with her without knowing it. For what concerns Alvie, she evidently notices his cane, but she comprehends that Stanley is affected by OI only some weeks after the two of them have begun to hang out. Moreover, the two of them meet in the park, talk online, and their dates take place in restaurants, at the ice rink, at the zoo where Alvie works, and at Stanley’s house – all ordinary locations.

To continue, it is important to reflect on how the disabled protagonists of the novels define their identity. Even though discovering about her parents’ perception of impairment certainly does not help Arianna to change her consideration of herself, she seems to have viewed her disability as a negative aspect of her identity all her life. In her conversations with Leon, not only does she describe herself numerous times as ill, but she also claims to be sicker than others: “Forse non sarò l’unica malata sulla faccia della Terra […] ma lo sono più degli altri” (Faranda 2018:214). Alvie and Stanley consider their disability negatively as well, but Steiger highlights that it is the result of them having internalized others’ opinions about them. For instance, Alvie defines herself as “broken” and “damaged” various times throughout the novel, but when she recounts memories from when she was a child, it is evident the effort she made to convince others, especially her mother, that there was nothing wrong with her. Furthermore, the first time she goes to Stanley’s, and she discovers he has purchased a book about autism, she claims: “I don’t like to be sorted and categorized, […] I am who I am. I shouldn’t need a word for it. I don’t understand why I can’t just… be” (Steiger 2018:113), rejecting the labels other people puts on her. When she goes to Court for her emancipation, she is obliged to deny having autism because otherwise, the Judge would not grant it to her, but this does not mean Alvie agrees with the Judge’s belief that her

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[58] Another example where this “normalcy narrative” can be found is *The Year We Fell Down* (2014) by Sarina Bowen. Corey Callahan suffered from a spinal cord injury while playing hockey which made her a wheelchair user. When she starts her freshman year of college, she meets Adam Hartley and the two fall in love. However, the protagonists meet only because at the beginning of the novel Adam’s leg is fractured and he lives in a wheelchair-accessible dorm room in the same hallway as Corey.

disability is what would be an obstacle to her living independently: “I want to tell her that it’s not that simple. Being able to hold down a job doesn’t mean I’m not *different*. My brain hasn’t changed just because my situation has.” (Steiger 2018:207). Moreover, it is remarkable that Alvie thinks “about pointing out that Asperger’s isn’t a mental disability, it’s a social disability, or perhaps a natural variation on the standard neurological configuration.” (Steiger 2018:207)[59]. As regards Stanley, when he confesses to Alvie he has OI, he declares: “I’m okay with who I am. Sort of. But I know what it’s like to have a diagnostic label hung around your neck, being told by the world that you have limitations, that there are certain things you’ll never be able to do” (Stieger 2018:158). Despite the fact that Stanley has not totally accepted his condition, the crucial aspect here is him utilizing the expression “the world”, which underlines that he is influenced by the society in his self-consideration and that he is distancing himself from it and working on building his own identity. Therefore, while Faranda adheres to the “normalcy narrative” that disability is a negative and the most crucial facet of one individual’s identity, Steiger tries to propose a “disability counternarrative” with characters that are influenced by social views of them, but that at the same time reclaim and accept their impairment as one part of their identity among numerous others. However, neither author has focused on the importance of having a community.

Lastly, Faranda employs the “normalcy narrative” that a life with a disability is unworthy in making Arianna’s parents hope for their children to not survive, and in depicting Arianna constantly feeling sorry for herself. Leon is the only character that suggests a “disability counternarrative” inviting Arianna to realize everyone is fragile in their own way. When Arianna informs him she has OI, he interrupts her saying “Io ho male al legamento” (Faranda 2018:81), and when they face each other after that Arianna discovered he is going to be discharged, he accuses her of being unable to talk about anything else except her disability. Arianna ironically apologizes for being ill to which Leon replies: “Chi non lo è, qui dentro? […] Non sei unica a rompersi. […] Ognuno è di vetro a modo suo. […] La gente si rompe sempre, Arianna. E anche i legami, i sogni, i giuramenti…” (Faranda 2018:213-214)[60]. In the epilogue, set in the present, Arianna has

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[59] In this case, “social” is used by Alvie to explain that autism makes social interactions difficult for people affected by it, and not to claim that it is a socially constructed disability. Nonetheless, the fact that she states that it is a variation of what is considered to be the norm can be viewed as Alvie’s adherence to the social model of disability.

