The importance of social inclusion of disabled people and the role of Design and Technology

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Declaration of Originality

This dissertation is submitted by the undersigned to the Institute of Art Design & Technology, Dun Laoghaire in partial fulfilment of the examination for the BA (Honours) (Three-Dimensional Design, Modelmaking and Digital Arts). It is entirely the author's own work except where noted and has not been submitted for an award from this or any other educational institution.

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Abstract

Society has the main responsibility for the marginalisation of people with physical and mental disabilities who, due to an unwelcome environment and scarcity of policies, are excluded from social life; this also produces an alarming risk of poverty. Design, whose core aim is to find a solution to problems, has to find a way to improve the situation.

If we consider that disability results from an inadequate environment, its correction should trigger inclusion naturally.

There are already successful models that can be replicated and spread to simplifying the process. Those involve the design industry (and its actual implementation) and the show business (that helps build familiarity).

Workplace's inclusion is also a vital step forward to take; that is productive both for the worker and the employer.

Inclusion also means a growth of interaction and cultural development. Creativity is another field that can benefit from inclusion and vice-versa.

The main goal of the inclusion is to create "Normality".

As opposed to the "hero" disabled figure, who fights to claim his/her rights, the "ordinary" disabled figure cannot or doesn't want to fight any war and aims to have an average life, made of normality.

Personalised and artistic prosthetics help the acceptance either from an able-bodied population (more inclined to approach a disabled that emphasise artistically the deficiency, rather than hiding it) and from the disabled themselves (who, due to a personalised prosthetic, feel more "unique" than "stigmatised"). However, wear a prosthetic should be a choice, not the strategy to be aesthetically accepted by society. Technological progress makes it possible to regain functionality and accomplish tasks denied before, hence inclusion.

The growth of empathy and interaction, from society and professionals (as makers of the world in which we live), can benefit everyone in many ways. Virtual Reality is a tool that has a big chance to make this happens.

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Introduction

This thesis aims to suggest a way to assist the inclusion of disabled people in society, identified as a marginalised minority, through technology and design.

In fact, besides the concrete difficulty of interacting in surroundings made of physical barriers, disabled people face cultural biases and misconceptions towards them. On one side, this widespread unfamiliarity with the subject marginalises them from workplaces because they are often considered ineffective. On the other, social rejection of physical differences, generates discomfort to themselves, often moving them away from participating in social life by choice, even when physically allowed.

The success of characters with physical impairments in blockbuster films, as well as Paralympic athletes, show how Media has the power to influence our level of acceptance. The role model is a subject closely related to inclusion, is the key to the bridge that inclusion has to cross. Nevertheless, the figure of the "hero" who fights the battles of human rights through the use of an implausible "super-power", is accused of not considering, if not to damage, the process of normalisation that "ordinary" disabled people aspire to. Therefore, to promote inclusion, it will be suggested to increase the presence of "ordinary" disabled people's representatives in the entertainment field, as a crucial part of the process.

That will result in giving a role model to all those young and insecure people, who find it particularly hard to deal with their differences, in a society that dictates the standard of aesthetics. Moreover, they would show the public the best way to behave, preventing awkward interactions and easing familiarity through the sight.

There is an inspiring speech made on TED talk (2018) by the British model Kelly Knox, born without her left forearm.¹ She does not feel disabled. As she states, she can do anything, even climbing, which is why she refuses the description. Proudly she does not wear any prosthetic and believes that beauty dwells in our uniqueness, which I approve, even though her canonical beauty is a matter of fact. She is a model in the fashion industry, and doing so, questions the stereotype of beauty dictated by society. She has made a breakthrough in her field of expertise, widening the notion of beauty and normality.

Inclusion is a multidirectional process that needs to be fed by developing a universally enjoyable environment, by accepting diversity on the part of both society and disabled persons. Introducing more effective policies regarding public areas and working place requirements and breaking down all the preconceptions and wrong judges about the disability, starting from the belief that disability (in doing things), is nothing but the result of an inadequate environment.

My thesis is subdivided into three chapters. *Inclusion* (Chapter I), the pivotal point of my dissertation will stress the ambivalence of inclusion as "a way to", but also as "a result of". It will be reported about inclusion's stories that delivered successful results, using them as a recommended pattern to generate acceptance, awareness and willingness to succeed in the process of normalisation. I will also underline the cruciality of surroundings as a welcoming or a marginalising factor.

In *Design* (<u>Chapter II</u>), I will demonstrate how and why people with physical differences are marginalised from society. What Universal and Inclusive Design are already doing and what could be done better by the Design side; that will lead to the

¹ Knox, Kelly. *The Universe Within*. TEDxYouth@Glasgow, 2018 <u>https://www.ted.com/talks/kelly_knox_the_universe_within</u>.

importance of disabled persons' inclusion into the Design field with the purpose of inclusion itself, benefitting many, in any case. I will go through the connotation of empathy, regarding this whole debate and the role of the designer, and how it can be constructive if assisted by a disabled representative, or even harmful if done disregarding specific circumstances.

To conclude, *Technology* (Chapter III), will report about the progress technology is making and how it can actually improve people's lives and how sometimes a prosthetic is a mere accessory that does not bring any added value, required only to be accepted and not appearing different. After investigating the "physical/material" improvement through technology, I will analyse the other kind of technology, the intangible/virtual one, which affects the behaviour rather than the physicality. I will discuss Virtual Reality's potential as a tool to generate empathy on subjects dealing with a disability. That will also be my final academic project, by which I want to create the "real" experience of being a one-armed person who deals with basic daily tasks such as the ones we perform in a kitchen. Aiming to empathise with diversity and raise awareness, especially between designers, architects, engineers who design the world we live in.

Both Design and Technology are tools to get to the target: the inclusion of disabled into society.

Chapter I

Inclusion

I.1 Acceptance

It is essential that society becomes more inclusive and environmentally conscious, concerning the disability topic. International Paralympic Committee (IPC) President Andrew Parsons in *a Declaration to further inclusion*, expresses his thought: "we must share the understanding that society must be built BY ALL and FOR ALL. Diversity must not only be tolerated or respected. It must be valued and encouraged".² Inclusion is the human right to exist in a physical barrier-free environment, no less than a social barrier-free mindset.

Article 3 of the document *Convention on the Rights of Persons with Disabilities*, raises a further fundamental matter of debate: "Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity"³. The embrace of diversity, because part of the cultural heritage. This practice of acceptance involves the disabled subject itself before anyone else. According to their own assertions, people with physical impairments, habitually suffer the burden of their diversity, the stigma of deficiencies. Many, especially in wearing a humanlike prosthesis, constantly experience the impostor's role. Fully aware of the others' understanding, that causes them discomfort. Disabled people's blogs and interviews, recurrently raise thoughts and concerns about "being stared at", as well as collecting "poor you" gazes and observations, whether or not they wear prosthetics. Eythor Bender, amputee and CEO of *UNYQ*, a global innovative medical device, admits: "I used to be bothered by people staring at me, I felt like a freak and

² Andrew Parsons, 10 dec.2020 "A declaration to further inclusion", Official Website of the Paralympic Movement • IPC https://www.paralympic.org/blog/declaration-further-inclusion,

³ "OHCHR | Convention on the Rights of Persons with Disabilities.", article 3, point d) <u>https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.</u> <u>es.aspx#preamble</u>.

like I was being judged".⁴ Nathasha Alvarez writes in her blog *Audacity magazine:* "I was born with a physical disability so stares came with the territory".⁵ Regrettably, those are not merely unfounded obsessions that cause a sense of discomfort to those who have physical impairments. The correlation between words such as disabled, marginalised, loss, impairment, inclusion (which assumes a pre-existing exclusion) elicit inevitably the perception that this kind of diversity would not lie in such a privileged position. Instead it gives the feeling of a below-average status. Suppose disability, in terms of consequences of an inadequate environment, facilities and tools, did not exist. In that case, people might start to notice different aspects of this being different, such as uniqueness, distinctiveness, individuality, as well as unpredictably, ways to accomplish tasks. Being different and have different needs is not a problem; contrarily, diversity could be such a wonderful thing, in every way. Films' characters are helping the cause showing us an alternative version of being physically different through extraordinary performances and heroicness, that might not be realistic, but there is no doubt, just as charismatic.