[60] Leon does not speak Italian impeccably because he is Slovenian.

comprehended this, but the fact that the author does not provide any other information about her life does not make this novel counter-discursive. Readers do not know if she has been capable to accept her disability and live an "ordinary" life, one that includes living independently and having a job. She is still in touch with Leon, who writes to her once a month from Canada[61], but it is unspecified if Arianna is in a romantic relationship with somebody else, meaning it is unsure whether something has truly changed for her. This risks confirming the assumption readers had before engaging with this novel. On the contrary, *When My Heart Joins the Thousand* (2018) offers two protagonists that despite their disability live a fulfilling life. Both Stanley and Alvie live alone and drive a car, and while Stanley goes to college, Alvie initially works in a zoo and then finds a new job in a center for exotic animals. The author does exploit the recurring trope in romances of "the burden" when Alvie ends things with Stanley after she punched him in the face – "the kindest thing I can do is to break his heart" (Steiger 2018:252) – because she is afraid to physically hurt him, and when Stanley declares: "Just for once, I want to make someone's life easier instead of more difficult. I want *not* to be a burden. Is that wrong?" (Steiger 2018:156-157). However, he transforms it into a counter-discursive narrative precisely because they are both disabled. At the end, Alvie and Stanley have learned that they will have to rely on each other for different reasons, but this does not mean they do not deserve to be loved because of this, allowing them to ensure their happily ever after.

To conclude, young adult romance novels that feature a character affected by Osteogenesis Imperfecta present some recurring themes that are specifically linked with the condition. These topics concern the disease in itself, its main symptoms, but also the ways in which it mentally impacts people who are affected by it and those that surround them. As regards whether the novels *Stringimi piano* by Irene Faranda (2018) and *When My Heart Joins the Thousand* by A. J. Steiger (2018) validate or challenge the typical narrations about disability, it is apparent that the answer is not straightforward. Unfortunately, both employ some "normalcy narratives" in how having a disability is perceived or in the romance tropes used. However, the American novel proposes more "disability counternarratives". Therefore, it offers a more positive, realistic and efficient representation of disability in general, and of Osteogenesis Imperfecta in particular.

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[61] This means the central couple of Faranda's novel has not secured the HEA.

Conclusion

To conclude, this work has examined the literary representations of Osteogenesis Imperfecta in two young adult romance novels, one Italian and the other American. The central analysis has been preceded by an overview of the disability rights movement in the United States and an explanation of the complex process of definition of identity for an impaired individual. It has been possible to deduce that it is only because the disability community began making their voices heard and because single individuals started shaping a new vision of themselves that disability studies developed and that, consequently, researches like this one can exist.

In the first chapter, I have underlined that only when subjects with disability gathered together for the first time they realized they justly deserved the same rights as everyone else. In fact, it is when the first organizations began to form, that the first battles occurred. Successively, the creation between the '50s and the '70s of the first Independent Living Centers, which allowed people with disabilities to live together autonomously, prompted an intensification of the fight for rights. As a result, the disabled population obtained laws that defended their rights as never before, like the Rehabilitation Act, and its Sections 501 to 504. Seeing their rights recognized and guaranteed for the first time has reinforced the community that began issuing lawsuits, requiring the accessibility of buildings and the transportation system.

Nonetheless, it is only in 1990 that the disability movement reached its peak with the ratification of the Americans with Disabilities Act, which represented evidence that their struggles had not been useless. However, they did not settle for it, and when they risked being deprived of what they had so hardly achieved, they powerfully engaged in activism again to ensure the passage, in 2008, of the ADA Amendments Act. It can be concluded that if it were not for the disability community's decision to not surrender and to continue to fight for decades, the attainment of all these legislations would not have been possible.

Moreover, the fact that the community made itself visible for the first time, overturning the public's idea that suffering from a disability meant being passive and miserable, lead to the development of disability studies. Not only does this discipline focus on analyzing how disability had been conceptualized during the centuries, it also investigates its impact on culture, including literature. It can be deduced that engaging in this discipline is the only way to improve the situation of the disability community and that it is for this reason that more and more people should dedicate themselves to its study.

In the second chapter, the topic of the shaping of identity for a person with a disability has been exhaustively investigated. It can be concluded that it is true that every person's definition of their identity is influenced by the people and institutions that surround them (identity from "above") and by a process of self-identification (identity from "below"), but for an individual with an impairment positive self-identifying is more complicated because they must detach themselves from a widespread negative consideration of a part of their being to which are associated assumptions, stereotypes, and prejudices. The phenomenon of "inspiration porn" that has been discussed is merely one example of this among many others, but it is emblematic as it gathers many elements that compose society's consideration of disability. Additionally, it has been observed that there are countless possibilities, negative and positive, as concerns self-identification but, because it brought together impaired individuals for the first time, the development of a disability movement has represented a key factor in proposing an alternative vision of disability. Highlighting that considering disability in a more favorable way is extremely complex has emphasized the necessity for disabled people to reject society's oppression and surround themselves with other impaired individuals, and for the able-bodied to change their minds about the subject of disability and engage in the fights of the disability community so as to be more inclusive and less marginalizing towards it.

From the examination of the recurring patterns in disabled people's life-writing narratives, it can be evinced that the internalized oppression people with disabilities suffer from has repercussions on their work as well. In fact, a correspondence between the way they identify themselves and the rhetorics they employ when they write can be remarked. This applies particularly when individuals negatively self-identify with their handicap, but also on the rarer occasions they see themselves more positively. Mattia Muratore's autobiography *Sono nato così, ma non ditelo in giro* is proof of everything that has been explained in the second chapter. It is evidence that it is possible for a disabled person to be proud of their condition, but that does not mean being unaware of the ableist attitude they must face. From this book, it can also be acknowledged that it is possible to combine the "medical model", according importance to the effects that a disease has on individuals' bodies and experiences, and the "social model", considering society the major impediment in conducting a normal life. Furthermore, it highlights the significance of having a community. Therefore, this book is the confirmation that the "quality-of-life writing" Couser referred to is possible and is an efficient way to challenge the assumptions abled subjects have and to propose a new version of what it means to be disabled. It also remarks that irony is a potent instrument to achieve this result, as it allows the author to criticize the situation without being boring.

The third chapter has explained what Osteogenesis Imperfecta is. Explicating how it is inherited, its symptoms, and its diverse forms is essential to better understand its representations in the two novels that have been the center of this research.

Pointing out that even if literary works for young adults are conceived for teenagers, they are appreciated by older people as well, and dwelling on their characteristics has proved relevant to explicate why they are so largely employed to challenge stereotypes and why they can be the key topic of a study like this one. Additionally, an introduction to this category has been useful to introduce the distinction between "normalcy narratives" and "disability counternarratives". As it can be evicted, this type of division has recurred various times in the disability studies field and in this work, making people realize that one of the primary goals of the discipline is establishing whether a certain narrative choice adheres to the traditional stereotypical vision of disability or if it challenges it. Illustrating the fundamental characteristics of the romance genre has provided a framework to better analyze the novels, and listing the recurring tropes employed when a character with an impairment is included has permitted to verify whether the two books exploit ableist narrations or if they propose some alternatives. Moreover, when used correctly, from a genre that envisages a happily-ever-after, it can be deduced that a future that includes simultaneously a disability and happiness is conceivable.

To conclude, the Italian novel *Stringimi piano* (2018) by Irene Faranda and the American one *When My Heart Joins the Thousand* (2018) by A. J. Steiger offer an exhaustive, even if occasionally too pessimistic, description of what life with Osteogenesis Imperfecta is and its impact on the people affected and those who surround them. The fact that themes in common have been identified means that there are some tropes that recur when this disease is depicted. As concerns whether the two books reiterate or challenge the typical narrations about disability, the answer is not straightforward and numerous aspects need to be considered. However, while both works exploit some “normalcy narratives”, Steiger’s novel proposes more “disability counter-narratives”, offering a more realistic and efficient portrayal of disability.