I.2 Entertainment Industry and Disability

Cinema and Media have a massive impact on social trends; they influence people's tastes and make audience accept new styles and forge leanings. They teach us, as a society, what we can accept and what we cannot. They let us get used to the sight of new features. We are already buying and admiring cyborg culture thanks to Hollywood; countless examples of body empowered characters make us think that a prosthetic arm is "actually cool". Blockbuster films such as *Mad Max: Fury Road*

⁴ <u>http://unyq.com/9-things-i-wish-i-knew-when-i-became-an-amputee/</u>

⁵ <u>https://www.audacitymagazine.com/stare-all-you-want-i-am-beautiful-and-disabled/</u>

(George Miller, 2105) (fig.1), *Robocop* (Paul Verhoeven, 1987) (fig.2), *Kingsman: The Secret Service* (Matthew Vaughn, 2015) (fig.3), *Captain America: the Winter Soldier* (Anthony and Joe Russo, 2014) (fig.4), *The Terminator* (James Cameron, 1984) (fig.5), as well as series and comic books (fig.6), helped making the blend between body and technology incredibly appealing. They play a part of fearless, limitless and self-confident role-models to admire.

Paralympic athletes, likewise, shown us how legless people can run faster than biological legs-equipped athletes (fig.7). They have a crucial role in inclusion; they gentrify the image of the disabled, making them "not-anymore not-able", even "super-able". Despite this idea of a superhero it is controversial among part of the disable community who claims normality and rejects the role-model label, even blaming the "supercrip"⁶ figure for being destructive, false and disrespectful, no less;^{7 8} I am persuaded that creating such a figure is a required first step to build inclusion and familiarisation, through respect and esteem.

⁶ Alaniz, Jose, Supercrip in Death, Disability, and the Superhero: The Silver Age and Beyond (University Press of Mississippi, 2014). Jackson, UNITED STATES: University Press of Mississippi, 2014. 26-31 <u>http://ebookcentral.proquest.com/lib/iadtebooks/detail.action?docID=1820999</u>.

⁷ Ibid, The Supercrip. 31-33

⁸ Silva, Carla, and P. Howe. "The (In)Validity of Supercrip Representation of Paralympian Athletes." *Journal of Sport & Social Issues* 36 (May 1, 2012): 174–94. https://doi.org/10.1177/0193723511433865.



Figure 1 Imperator Furiosa (Charlize Theron) is the charming character, who's missing an arm, in Mad Max. Source:https://movies.mxdwn.com/news/charlize-theronsimperator-furiosa-might-not-return-for-mad-max-sequels/



Figure 2 Alex Murphy (Peter Weller) resurrected and transformed into the cyborg entity RoboCop. Source: https://robocoparchive.com/info/thesuit.htm



Figure 3 Gazelle (Sofia Boutella) the beautiful villain antagonist in the film Kingsman. Source:https://www.syfy.com/syfywire/chosen-one-of-the-day-gazellefrom-kingsman-the-secret-service



Figure 4 Bucky Barnes (Sebastian Stan) fictional marvel comics' character, who weasr a cyborg arm. Source: https://www.pinterest.it/pin/780741285379759581/



Figure 5 Cyberdyne Systems Model 101 (Arnold Schwarzenegger) the legendary villain in The Terminator. Source: https://www.barnebys.com/auctions/lot/terminatorarnold-schwarzenegger-vu0bzeleh



Figure 6 Misty Knight, who has a bionic arm created by Tony Starck (Ironman). Marvel 1975 source:http://www.blerdsonline.com/2017/02/black-superhero-misty-knight.html



Figure 7 Oscar Pistorius, the first amputee runner to compete at an Olympic Games (London, 2012). In the 400-metre race, he took second place with a time of 45.44 seconds. Source: <u>https://www.dailymaverick.co.za/article/2011-08-29-no-400m-final-for-blade-runner/</u>



Figure 8 Toy Company Mattel dedicates a Barbie doll to Bebe Vio, the 22-yearold Italian paralympic fencing champion. Source: https://www.tpi.it/costume/bebevio-barbie-20191129506671/

Paralympic athletes, in their interviews, often declare they do not want to have (or get back) their loss limb/sense anymore, because otherwise, they would not be who they are today. That is an astonishing, and enviable, consideration of pride and fulfilment that we all should be able to make. Among those satisfied and successful people, the common denominator is usually having proactive parents, who never let them, as kids, have self-pity. They believed in them. They are the ones who left them do and try things all the kids do. To be precise, they treated them "normally". They told them they could been able to do whatever other people do, whatever they wanted, making them "special".⁹

We are there, we almost envy them, and that is great! (fig 8).

But again, that is about fighting and taking action; it is a matter of "superheroes". The Dubliner freelance journalist and broadcaster Louise Bruton, in her blog *Legless in Dublin* remarked that, the cinema industry involves disabled characters only when they have to be meaningful and inspiring for the audience.¹⁰ She was able to mention only one example of an unpretentious disabled character among the films she watched, and that was an ordinary guy in the film *Saved*!¹¹ (2004).

What I understood most, regarding people with physical difficulties, is the need to live their lives seamlessly, and be treated like anyone else. The majority of them claim "normality", normality in doing normal daily things. "To be normal", not

⁹ Bonhôte, Ian, and Peter Ettedgui. *Rising Phoenix*. Documentary, Sport. HTYT Films, Misfits Entertainment, Passion Pictures, 2020.

¹⁰ Louise Burton, Leg less in Dublin, Blog <u>http://leglessindublin.com/2016/06/actually-life-disability/</u>

¹¹ Dannelly, Brian. *Saved*! Comedy, Drama. United Artists, Single Cell Pictures, Infinity Media, 2004.

to ask, not to fight, not to challenge themselves to obtain what is supposed to be "normality".

I.3 Non-inclusion as a consequence of biases and ineffective surrounding

"In developing countries, 80% to 90% of persons with disabilities of working age are unemployed, whereas in industrialized countries the figure is between 50% and 70%".¹² The excuse is given by employers' belief of incurring higher costs in hiring a disabled person or, in some cases, because they suppose they would not obtain comparable efficiency from a disabled employee; when, accordingly to the UN department of economic and social affairs disability *factsheet 2*, disabled people demonstrated to be particularly efficient in the work place; while, the 'costs' aspect is still very vague, though.¹³ The first point of Art. 23 of *The Universal Declaration of Human Rights (UDHR)* proclaims the right to work and the protection against unemployment.¹⁴ *The Office of the High Commissioner for Human Rights* (*OHCHR*)¹⁵, a worldwide organisation established in 1993, adopted by 171 States¹⁶, is in charge to ensures that those states upholds the principles set out in the *UDHR*. The *OHCHR* assists governments in accomplishing the international human rights standards they have committed to; furthermore, provides legal research and

¹² United Nation, Department of economic and social affairs, disability, Fact sheet 1 <u>https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities/disability-and-employment.html</u>

¹³ United Nation, Department of economic and social affairs, disability, Fact sheet 2 <u>https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities/disability-and-employment.html</u>

¹⁴ 'Universal Declaration of Human Rights', 6 October 2015. <u>https://www.un.org/en/universal-declaration-human-rights/</u>.