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Summary in Italian

La discriminazione delle persone con disabilità negli Stati Uniti iniziò all'epoca in cui le tredici colonie, fondate e dominate dall'impero britannico, non avevano ancora dichiarato la loro indipendenza. All'inizio del XX secolo, con lo sviluppo delle teorie eugeniche, che prevedevano un miglioramento del genere umano da un punto di vista genetico, la situazione peggiorò. Si dovette attendere il ritorno dei veterani dalla Grande Guerra perché venissero riconosciuti i primi diritti ai disabili. Negli anni '30, questi ultimi fondarono le prime associazioni e il fatto di trovarsi insieme per la prima volta fece loro comprendere la necessità di lottare per ottenere più legislazioni a loro favore. La *League of the Physical Handicapped* fu una delle prime e si batté per migliorare la condizione lavorativa, sostenendo che il *Social Security Act* del 1935, che garantiva degli aiuti economici per gli individui disabili disoccupati, non fosse sufficiente. Non ottenne però grandi risultati. Alla fine degli anni '50 si diede avvio ad un processo di deistituzionalizzazione delle persone disabili che erano state fino a quel momento rinchiuse in istituti ed ospedali. Il simbolo di questa battaglia fu Edward Roberts, che istituì nel 1972 a Berkeley il primo centro in cui potevano vivere in modo indipendente. Vivere in autonomia non era però sufficiente. Nel 1973, Judith E. Heumann diventò la leader delle proteste per l'approvazione del *Rehabilitation Act*, che stabiliva il processo di inserimento dei disabili nella forza lavoro. L'atto venne firmato a settembre, ma fu solo nel 1977, dopo diversi sit-in, che le sue sezioni dalla 501 alla 504 entrarono in vigore. Oltre a proibire la discriminazione, assicuravano finalmente alla popolazione disabile i primi diritti civili. Purtroppo, però, gli obblighi sanciti non furono rispettati e si dovette spesso ricorrere a procedure legali. Anche in questo caso, il merito è delle associazioni come *Disabled in Action*, fondata nel 1970 da Judith E. Heumann.

Dopo otto anni di battaglie per la sua stesura e la sua adozione, nel 1990 l'*Americans with Disabilities Act* fu finalmente approvato. Composto da un'introduzione, che fornisce una definizione di "disabilità", e cinque titoli, l'atto regolamenta diverse sfere della vita quotidiana di un cittadino. Il primo titolo è dedicato all'occupazione lavorativa: proibisce che a una persona venga negata la possibilità di ottenere un determinato impiego esclusivamente a causa del proprio handicap e obbliga a prendere tutte le misure indispensabili per rendere il posto di lavoro accessibile. Il secondo, invece, asserisce che nessuno può essere escluso dal beneficiare dei trasporti e dei servizi pubblici, i quali devono essere resi più inclusivi possibili. Il terzo titolo vieta la discriminazione nei luoghi pubblici e gestisce alcuni tipi di trasporto privato. Inoltre, stabilisce che tutti gli edifici costruiti o ristrutturati dopo il 1993 debbano essere accessibili a chi utilizza una sedia a rotelle. Per quelli già esistenti, invece, prevede che siano rimosse più barriere architettoniche e comunicative possibili. Il quarto ordinava l'istituzione di un servizio che permettesse alle persone con disabilità uditive o con difficoltà nel parlare di conversare con chi usa un telefono. L'ultimo titolo, invece, spiega la valenza dell'ADA in relazione con le altre legislazioni che garantiscono dei diritti alle persone con disabilità. Anche in questo caso, numerose cause legali sono state indispensabili perché l'ADA venisse messo in pratica. Tuttavia, nel 1999, la Corte Suprema ha decretato in tre differenti casi contro la persona disabile, affermando che l'ADA non si applica a chi ha un handicap la cui gravità può essere diminuita attraverso farmaci o terapie, limitando così gli individui protetti dall'atto. Dopo anni di proteste, nel 2008, *l'ADA Amendments Act*, che stabilisce che l'esistenza di cure che allevino gli effetti di una disabilità non è un criterio determinante nel definire se una persona è disabile o meno, venne approvato dal Congresso.

Il fatto che la popolazione disabile abbia iniziato a farsi valere ha avuto altre conseguenze oltre all'ottenimento dei diritti civili. A partire dagli anni '70, infatti, si sviluppò un nuovo campo di ricerca orientato a studiare come la disabilità sia stata concepita nel corso dei secoli e ad analizzare l'impatto che ha avuto sulla cultura. Per quanto riguarda il primo aspetto, gli studiosi hanno identificato diverse maniere di vedere la disabilità. Tra il XIX e il XX secolo, questo modo di essere veniva interpretato secondo il "modello eugenico", che considerava la disabilità come un difetto da estirpare a livello genetico, attraverso il controllo della riproduzione, la sterilizzazione e l'eutanasia. Il "modello medico", invece fu quello che prevalse fino agli anni '70, ed era basato sull'idea che la disabilità dovesse obbligatoriamente essere curata. Contemporaneamente allo sviluppo della disciplina, un'altra visione entrò in auge, chiamata "modello sociale". La disabilità veniva ritenuta un costrutto sociale e le barriere, l'esclusione e i pregiudizi ciò che davvero impediva alle persone di essere uguali tra loro. Ciò nonostante, anche quest'ultimo modello si rilevò inadeguato. Mentre il "modello medico" era eccessivamente focalizzato sul corpo, il "modello sociale" lo escludeva completamente dalla propria concezione, negando quindi un aspetto fondamentale dell'identità di un essere umano. Quindi, si cominciò a leggere la disabilità attraverso il cosiddetto "modello culturale" che combina la dimensione storica e sociale dell'idea di disabilità con le esperienze individuali. Questa visione fece sì che negli anni '90 questi studi hanno iniziassero ad occuparsi del rapporto tra disabilità e letteratura. I primi a dedicarsi a questo campo furono Lennard J. Davis e Rosemarie Garland-Thomson. Entrambi basarono la loro ricerca sull'idea che se la disabilità è una differenza considerata negativamente, allora esiste un concetto di "norma" da cui devia. Sebbene questa non sia altro che una costruzione ideologica a cui pochi individui possono aderire, è ciò su cui si fondano la maggior parte delle rappresentazioni della disabilità in letteratura. Altri studiosi degni di nota sono stati David Mitchell e Sharon Snyder che per primi divisero le raffigurazioni letterarie della disabilità in due categorie: quelle che poggiano sull'idea che la disabilità sia un aspetto negativo, e quelle che ribaltano questa concezione. Ci sono diverse ragioni per cui un individuo dovrebbe interessarsi allo studio della disabilità. Innanzitutto, perché le persone disabili rappresentano il 15% della popolazione mondiale, facendo di essa la più grande minoranza. Successivamente, perché è una condizione potenzialmente universale: tutti possono diventare disabili a causa di un incidente, una malattia o l'invecchiamento. Infine, perché se tutti si impegnassero nello studio di questa disciplina, si potrebbe avere una società meno discriminante.

Nel processo di definizione della propria identità, gli esseri umani sono influenzati da due fattori: ciò che gli altri individui pensano di loro e ciò che loro pensano di loro stessi. Tuttavia, la realtà esterna con cui le persone disabili si devono confrontare è permeata da stereotipi e pregiudizi che fanno sì che la disabilità sia prevalentemente considerata come una caratteristica negativa, ed è estremamente complesso per loro dissociarsi da questa visione. Ci sono diversi modi in cui la società definisce le persone disabili, oltre al "modello medico" e a quello "sociale". Una di queste è ritenerle una fonte di ispirazione. Questo fenomeno è il risultato delle basse aspettative che la società ha su di loro che, in questo frangente, sono un mero strumento per i cosiddetti "normodotati" per sentirsi meglio riguardo a sé stessi. L'estremizzazione di questo atteggiamento, l'*inspiration porn*, o "porno motivazionale" in italiano, è un concetto descritto dall'attivista Stella Young, nel suo discorso tenuto nel 2014 ad un evento TED.

Young ha spiegato che il termine “porno” è usato deliberatamente, perché questo fenomeno oggettiva un gruppo di persone (i disabili) per beneficiarne un altro (i normodotati), basandosi sull’idea che la disabilità sia indesiderabile e che condurre una vita con essa renda eccezionali. Per quel che riguarda, invece, l’auto-identificazione come disabile da parte di un soggetto con un handicap, questa può essere sia negativa che positiva. Il primo caso avviene normalmente perché l’individuo aderisce all’idea di disabilità proposta dal “modello medico”. L’handicap è quindi ritenuto una tragedia e non viene accettato. Diversi meccanismi di negazione possono essere messi in atto, come affermare di essere normali e nascondere la propria disabilità, considerarla come voluta da Dio e sopportarla nella speranza di una ricompensa dopo la morte, o impegnarsi in attività che vanno al di là delle proprie capacità. È evidente che queste soluzioni non sono efficaci né salutari per il soggetto. Gli individui che invece ritengono che la propria disabilità sia un aspetto positivo della loro identità sono coloro i quali si avvicinano al “modello sociale”. Normalmente ciò è il risultato di una transizione da una visione all’altra, che porta il soggetto in questione a dissociarsi dalle opinioni esterne. Nella maggior parte dei casi, la condizione fondamentale perché ciò accada è il circondarsi di persone che sono a loro volta disabili. Questo processo è, però, molto complesso a causa dell’effetto psicologico che la considerazione della società della disabilità ha sugli individui che ne sono affetti e a causa del fatto che quest’ultimi sono spesso isolati e separati tra loro.