¹⁵ United Nations Human Rights, office of the high commissioner, about us: who we are: an overview <u>https://www.ohchr.org/EN/AboutUs/Pages/WhoWeAre.aspx</u>

¹⁶ 195 are the world's independent States in 2020, according to the Fact Sheet Bureau Of Intelligence and Research Washington, DC -July 16, 2020

secretarial support to the core human rights treaty bodies.¹⁷ "These (10) committees of independent experts are mandated to monitor State parties' compliance with their treaty obligations. They meet regularly to examine reports from State parties and issue their recommendations"¹⁸. Among them, there is the committee of the *Rights of Persons with Disabilities*, (CRPD), sanctioned on December 13th 2006, composed of 18 independent expert members¹⁹, elected by the States that ratified the Convention on the Rights of Persons with Disabilities, and they are called to monitor and examine reports, regularly submitted by the UN states, and makes suggestions and general recommendations to them.

Thus, there are proper Authorities to protects their rights. So, why should be so hard to find a job when you have a disability? If employers think it is uneconomical, and it is not so, who is to blame? Or, maybe is that true, and it might be so uneconomical indeed. The law regulating depends individually on the States, and it is unclear if hiring someone with a disability would be fiscally balanced (by a tax cut for instance) since costs for renovation of the workplace have been addressed, or even whether there are some sort of obligations. Besides that, would it be still fair to use the term "disability" so generically? Disability is an unknown subject, filled with generalisations, biases, misconceptions.

An emblematical example of the achievement of inclusion, (spoilt by lack of familiarity with the sight of physical diversity) of someone perfectly capable do her

¹⁷ United Nations Human Rights, office of the high commissioner, Monitoring the core international human rights treaties, What are the treaty bodies? <u>https://www.ohchr.org/EN/HRBodies/Pages/Overview.aspx</u>

¹⁸ Ibid, *Committee on the rights of persons with disabilities, Questions and answers* <u>https://www.ohchr.org/EN/HRBodies/CRPD/Pages/QuestionsAnswers.aspx</u>

¹⁹ Ibid, It is required that those members have disabilities as well as knowledge on regional approaches to disability laws and policies. It also suggested to nominate expert females disabled to address the gender imbalance in the Committee, occurred until 2018

job without the need of adjustments of the working space (but still labelled "disabled"), is given by the episode of the English former presenter for the BBC children's channel CBeebies (2009-2017) Cerrie Burnell. She was born with her right arm ending below the elbow, and worked indeed as a public figure in a generic working environment, which is great but, probably because this can be considered an unusual circumstance, she faced prejudices and complaints, about her diversity. According to an interview in the *The Guardian*, a mother once wrote on the message-board of the program: "Between the programmes I have to turn CBeebies over because my daughter is so frightened of Cerrie it's giving her nightmares"²⁰. That is the self-evident result of unfamiliarity with the sight of "different normalities". Over a billion people, about 15% of the world's population, have some form of disability, states the World Health Organization in its *factsheet* of January 16th 2018.²¹ That is means fifteen people in a hundred have a disability, which should be enough to run into one of them quite often I guess, hence familiarising to the view. Everyday barriers, not only environmentally, keep away people who cannot deal with them appropriately. Public space (as well as common mindset) needs a massive redesigning in order to let people with physical and mental impairments join the rest of the world.²²

Inclusion, through the reshaping of surrounding, would foster the process of "normalisation"²³ and, as a result, disposing of that sort of "fear of the unknown" so

²⁰ Saner, Emine, TV Presenter Cerrie Burnell: 'I Don't Care If You Are Offended, the Guardian, article, February 21, 2011. <u>http://www.theguardian.com/society/2011/feb/21/tv-presenter-cerrie-burnell</u>.

²¹ World Health Organization, factsheet of January 16th 2018 <u>https://www.who.int/en/news-room/fact-sheets/detail/disability-and-health</u>

²² CDC. 'Disability and Health Disability Barriers | CDC'. Centers for Disease Control and Prevention, 4 September 2019.

https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html. ²³ Debenham, Lucy Normalisation and Learning Disabilities, article, 2017

http://www.aboutlearningdisabilities.co.uk/normalisation-learning-disabilities.html.

persistent as a employers' reason not to hire disabled persons.²⁴ Maybe a day will come where there will no longer be any differences in choosing a person to a job, a film role or a beauty competition, no matter whether they have a leg or not!

I.4 Workplace inclusion and "normality"

Mike Montero, a designer advocate in promoting the ethical aspect of the design process, in his book *Ruined by design* (2019), legitimately questions: "Why teach people to think outside the box when you can hire people outside the box".²⁵ As shown in the paragraph *The Ideal Worker Norm as a Cultural Mechanism of Gender Inequality* of the book *Handbook of the Sociology of Gender*²⁶, historically, the stereotypical ideal worker is a white man, middle-class, middle-aged, masculine, definitely able-bodied. In fact, it is an absurdity when the design industry asks 30 year-old white men to think differently to satisfy a wide variety of clients, rather than turn to people with a different background. Eventually, big companies realise the advantages of including a wide variety of employees in the workplace, disabled included. "Diversity policies inure to the benefit of the companies by enabling them to attract and retain a workforce that generates new ideas and help[s] companies be more responsive in a diverse marketplace".²⁷

²⁴ United Nation, Department of economic and social affairs, disability, Fact sheet 2, Employing persons with disabilities: Fears and Realities <u>https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-withdisabilities/disability-and-employment.html</u>

²⁵ Monteiro, M., and V. Castillo. *Ruined by Design: How Designers Destroyed the World, and What We Can Do to Fix It*. Mule Design., 2019. p.74.

²⁶ Kalev, Alexandra, and Gal Deutsch. "Gender Inequality and Workplace Organizations: Understanding Reproduction and Change," 257–69, 2018. <u>https://doi.org/10.1007/978-3-319-76333-0_19</u>.

²⁷ Ball, Phoebe, Gregory Monaco, James Schmeling, Helen Schartz, and Peter Blanck. "Disability as Diversity Infortune 100 Companies." *Behavioral Sciences & the Law* 23, no. 1 (January 2005): 97–121. <u>https://doi.org/10.1002/bsl.629</u>.

The article *Macho, mobile and resilient? How workers with impairments are doubly disabled in project-based film and television work* published in 2016, points out the further disadvantage of disabled people in the UK film and television production, compared with other minorities excluded on the basis of race, gender and class.²⁸ Ironically, the UK gives the impression to be a very inclined country towards the inclusion of disabled people in workplaces, at least in the entertainment field, where most representants of the category come from. I have seen disabled TV presenters such as Sophie Morgan, or Cerrie Burnell who is also an actress; the model Kelly Knox; or the singer Viktoria Modesta (whose official video clip *Prototype* (2014) advises, at the very beginning, "forget what you know about disability", no less²⁹). There is even the stand-up comedian Rosie Jones³⁰ who suffers a cerebral palsy that causes her Apraxia, or the unspecified model of the Londoner *Bluebella lingerie*, who is shown among others able-bodied colleagues, without any specific caption on the picture, perfectly blended in. (fig.9)

 ²⁸ Randle, Keith, and Kate Hardy. "Macho, Mobile and Resilient? How Workers with Impairments Are Doubly Disabled in Project-Based Film and Television Work." *Work, Employment and Society* 31, no. 3 (June 1, 2017): 447–64. <u>https://doi.org/10.1177/0950017016643482</u>.
 ²⁹ https://youtu.be/jA8inmHhx8c

³⁰ Rosie Jones at Comedy Central UK (2018) <u>https://youtu.be/0QrS_giwJxY</u>



Figure 9, source: post on instagram Bluebella 8th december 2020

I honestly think at this as the best way to familiarise, including and making representative role models. However, I am not the only one who thinks this. Louise Bruton emphasises in her blog *Legless in Dublin* the beneficial effects of employing disabled actors and actresses in the film industry, in terms of normalisation process. "We can learn a certain amount from those big Films About Disability but we could learn so much more if we are just included in the cast. Actually functioning and socialising without being made an example of. A lot of us aren't trying to "overcome something" and we're not here to change your minds or inspire you, we have other shit to do and it's about time Hollywood realised that"³¹. Louise also wears an alternative, personalised prosthetic leg, called *Priscilla* (fig.10).

³¹ Louise Burton, Leg less in Dublin, Blog <u>http://leglessindublin.com/2016/06/actually-life-disability/</u>



Figure 10, Priscilla, Luise's prosthetic leg by Aternative limb project source: https://www.pinterest.es/pin/419960733986269875/

Exploring her thoughts has triggered a reflection about the other side of the coin: the importance of normality, in contrast to the "superhero" stereotype that challenges, struggles and wins its own war against an inadequate system. Not all disabled people want to fight, not all of them have to! Her point in the statement is straightforward. Enrolling disabled actors and actress for "ordinary" roles in the film industry would convey the feeling of normality indeed.

Chapter II

Design

II.1 Design for people

Designers have a significant role in society. They can find ways to improve the quality of others' lives, fill a gap, and figure out how to make things work. As a definition, they see problems and they find solutions (or at best, they are asked to find them). (Fig.11)



Figure 11 Scheme of the Design process of artifacts in society. Source: Course "Design: Creation of Artifacts in Society" By Professor Karl T. Ulrich. Co-author of the textbook "Product Design and Development" 7th ed., McGraw-Hill Education, 2020.

As stated by the authors of the paper *Relational Services*, Cipolla C. and Manzini E., there are two existing approaches to interact in the production and consumption design field: *Standard service* and *Relational service*. Those, according to the authors, are respectively interrelated to the concept "I-It" and "I-Thou" (where "It" denotes the remoteness with any subject and "Thou" indicates the mutual relationship). Here, they explain that the first is associated with the methodology adopted by the mainstream design pattern at offering services, in which we can find the conventional relationship "agent/client at the service-counter". While the second, focusing instead on the interpersonal and mutual relationships, challenges this last.³²

 ³² Cipolla, Carla, and Ezio Manzini. "Relational Services." *Knowledge, Technology & Computer Services*, no. 1 (n.d.):.

The supporter of the "I-It" and "I-Thou" conceptual framework, is the philosopher Martin Buber³³ (1878-1965), who considers the "encounter" the fundamental fact of the human existence.³⁴

Therefore, a *Standard service*, centred more on "Hows" of an action, rather than "Whys",³⁵ and focusing on an undefined target, cannot aim to fill someone's specific gap. At best, since there is no interaction, it focuses on "an own version of" the problem, based on a subjective perception of the inconvenience. As a result, others' (kind of people) discomfort, would hardly be perceived or identified. On the opposite side, the *Relational service*, entirely based on interpersonal interaction, exchange and sharing, tends to create a collaboration between the involved participants and, introducing a circular interaction model, produces reciprocal benefits.

A design process, conscious and inclusive that considers an "I-Thou" factor and aimed to reach the broadest possible range of people can make significant changes, contributing to turning the world into a better and more comfortable place to live, with no distinctions.

³³ Jones, W. Paul. "I and Thou by Martin Buber." In Salem Press Biographical Encyclopaedia. Salem Press, 2020. <u>https://ezproxy.iadt.ie/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=</u>ers&AN=89876435&authtype=shib&site=eds-live&scope=site.

³⁴ "A person makes his appearance by entering into relation with other persons. (...). The aim of relation is relation's own being, that is, contact with the *Thou*. For through contact with every *Thou* we are stirred with a breath of the *Thou*, that is, of eternal life. He who takes his stand in relation shares in a reality, (...). All reality is an activity in which I share without being able to appropriate for myself. Where there is no sharing there is no reality. Where there is self-appropriation there is no reality. The more direct the contact with the *Thou*, the fuller is the sharing" Buber, Martin. "I and Thou". Transalted by Ronald Grefor Smith. *Morrison and Gibb LTD*, Edinburg: T. & T. Vlarl, 38 George Street, 1937. P 62-63

³⁵ Cipolla, Carla, and Ezio Manzini. "Relational Services." *Knowledge, Technology & Camp; Policy* 22, no. 1 (n.d.): p 4.

II.2 Disability

The marginalisation of citizens with physical and mental impairments is a well-known issue that affects all the world's countries.

There is a UN *Convention on the Rights of People with Disabilities*³⁶, which is a central and global statement that all countries should meet it. Therefore, a standard has been established; applying it, though, it might make a huge difference to which all could benefit.

According to the *European Human Rights Report Issue* $4 - 2020^{37}$, that addresses specifically the subject of poverty and social exclusion of persons with disabilities, they face a higher risk of unemployment and poverty than persons without disabilities.³⁸ In fact, as a result of physical and mental differences, a consistent portion of the society is marginalised from social life and public services. Whereas, as stated by the *Universal Declaration of Human Rights* (UDHR)³⁹, we all should enjoy the same opportunities and have the right to participate in social life without inequity or restrictions. The *European Human Rights Report Issue* 4 includes a selection of the most relevant *European Pillar of Social Rights* (2017), to address poverty and exclusion of disabled people. Among main points such as *housing and assistance*, *wages*, *social protection*, *long-term care* (which all evidence, along with the numbers, a problem made of inequities, discrimination and lack of services); there are some in which the Design field is implicitly involved such as *education*,

³⁶ <u>http://nda.ie/Disability-overview/Legislation/UN-Convention-on-the-Rights-of-Persons-with-Disabilities.html</u>

 ³⁷ Hammersley Haydn, European Human Rights Report Issue 4 – 2020, Executive summary, p. 14 <u>https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF HR Report final tagged interactive v2 accessible.pdf</u>

³⁸ Ibid, executive summary p 14

³⁹ "Universal Declaration of Human Rights," October 6, 2015. <u>https://www.un.org/en/universal-declaration-human-rights/</u>.

equal opportunities, the inclusion of people with disabilities and access to essential services. ⁴⁰

Education, as a substantial right of the human being and vehicle for inclusion, can be in fact, guaranteed by the support of the design, which can supply features such as properly designed software and hardware, tools, equipment, furniture, and suitable access to academic courses and activities. A great example of how things can change on the education environment, is given by the *DO-IT* (Disabilities, Opportunities, Internetworking, and Technology) *centre*⁴¹, based in the University of Washington, Seattle. Their framework is practically, theoretically and technologically, entirely based on the Universal Design principles of inclusion, which we will explore shortly. The definition of disability, provided by the preamble of the *Convention on the* Rights of Persons with Disabilities, is emblematic: "Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".⁴² It is clear how disability is nothing but the product of a hostile environment, and how, if we could equally enjoy and access to study, services, leisure, public utilities and opportunities, the "disability at doing things" would not even have reasons to exist.

⁴⁰ European Commission, The European Pillar of Social Rights in 20 principles, a collection of 20 key principles to deliver new and more effective rights for citizens, signed up by the EU and member states, which agreed thus, to perform it. official website of the European Union<u>https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en</u>

⁴¹ DO-IT (Disabilities, Opportunities, Internetworking, and Technology) Center, 1992-2020 DO-IT, University of Washington (UW) <u>https://www.washington.edu/doit/</u>

⁴² "OHCHR | Convention on the Rights of Persons with Disabilities.", preamble, point e) <u>https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities</u> <u>es.aspx#preamble</u>.

Adjustments, applied to online classes to be welcoming and universally accessible, as well as a disabled-friendly technology and a barrier-free environmental, are all designer's tasks. Access to education is a major step towards social inclusion, equal opportunities and access to essential services too.

II.3 Universal Design

Due to this widespread limited-access to amenities and environments, to people with disabilities, the mainstream Design industry had to evolve. In order to meet needs and prevent discrimination, in 1997, a group of architects, designers and engineers, collaborated to establish the *7 Principles of Universal Design*. "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design"⁴³. Universal Design respects human diversity and promotes the inclusion of all people in all activities of life. Products such as an Oven that, placed above the counter, lift its floor to access it, with a self-supporting tray that does not require the use of both hands. Or the Washbasin with electronically adjustable height. Up to the batteries packaging, easy to remove, or the bigger and more visible Light switch, or *good grips* Kitchen utensils, are all now made accessible to a broader user base.⁴⁴ As soon as basic measures such as the ones mentioned above will be applied regularly or even required in public environments, along with a barrier-free environmental design, a significant change would be made.