A partire dagli anni ’50, le opere letterarie che trattano della vita di un individuo sono state utilizzate per raccontare la propria storia da chi fino a quel momento non aveva avuto modo di esprimersi. Nello specifico, le persone con disabilità si sono servite di questo strumento dagli anni ’80. Tuttavia, già nei decenni precedenti, i genitori dei bambini con disabilità scrivevano libri di questo genere per diffondere la consapevolezza sulle malattie dei propri figli. Queste narrazioni (e ovviamente anche quelle scritte dai disabili stessi) non solo fanno sentire meno soli, ma offrono alla società un punto di vista personale e diretto su cosa significhi avere un handicap. Purtroppo, però, influenzati dalle opinioni su questo argomento, gli autori hanno spesso ripiegato su narrazioni che rinforzano i pregiudizi. La prima è la cosiddetta “retorica del trionfo” in cui il protagonista riesce a superare gli ostacoli dati dalla sua disabilità arrivando ad ottenere risultati insperati. Nel secondo tipo di narrazione, detto gotico o horror, la disabilità viene descritta come spaventosa, provocando paura nel lettore, che viene, però, poi tranquillizzato poiché il narratore è riuscito a fuggirne. Una variante di questa narrazione è la "retorica della restituzione", in cui il protagonista non è l'eroe della storia, visto che non ha contribuito sostanzialmente al cambiamento della situazione, ma il medico che l'ha curato. L'ultimo tipo è la "retorica della compensazione", in cui il protagonista è affetto da una malattia cronica o progressiva che non può migliorare. Si sente, quindi, come un servo di Dio e spera in una compensazione dopo la morte. Negli ultimi anni, però, sono state impiegate anche narrazioni più positive, come quella detta del "coming out", che racconta del passaggio da una considerazione negativa a una positiva della propria identità di persona disabile. È evidente, quindi, la necessità di sempre più opere letterarie che si servano di quest'ultimo tipo di storie, per proporre un'alternativa a chi crede che la disabilità sia una disgrazia. Un esempio di questo genere di lavoro è l'autobiografia di Mattia Muratore *Sono nato così, ma non ditelo in giro*, pubblicata nel 2022. Affetto da Osteogenesi Imperfetta che gli ha causato numerose fratture nel corso della vita, Muratore utilizza una narrazione innovativa. Infatti, la sua non è una storia di coming out: Mattia è orgoglioso di essere disabile, ma sembra esserlo sempre stato. Ciò però non gli impedisce di criticare i preconcetti, gli atteggiamenti e i comportamenti abilisti che permeano la società, attraverso l'ironia. Muratore condanna lo stereotipo che i disabili non possano condurre una vita soddisfacente e che non possano avere né partner né figli. Inoltre, rimprovera aspramente le persone che muovono chi è in sedia a rotelle senza chiedere prima il loro permesso, quelle che, senza neanche conoscere la persona in questione, vogliono sapere quale sia la sua diagnosi, e quelle che si rivolgono al normodotato che è in compagnia di un individuo con una disabilità, come se quest'ultimo non sia in grado di rispondere. Un altro motivo per cui l'autobiografia di Mattia è innovativa è che in essa sono spiegate le ragioni che hanno spinto l'autore a provare orgoglio per il suo modo di essere. Il primo è la sua aderenza al "modello sociale". È vero che dedica un intero capitolo a spiegare in cosa consista la sua malattia, ma il resto del libro si focalizza sul racconto di episodi di vita quotidiana resi più complicati dalla società, come l'andare in bagno, il prenotare un tavolo al ristorante e il guidare la macchina. Il secondo motivo è che si è circondato di persone che sono come lui. Diversi infatti sono i personaggi con un qualche handicap di cui viene raccontato.

L'ultima spiegazione, che è anche la più semplice e sincera, è che Mattia ama la vita e che i piaceri che essa offre sono gli stessi che siano sia vissuti da in piedi o da seduti.

L'Osteogenesi Imperfetta, la malattia da cui è affetto Muratore, è una condizione rara che colpisce circa 500 mila persone nel mondo. Nella maggior parte dei casi, è causata da una mutazione del gene che si occupa della produzione del collagene di tipo 1, responsabile della formazione e della resistenza delle ossa. Nel caso in cui sia trasmessa dai genitori, l'individuo può avere una forma dominante o una recessiva. L'Osteogenesi è una malattia molto variabile e ne esistono diversi tipi, anche se sono otto quelli più frequenti. I sintomi più comuni sono: fragilità e deformazione scheletrica, bassa statura, complicazioni cardiache o respiratorie, perdita di udito e sclere di colore bluastro.