⁴³ Bettye Rose Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, and Gregg Vanderheiden, THE PRINCIPLES OF UNIVERSAL DESIGN, Version 2.0 - 4/1/97, Copyright 1997 NC State University, The Center for Universal Design

⁴⁴ <u>http://universaldesign.ie/What-is-Universal-Design/Case-Studies-and-Examples/Examples/</u>

Ireland is the first country in the world to place Universal Design on a statutory footing.⁴⁵ This deep engagement on the topic, though, as shown in <u>fig.12</u>, is devaluated by the high risk of poverty and social exclusion of disabled persons, which is also unfairly disproportionately compared to persons without disabilities. That occurred due to the economic crisis in 2008, that was accompanied by a massive increase in unemployment and poverty and where funding to public services was also cut drastically, according to the description on the *Poverty and Social Exclusion of Persons with Disabilities European Human Rights Report Issue 4* – 2020.⁴⁶



Figure 12 EU's data of poverty and social exclusion risk of people with disabilities. source "Poverty and Social Exclusion of Persons with Disabilities European Human Rights Report Issue 4 - 2020" p.18 <u>https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad</u>

⁴⁵ <u>http://universaldesign.ie/About-Us/Partners-Associates/Partners-Associates.html</u>

 ⁴⁶ Hammersley Haydn, European Human Rights Report Issue 4 – 2020, Poverty and Social Exclusion of person with Disabilities.Executive summary, pp. 42-43
 <u>https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF HR Report final tagged interactive v2 accessible.pdf</u>

Universal Design, along with Inclusive Design,⁴⁷ can be a starting point, through insisting on amending workplaces and public spaces to make them suitable and equally enjoyable from anybody. The relation with the subject gives a key role in the development of these kind of design processes, based on an "I-thou" structure, as we saw before they include, inevitably, a beneficial interaction and exchange activity.

II.4 Empathy and Design

"Einfülhung", the German term from which the English "Empathy" comes, "gained refinement with Theodor Lipps, (...) accounting empathy as the primary basis for recognizing each other as minded creatures. It's worthy to note that for Lipps the nature of aesthetic empathy is always the 'experience of another human"⁴⁸.

Empathising with the need of others would be a key to stop biases and underqualified judgments. Nevertheless, to identify other gaps, others' limits through meaningful consideration and a thorough empathy, aiming to the "I know what that means" feeling.

Although the "empathy-building design process"⁴⁹ is already a well-known approach practised by several design industry companies, with various purposes such as "regaining perspective on what customers want and really care about (...) by

⁴⁷ Mourichon, Amélie 'Understanding Universal Design vs Accessibility vs Inclusive Design', article, Say Yeah!, 12 May 2020. <u>https://sayyeah.com/digital-insights/universal-design-accessibility-inclusive-design/</u>.

⁴⁸ Devecchi, Alice, and Luca Guerrini. "Empathy and Design. A New Perspective." *The Design Journal* 20, no. sup1 (July 28, 2017): S4357–64. p1905-49 <u>https://doi.org/10.1080/14606925.2017.1352932</u>.

⁴⁹ Bennett, Cynthia L., and Daniela K. Rosner. 'The Promise of Empathy: Design, Disability, and Knowing the "Other". In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, Glasgow Scotland Uk: ACM, 2019. 2.2 Empathy-Building Around Disability, p3-4. <u>https://doi.org/10.1145/3290605.3300528</u>.

presenting new opportunities and giving it a means to address them", to name one, as the global design company IDEO⁵⁰ explains;⁵¹ the empathy-building formula, applied to design for disabled users, has been contested by the authors of the paper *The Promise of Empathy: Design, Disability, and Knowing the "Other"*⁵², as per the way, it has been approached so far. Questioning that, simulations of bodily impairments such as blindfolding (to empathise with blind people), as well as steering a wheelchair for the first time, may foreground a novel blind person or a beginner wheelchair operator's experience, but certainly may lead designers toward a false and limited conception of the disability experiences.

The paragraph *Methods by which a designer or team may gain empathy with some of the constraints on ADL (a daily living)* in *Universal Design: Empathy and Affinity in Human Factors and Ergonomics in Consumer Product Design: Methods and Techniques*⁵³; which proposes a list of procedures such as *Predictive modelling, Empathic modelling, Mixed methods research, Product/cultural probes* and *Product champion;* admittedly, considers a valid and substantial interaction with the subject only in the last one, the *Product Champion,* and in the "remote interview" phase, as an option of *Method research*—ignoring so, even as a further possibility, any "expertise consultancy" in the designing phase, or a temporary working relationship. The "champion user" role, though, further along in the chapter, is deepened.⁵⁴

"Empathy on the edge: scaling and sustaining a human-centered approach in the evolving practice of design" Article, (January, 2014): <u>https://new-ideo-</u> com.s3.amazonaws.com/assets/files/pdfs/news/Empathy_on_the_Edge.pdf.

 ⁵⁰ Human-centered design company IDEO, official website <u>https://www.ideo.com/about</u>
 ⁵¹ Battarbee, Katja. Jane Fulton, and Suzanne Gibbs Howard, IDEO

⁵² Bennett, Cynthia L., and Daniela K. Rosner. "The Promise of Empathy: Design, Disability, and Knowing the 'Other.'" In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, 1–13. Glasgow Scotland Uk: ACM, 2019. <u>https://doi.org/10.1145/3290605.3300528</u>.

 ⁵³ Torrens, George. "Universal Design: Empathy and Affinity." In Human Factors and Ergonomics in Consumer Product Design: Methods and Techniques, 233–48, 2011.
 ⁵⁴ Ibid, p. 244

Contrarily, what Bennett and Rosner suggest, is a switch from "being like" to "being with" that involve the user/disabled contribution in the design process, taking into account, her/his experience, authority and of course, feedback.⁵⁵ Among other attempts of building empathy, they explored a table game prototype called Adapt-o-Pack created by IDEO, made for revealing both the creativity of disabled people in solving their daily issues and the unconscious bias of non-disabled people (including designers). The development of the game itself required the contribution of disabled people who found straightforward solutions to problems, which, otherwise, would have been considered unsolvable. For example, they reported farmer Rajendra's story, who suffers severe arthritis that causes him to have critical physical consequences. Hence, as a person with a disability, unable to be employed in a livelihood like farming, according to the assumption of many people they spoke to. "Stories like Rajendra's completely discredited that. He'd made small changes to his farm, such as widening the paths between crops to make it easier for him to negotiate his space. It was a surprisingly simple solution. As the breadwinner for his family, he couldn't tell himself it was impossible-he just had to have the creative confidence to make his farm work for him"⁵⁶. It is clear how inclusion and involving are fundamental factors to be taken into consideration into the design process when "others", are the targeted users.

⁵⁵ Bennett, Cynthia L., and Daniela K. Rosner. "The Promise of Empathy: Design, Disability, and Knowing the 'Other.'" In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, 1–13. Glasgow Scotland UK: ACM, 2019. <u>https://doi.org/10.1145/3290605.3300528</u>.

⁵⁶ Megan Durlak. 2018. Unlocking Creativity in the Name of Inclusion. Retrieved August 1, 2018 from https://www.ideo.org/perspective/creative-inclusion-and-bias-breaking

II.5 Creativity that meets Disability

The people who contributed to the disabled's cause were, in various ways, involved in their stories and lives. They familiarised with facts and needs and (when possible) provided a creative solution based on their own personal competences and knowledge. That is, somehow, what happened when a cobbler met an amputee gamekeeper. Was 1866 when James Gillingham created the first prosthetic arm made out of leather. For free, by the way, because he liked the challenge. Until then, limb loss replacements were made of wood, firm, not functional and not visually pleasant. The improvements have been substantial, his prosthetics were strong but light, durable, rigid, stylish, and above all, they perfectly fitted the limb (which the shoemaker used to mould like a pair of shoes). What he focused on, as a shoemaker, was the fit. He stressed comfort, suppleness and wearability and, as a result, he alleviated the torment of wearing what was an obsolete and bulky device, among other advantages.

Fortunately for us, he took beautiful black and white photos of each of his work. I can only agree, they are incredibly good-looking prostheses. He did it for over 15000 patients, who restored mobility and function.⁵⁷ (fig. 13, 14, 15, 16)

⁵⁷ Invented in the West Country 29min, BBC Documentary, TV Series (2017) <u>https://www.bbc.co.uk/programmes/b08w1f4j</u>



Figure 13 Picture of a Gillingham's prosthetic source: https://mashable.com/2015/07/26/early-prosthesis/?europe=true



Figure 15 Picture of a Gillingham's prosthetic source: https://www.ripleys.com/weird-news/james-gillingham/



Figure 14 Picture of a Gillingham's prosthetic source: https://rarehistoricalphotos.com/earlyprosthesis-james-gillingham-1900/



Figure 16 Picture of a Gillingham's prosthetic source: https://mashable.com/2015/07/26/early-prosthesis/?europe=true

This was nothing but the story of a creative who met a man who had a need, who pondered the options and achieved a result, who lived a first-hand experience that triggered the challenge and so, he changed others' lives.

Sophie De Oliveira Barata, a modern-day limb's sculptor/designer, based her work on the idea that people do not want to hide their limb differences anymore, "And (...) like anyone with a wardrobe of different clothes (there are people) who want a realistic limb and an alternative-style one". What before was meant as a replacing for a deficiency, a tool to hide as best as it could the physical difference, now is an accessory, icon of a new era, to show personal, powerful statements of pride. "Having an alternative limb is about claiming control and saying Tm an individual, and this reflects who I am" she declares.⁵⁸ Some people do not want to use prosthetics and assert their self-sufficiency and the right to be as they are. And there are who prefer to have one, but are tired of hiding the fact is not "biological", pretending that people would not notice they are wearing a fake limb. Putting on a prosthetic should be an option (unless that adds an actual value), like wearing stylish handcrafted boots. Sophie's prosthetics are authentic pieces of art, though. They succeeded in letting those who wear it regain self-confidence, also making them happy, emphasising their diversity through a symbol that conveys the message "this is who I am, and it is cool", just like a beautiful dress, that fits our shape perfectly (fig.17, fig.18, fig.19). Her major inspiration was a little girl who, every year, asked Sophia to make a different model based on the creative design she used to send to the artist (fig.20).

⁵⁸ TEDMED. "Expressing Identity with Aesthetic Prosthetics." (2014) <u>https://www.tedmed.com/talks/show?id=293048</u>.



Figure 17 Snake-arm, Jo-Jo Cranfield's prosthetic (British Swimmer, Motivational/Inspirational Speaker and Swimming Teacher) source: <u>https://thealternativelimbproject.com/limbs/snake-arm</u>



Figure 18 Anatomical-leg, Ryan Seary's prosthetic (Exserviceman for explosive ordnance disposal). source: https://thealternativelimbproject.com/limbs/anatomical-leg/



Figure 19 gadget-arm prosthetic, source:https://thealternativelimbproject.com/limbs/gadget-arm/



Figure 20 source: Screenshot TEDMED. "Expressing Identity with Aesthetic Prosthetics.". <u>https://www.tedmed.com/talks/show?id=293048</u>.

That is probably the greatest, pure and uncontaminated, evidence of how beneficial it can be express themselves. Sophie is also the creator of *Priscilla* (<u>fig.10</u>), the Louise Bruton's fake leg I mentioned before.

Turning a stigma into an icon seems to be a valuable way to make people deal with their physical diversity.

Another example of this sort of success is the UK company *OPEN BIONICS*, which develops low-cost bionic, functional, and attractive prostheses for upper limbs (making "bionic" accessible). It is targeted at a younger audience, but not them only. "These arms aren't meant to be hidden or tucked away. They're meant to reverse the dynamic of the playground. They aren't disguises; they aren't even armour. They're statements: brave, aspirational and cool", as themselves state.⁵⁹ They offer opensource designs, freely available to adapt, modify and develop them. They keep affordable prices. They have also given one of their firsts prototype to a little girl, Tilly, who now is a loyal testimonial (fig.21). They listened to her feedback providing the required functionality and, above all, the aesthetic features a kid needs to feel not ashamed nor uncomfortable, but rather, feeling little superheroes and growing up so, more confident.⁶⁰ In fact, the slogan of the product (called *Hero Arm*) is "Your limb difference is your superpower"⁶¹.

Emphasising diversity through an "accessory" can be a viable option. Nevertheless, that should be an essential and independent choice free from biases and discriminations of any sort.

⁵⁹ Wordsworth, Rich. "When Prosthetics Meet Aesthetics," January 20, 2020.

https://eandt.theiet.org/content/articles/2020/01/when-prosthetics-meet-aesthetics/.

⁶⁰ <u>https://openbionics.com/how-to-use-a-hero-arm/</u>

⁶¹ https://openbionics.com/



Figure 21 Tilly Lockey, the 15-year-old bionic girl, source: <u>https://www.dazeddigital.com/beauty/body/article/44979/1/tilly-lockey-amputee-</u> prosthetics-open-bionics

Chapter III

Technology

III.1 A win-win competition

The CYBATHLON of ETH Zurich Championship⁶² is an international competition between people with disabilities who play against each other to complete everyday tasks, assisted by their team of technicians and professionals in science and technology. The purposes are multiple, "offers a platform to advance research in the field of assistive technology and to promote the dialogue with the public about the inclusion of people with disabilities in everyday life"⁶³, as they affirm in their webpage. Besides, of course, providing actual help to people who struggle with significant deficiencies, that preclude them from the basic and daily performances. Healthy competition is beneficial, in this specific case for both sportsmanship and technological development. What surprised me most was the completely different approach to the same problem by the competitors. They all seemed to gain efficient results, but the ways they got to the final product were not consistent with each other. I am referring to the prosthetic arms mainly, which are more affected by the necessity of diversified functionalities. Some of the players switched the grips to accomplish different tasks. Others had their arm powered by a massive backpack. Some had a very futuristic and stylish cyborg arm that seemed to work independently (but had an Iphone as a controller to set the kind of functions in advance). Finally, the winning team, whose pilot achieved effortlessly, a series of tasks through this 3d printed arm (fig.22) that, as the design maker stated, costs about 30 dollars (and it is also an opensource project). The prosthesis is anything but fancy, although polyfunctional.⁶⁴ The engineer chose to design an efficient prosthetic arm, rather than a leg like he said he

⁶² Cybathlon competition, Zurich, 2020 <u>https://cybathlon.ethz.ch/en/cybathlon</u>

⁶³ https://cybathlon.ethz.ch/en/cybathlon/mission-statements-goals

⁶⁴ Maker hand profile (the Croatian team winner of the competition of "powered arm" discipline) within the website of the Cybathlon competition <u>https://cybathlon.ethz.ch/en/teams/maker-hand</u>

wanted to do initially, because he thought that he could never have done a leg if he lost the use of his hands. I guess he reached a state of empathy through his mental process, which drove him to make a valuable product, worrying about it as he needed it for his own cause, identifying himself as someone who has not got their arms anymore. That is what empathy is capable of generating.