In questa ricerca vengono analizzate le rappresentazioni di questa malattia in due romanzi romantici per giovani adulti. Sebbene le opere di questo genere siano concepite per i lettori con un'età compresa tra i 12 e 18 anni, sono apprezzate anche dal pubblico adulto, per via del fatto che trattano temi sempre più profondi, come l'abilismo. Sono, infatti, sempre di più i romanzi che includono un personaggio disabile. Mitchell e Snyder hanno diviso le opere letterarie in cui la disabilità è presente in due categorie: le "narrazioni della normalità" in cui avere un handicap è rappresentato in modo negativo, e le "contro-narrazioni della disabilità" che offrono, invece, un ritratto più positivo. Per quel che riguarda il genere letterario a cui appartengono i romanzi analizzati, due sono le sue caratteristiche principali: una storia d'amore centrale e una conclusione entusiasmante. Considerando che si sa fin dall'inizio che il libro si concluderà con l'unione della coppia protagonista, il tema principale sono gli ostacoli che quest'ultima deve superare per potersi mettere insieme. Quando il personaggio con disabilità riveste un ruolo secondario, normalmente interpreta un bambino bisognoso di cure. Tradizionalmente, è il figlio/a del protagonista maschile, che incontra la protagonista perché diventa l'assistente del(la) figlio/a. Quest'ultimo/a funge anche da parametro su cui si misurano gli altri personaggi, rendendo evidente se si meritino o meno l'amore. Lavorare per o anche solo riconoscere la persona disabile come un essere umano è segno che il personaggio è degno di essere amato. Quando il personaggio disabile è uno dei membri della coppia, la questione si complica, poiché nell'immaginario comune un futuro che include la disabilità è l'opposto di quello felice che ci si aspetta da questo genere. Gli autori che si basano su questa idea ricorrono a due tropi. La prima implica un personaggio maschile normodotato che respinge l'idea di una relazione con la protagonista disabile e finisce per sposare l'eroina normodotata. La seconda trama comprende la cura dell'handicap ed è composta da tre elementi: la cura in sé per sé; il merito del partner normodotato nel convincere il/la disabile a sottoporsi ad essa; il protagonista con disabilità che si crede un peso a causa di essa e che per questo decide di interrompere la relazione. Anche se la "narrazione della cura" prevede che alla fine i due protagonisti si mettano insieme definitivamente, il messaggio che viene trasmesso è che una persona che non può guarire non merita di essere amata. Alcuni espedienti, però, possono essere utilizzati per ribaltare queste trame abiliste. Il primo consiste nel rappresentare un protagonista normodotato che ripete che non gli importa della disabilità del/la compagno/a, proponendo così l'idea di un futuro che include sia la disabilità che il "e-vissero-per-sempre-felici-e-contenti". Il secondo, è utilizzare una "pseudo-cura", in modo che il protagonista migliori, ma rimanga comunque disabile, senza per questo dover rinunciare al lieto fine con il/la suo/a partner. Ancora meglio è ricorrere a narrazioni totalmente innovative, come far realizzare al proprio protagonista normodotato che le sue opinioni sulla disabilità sono influenzate dalla società o riunire tutti i pregiudizi in un unico personaggio che risalta in mezzo agli altri per il suo atteggiamento discriminante. Altre alternative sono rappresentare gli individui disabili come potenziali partner e sfruttare il coinvolgimento emotivo dei lettori per far sperimentare loro i preconcetti che i disabili devono subire quotidianamente.