Figure 22 "Making hand" team's prosthetic, winner of Cybathlon competition 2020. source: https://www.total-croatia-news.com/made-in-croatia/48543-andrej-djukic

III.2 Enhancement

Prosthetics, as we have seen, can either have an essential part in the process of aesthetic acceptance and consequent inclusion (even when there is not any practical function involved), or contributing to retrieve (or to acquire) operability and functionality, giving the chance to accomplish extra tasks and interacting even more within "non-so-inclusive" environments, in which was precluded before. The artist Neil Harbisson (fig.23) was born with a rare visual condition called achromatopsia, which means total colour blindness. He chose to implant a microchip on his back head that transmits, through the bone, a signal to an antenna, that drops in front of his forehead and allows him to "hear" colours. And since this device is a part of his body, the UK passport office legitimated him to show this on his passport photo (electronic equipment are not allowed on the passport photos), which makes him the world's first official cyborg. ⁶⁵ ⁶⁶ Neil promotes turning into a cyborg for the benefit of personal expression. He feels the world in a completely different way and claims the right of filling a void that somehow would marginalises him from society, turning a deficiency into something unique (and beneficial).



Figure 23 Neil Harbisson, the world's first Cyborg, "listening" colours through his antenna. source: https://munsell.com/color-blog/neil-harbisson-color-associations/

⁶⁵ National Geographic News. "How a Color-Blind Artist Became the World's First Cyborg," April 3, 2017. <u>https://www.nationalgeographic.com/news/2017/04/worlds-first-cyborg-humanevolution-science/</u>.

⁶⁶ Harbisson, Neil. "Transcript of 'I Listen to Color.'" <u>https://www.ted.com/talks/neil harbisson i listen to color/transcript</u>.

New features such as brain-controlled interface⁶⁷, neuromodulation⁶⁸, electric stimulation of paralysed muscles⁶⁹, powered arms⁷⁰, affordable bionic prosthetics and neural prosthetics,⁷¹ ⁷² help the "normalisation"⁷³ process, expanding the chances of interchange. Social life is a precondition for empathy.⁷⁴

Inclusion generates empathy through interaction, and vice-versa.⁷⁵

Physical upgrade, though, is not the only way technology can help functionality and inclusion. Empathy, as seen, can be the result of social interaction, nevertheless the precondition to generate inclusion. Studies demonstrated how, experiencing a condition through a simulation of someone else's context, can raise a state of empathy towards that person.⁷⁶ The pinnacle of this sort of experience is given by the embodiment of someone's condition through a Virtual Reality (VR)

 ⁶⁷ Schwartz, Andrew B., X. Tracy Cui, Douglas J. Weber, and Daniel W. Moran. 'Brain-Controlled Interfaces: Movement Restoration with Neural Prosthetics'. *Neuron* 52, no. 1 (5 October 2006): 205–20. <u>https://doi.org/10.1016/j.neuron.2006.09.019</u>.

⁶⁸ <u>https://medicine.hsc.wvu.edu/who-we-are/faculty-staff/ali-rezai-md/</u>

⁶⁹ McDaniel, John, Lisa M. Lombardo, Kevin M. Foglyano, Paul D. Marasco, and Ronald J.Triolo. 'Cycle Training Using Implanted Neural Prostheses: Team Cleveland'. *European Journal of Translational Myology* 27, no. 4 (6 December 2017). https://doi.org/10.4081/ejtm.2017.7087.

⁷⁰ Sherstan, Craig. 'Towards Prosthetic Arms as Wearable Intelligent Robots', n.d., 150.

⁷¹ Godfrey, Sasha, Kristin Zhao, Amanda Theuer, Manuel Catalano, Matteo Bianchi, Ryan Breighner, Divya Bhaskaran, et al. 'The SoftHand Pro: Functional Evaluation of a Novel, Flexible, and Robust Myoelectric Prosthesis'. *PLOS ONE* 13 (15 October 2018): e0205653. <u>https://doi.org/10.1371/journal.pone.0205653</u>.

⁷² Read 'Smart Prosthetics: Exploring Assistive Devices for the Body and Mind: Task Group Summaries' at NAP.Edu. <u>https://doi.org/10.17226/11864</u>.

⁷³ Lucy Debenham BA, Normalisation and Learning Disabilities'. 2017 <u>http://www.aboutlearningdisabilities.co.uk/normalisation-learning-disabilities.html</u>.

⁷⁴ "Studies (..) shown that in any given population there is a spread of scores from low to high empathy(..). In general, the lower the empathy score, the more puzzling and difficult the individual is likely to find social life". Howe, David. *Empathy: What It Is and Why It Matters*. Macmillan International Higher Education, p 17, 2012.

⁷⁵ "We rarely observe someone else without wanting to know something of the mind that lies behind what they say and do." ibid, p.15

⁷⁶ Yee, Nick, and Jeremy Bailenson. "Walk A Mile in Digital Shoes: The Impact of Embodied Perspective-Taking on The Reduction of Negative Stereotyping in Immersive Virtual Environments," n.d., 9.

experience.⁷⁷ A state of empathy can be induced with the purpose to expand familiarisation and encouraging acceptance and inclusion. Moreover, from the designers point of view (the professionals who provide solutions), such a perspective-taking experience, could result in more inclusive design usable by all people, universally. Thus, promoting the physical inclusion in life's activities too.

III.3 Virtual Reality Empathy experience

What if we would be able to experience and feel, at least once, the limits a disabled person could have in doing something we, instead, take for granted? Such an experience could quickly put anyone in someone else shoes, and in the case of a designer, that would mean producing actual benefits. While in other circumstances, it could simply help to sympathise and familiarise with diversity.

"We are in the dawn of the Virtual Revolution"⁷⁸, studies made by The Virtual Human Interaction Lab of Stanford University show how our interactions and behaviours can be affected by the use of this steady growth technology. Their mission is benefit from VR, enhancing instead of detract from the real world around us. They offer solutions that allow to groups of people across the world to make eye contact and communicate nonverbally in other nuanced ways, through realistic virtual meetings that replace the physical ones, to avoid commutes and CO₂ emissions.⁷⁹

⁷⁷ Herrera, Fernanda, Jeremy Bailenson, Erika Weisz, Elise Ogle, and Jamil Zaki. 'Building Long-Term Empathy: A Large-Scale Comparison of Traditional and Virtual Reality Perspective-Taking'. Edited by Brock Bastian. *PLOS ONE* 13, no. 10 (17 October 2018): e0204494. <u>https://doi.org/10.1371/journal.pone.0204494</u>.

⁷⁸ VHIL. 'VHIL'. https://vhil.stanford.edu.

⁷⁹ VHIL. 'VHIL Research Examines How Augmented Reality Affects People's Behavior, Stanford News', 15 May 2019. <u>https://vhil.stanford.edu/mm/2019/05/stanford-ar-behavior.pdf</u>

Filmmaker Chris Milk describes VR as "the ultimate empathy machine" in a TED talk in 2015. Since, as a VR player himself when he was a child, experienced personally the result that such an involving experience left on him after so many years. He thinks that this machine can change minds. He shot a VR film based on a Syrian 12 year-old girl, made on a refugee camp in Jordan. He showed it to the World Economic Forum in Davos, to a group of people whose decisions affect the lives of millions of people, that suddenly, thanks to the technology, "they all found themselves there". He saw them affected by it. He is working with the United Nations to shoot more series of these kinds of films and show them to the people who can change the people's lives inside the films—adding that "we just start to scratch the surface of the true power of virtual reality. It's not a video game peripheral. It connects humans to other humans in a profound way that I've never seen before in any other form of Media. And it can change people's perception of each other. And that's how I think virtual reality has the potential to actually change the world".⁸⁰

Would certainly agree with this opinion the authors of the article *Virtual Superheroes: Using Superpowers in Virtual Reality to Encourage Prosocial Behavior*⁸¹, who claim that, when the player occupies an avatar, he/she psychologically "becomes" the avatar and that affect their life in the real world, increasing, afterwards, a prosocial behaviour (in the case of their studies). In the research, they compared playing the role of a flying superhero to a helicopter

⁸⁰ Milk, Chris. How Virtual Reality Can Create the Ultimate Empathy Machine. 2015 <u>https://www.ted.com/talks/chris_milk_how_virtual_reality_can_create_the_ultimate_emp_athy_machine</u>.