Il romanzo *Stringimi piano* di Irene Faranda ha come protagonista Arianna, una ragazza di diciannove anni affetta dall'Osteogenesi Imperfetta, che si trova in ospedale a causa di un incidente che le ha provocato numerose fratture. Lì conosce Leon, un giocatore di pallacanestro ricoverato a causa di un infortunio. I due stringono da subito un'amicizia che si trasforma presto in amore da parte di Arianna. La storia principale è inframezzata da estratti del diario che la madre di Arianna ha tenuto in gravidanza in cui racconta delle emozioni provate allo scoprire della disabilità della figlia. I protagonisti di *When My Heart Joins the Thousand*, scritto da A. J. Steiger, invece, sono Alvie, diciassettenne con la sindrome di Asperger, e Stanley diciannovenne affetto da OI. I due iniziano a frequentarsi, innamorandosi pian piano uno dell'altra. In seguito a una crisi durante la quale colpisce Stanley in faccia, Alvie decide di allontanarsi da lui per paura di potergli fare del male. Obbligati a riavvicinarsi per una serie di vicissitudini, alla fine del romanzo, i due vanno a vivere insieme. I due romanzi hanno in comune numerosi temi. Innanzitutto, rappresentano entrambi l'Osteogenesi, poiché hanno un protagonista che ne è affetto e che si rompe alcune ossa nel corso della storia. Entrambi si soffermano anche sugli effetti collaterali che questa condizione implica come la perdita di autonomia che segue una frattura, l'essere di bassa statura, e il colore bluastro delle sclere. Tuttavia, ci sono delle differenze nel modo in cui la patologia viene descritta: nel romanzo italiano viene introdotta subito, mentre in quello americano solo circa a metà. In più, mentre Arianna è la narratrice e fornisce un punto di vista diretto sulla malattia, nell'opera di Steiger, viene presentata attraverso gli occhi di Alvie e attraverso ciò che Stanley decide di spiegarle direttamente. Il secondo tema che si trova in entrambi i libri è la paura: siccome è così facile rompersi, le persone con l'OI sono spesso terrorizzate da ciò che può sembrare innocuo. In più, vengono narrati in entrambi i casi sia la tendenza delle persone con OI a sfidare il destino, intraprendendo azioni potenzialmente pericolose, sia il ruolo che le cicatrici rivestono nell'autostima del personaggio e, specialmente per quel che riguarda Stanley, nella relazione con l'altro protagonista. Infine, in entrambi i libri viene data grande importanza ai genitori e al loro rapporto (in entrambi i casi negativo) con la disabilità dei propri figli, oltre alle ripercussioni che ha sulla loro vita coniugale. I genitori di Arianna non vanno d'accordo da quando hanno scoperto dell'handicap della figlia, mentre quelli di Stanley si sono separati dopo che il padre gli ha fratturato accidentalmente un braccio. In tutti e due i casi vengono anche ritratti genitori iper-protettivi che non permettono ai propri figli di condurre una vita normale per paura che possano farsi male. Dopo aver identificato i temi in comune collegati alla patologia, è rilevante analizzare se questi due romanzi sfruttino narrazioni stereotipate della disabilità o se ne propongano di nuove. Facendo conoscere i suoi protagonisti in ospedale, Faranda ne utilizza una del primo tipo, implicando che i normodotati si avvicinano alle persone disabili solo se le conoscono in un contesto non ordinario che li pone temporaneamente in una condizione simile. Per quel che riguarda Steiger, si potrebbe affermare che reitera il pregiudizio che le persone disabili possono mettersi insieme solo tra loro. Tuttavia, ciò che l'autore fa realmente è ribaltarlo, poiché Alvie e Stanley non sanno della disabilità dell'altro quando si incontrano. Anche per quel che riguarda la definizione dell'identità come persone disabili dei protagonisti, Steiger propone una narrazione innovativa. Sicuramente il fatto di leggere il diario di sua madre non aiuta Arianna a considerare positivamente il proprio handicap, ma dall'altra parte è evidente che lei l'abbia visto come un aspetto negativo tutta la sua vita. In *When My Heart Joins the Thousand*, è vero che Alvie e Stanley faticano ad accettare la propria disabilità, ma è reso evidente che ciò sia il risultato del loro aver interiorizzato le opinioni altrui e che si stiano sforzando di ritenerla solo una delle varie caratteristiche che li rendono ciò che sono. Infine, Faranda sfrutta lo stereotipo che una vita con una disabilità non sia degna di essere vissuta. Leon è l'unico personaggio che propone la visione opposta, cercando di convincere Arianna che tutti hanno i propri problemi. Sebbene Arianna alla fine del libro abbia capito che ognuno è fragile a modo suo, non venendo forniti altri dettagli su come sia cambiata la sua vita dopo il suo incontro con Leon e se abbia avuto una relazione con qualcun altro, il romanzo non riesce a rovesciare questa concezione e cambiare il modo di vedere la disabilità del lettore. Anche sotto questo aspetto, Steiger è più efficace, facendo condurre fin dall'inizio un'esistenza normale ai propri protagonisti. È vero che li fa attraversare la fase in cui si sentono un peso per l'altro, ma riesce a trasformare questo tropo abilista nel contrario, proprio perché i suoi personaggi sono entrambi disabili. Alla fine, infatti, hanno entrambi compreso che per ragioni diverse dovranno contare sull'altro, ma non per questo non si meritano di essere amati. In conclusione, tutti e due i romanzi ripiegano su delle narrazioni negative e stereotipate, ma *When My Heart Joins the Thousand* propone più "contro-narrazioni", offrendo quindi un ritratto più positivo e realistico della disabilità, e in particolare, dell'Osteogenesi Imperfetta.