⁸¹ Rosenberg, Robin S., Shawnee L. Baughman, and Jeremy N. Bailenson. "Virtual Superheroes: Using Superpowers in Virtual Reality to Encourage Prosocial Behavior." Edited by Attila Szolnoki. *PLoS ONE* 8, no. 1 (January 30, 2013): e55003. https://doi.org/10.1371/journal.pone.0055003.

passenger. Both had the same purpose of saving lives, but they demonstrated that, after the "active" and personally involving experience of the superhero, users were more inclined to prosocial behaviour than helicopter passengers. It has also been demonstrated that digital self-representation affects how a person behaves in the virtual environment itself; this phenomenon is termed *The Proteus Effect*. Participants who have been given an attractive avatar have been shown more casualness than participants with unattractive avatars",⁸² which confirm that a virtual experience can affect behaviours. That is explained so: "Embodied cognition theory postulates that cognition is an interaction of the body and mind that takes place within the context of a specific environment. Past studies show that physical movement can improve a participant's performance while completing cognitive tasks and that the physical experience of a particular environment can have an effect on both perceptions and behaviours".⁸³

The assumption of my thesis is to examine the best ways to create disabled people's inclusion into society, through the tools offered by technology and design. VR here is meant as a tool that generates empathy and assists the process of inclusion. Previously, regarding empathy-building process, it has been suggested "being with" rather than "being like".⁸⁴ Regarding this specific VR experience, I would rather say "being like, with".

⁸² Yee, Nick, and Jeremy Bailenson. "Walk A Mile in Digital Shoes: The Impact of Embodied Perspective-Taking on The Reduction of Negative Stereotyping in Immersive Virtual Environments," n.d., 9.

⁸³ Herrera, Fernanda, Jeremy Bailenson, Erika Weisz, Elise Ogle, and Jamil Zaki. "Building Long-Term Empathy: A Large-Scale Comparison of Traditional and Virtual Reality Perspective-Taking." Edited by Brock Bastian. *PLOS ONE* 13, no. 10 (October 17, 2018): e0204494. <u>https://doi.org/10.1371/journal.pone.0204494</u>.

⁸⁴ Bennett, Cynthia L., and Daniela K. Rosner. "The Promise of Empathy: Design, Disability, and Knowing the 'Other.'" In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, 1–13. Glasgow Scotland Uk: ACM, 2019. https://doi.org/10.1145/3290605.3300528.

As already described in <u>Chapter II</u>, paragraph 4 of this thesis; studies concerning empathising with disabled people, through perspective-taking tasks, show the risks to obtain detrimental rather than productive results, as well as being inaccurate.

The inexperience in simulating a disability might cause frustration, also they would focus on what they cannot do rather than on what they could do with appropriate access, technology, or skills.⁸⁵ For this reason, it is suggested to "consult people with disabilities when developing simulations and, when possible, involve them in the delivery, debriefing, and evaluation of simulation activities"⁸⁶. The warnings also confirm the power of building empathy methods and using them cautiously especially regarding medical conditions, and their potentially negative effects that can generate (despite the established growth of empathy), the spread of misinformation, and reinforce stereotypes.⁸⁷

Building-empathy techniques need to be handled with care.

Nevertheless, the VR experience has already been successfully applied as a tool to develop empathy and understanding of a specific category of subjects such as the homeless⁸⁸, elderly people⁸⁹, or to simulate a mental illness⁹⁰ (to mention a few).

⁸⁵ Burgstahler, Sheryl, and Tanis Doe. "Disability-Related Simulations: If, When, and How to Use Them in Professional Development." *Review of Disability Studies: An International Journal* 1 (January 1, 2004). p.11

⁸⁶ Ibid, p.13

⁸⁷ Ibid, p.4

⁸⁸ ibid

⁸⁹ Yee, Nick, and Jeremy Bailenson. "Walk A Mile in Digital Shoes: The Impact of Embodied Perspective-Taking on The Reduction of Negative Stereotyping in Immersive Virtual Environments," n.d., 9.

⁹⁰ "Sri Kalyanaraman, Sriram, David L. Penn, James D. Ivory, and Abigail Judge. "The Virtual Doppelganger: Effects of a Virtual Reality Simulator on Perceptions of Schizophrenia." *The Journal of Nervous and Mental Disease* 198, no. 6 (June 2010): 437–43. <u>https://doi.org/10.1097/NMD.0b013e3181e07d66</u>.

Interacting, familiarising, empathising, and learning from someone who experiences the world differently, along with an effective and aware program of inclusion, as suggested above, are beneficial solutions under every aspect. An empathic VR experience of physical or mental impairment, in the particular case of the designer, combined with a meaningful tutoring with disabled representatives, can set off a constructive change. That would be in making tools, furnishings, environments, software, technology, facilities and so on, universally, enjoyable for everyone, equally, welcoming every person to social life.

Inclusion, empathy, familiarity, interaction, understanding, are all powerful weapon against biases, misconception and racism, in every its form. Opening to diversity will inevitably open our minds.

Conclusion

People with physical impairments are discouraged from taking part in social life, either by physical barriers in public areas and a persistent diffuse lack of familiarity with the subject of diversity, that leads to misconception, biases and awkward interactions between "able-bodied" and disabled persons. Moreover, they often experience a sense of discomfort when they deal with others' curiosity, gaze and, in some cases, even fear that, rightly, question their belonging to the rest of society.

The UK Entertainment Industry taught me a practical approach to make inclusion happen. Most of the disabled public persons I have run into, during my research, belong to the English Media and Show-business. Due to the powerful impact Media has over our lives, this can be a successful way to "normalise" physical and mental differences, welcoming them in society's culture and familiarising with the sight of diversity. In addition, Media create role models that can help people who experience moments of confusion in dealing with their diversity, besides reframing the narrow conventional codes of ability, beauty and normality.

Normality, in fact, is the goal of inclusion. Not all the disabled aspire to be "special" fighting the war to assert their rights to participate in social life. Paralympic athletes and iconic disabled characters of films are often not accepted as representatives of this category from the disabled community itself, who thinks to be entitled to access to workplaces, education, transport, public places, like any other citizen, without fighting. Ideally, becoming a "hero", as a compensation of a physical impairment, should be a choice, an option, developed from a basis of a life lived

without fundamental limitations (a "normal" life), not a reaction to something wrong that makes you a warrior ready to fight.

This difficulty in living a normal life has drawn the attention to the "ineffective environment" issue, mainly responsible for their exclusion. Statistics show how this 15% of the population (that is indeed the presence of disability into society) risks poverty and marginalisation, more than any other minority community. Inclusion can prevent that happening, but the "traditional system" needs to be forced, and awareness has to raise, evaluating diversity as a cultural enhancement, until it will be integrated into normalcy, naturally.

Eventually, inclusion turned out being a beneficial factor, not only towards people who need to be included. The Design industry is adopting a new (and more profitable) attitude in creating a variated working environment, that delivers products that reflect a more comprehensive range of users and customers, contrasting the iconic figure of the ideal worker stereotype: the white man, 30 year-old, middle class, masculine and abled-body—implicitly required in the creative industry environment.

The designer's archetypal mind-set consists of seeing the problem and finding the solution, filling the gap. An aware design process should consider individual needs, nevertheless involving the broadest range of people to the use of the products designed, contributing to an indistinctive inclusion of all in society. It has to fight marginalisation of citizens with physical and mental impairments, affected by a senseless lack of regulations and policy, that excludes them from ordinary daily activities. When, instead, they are entitled to claim those rights, as citizens, part of society.

Disability, in fact, can be summarised as a result of a not welcoming environment, due to physical barriers that still subsist, scarcity of intentions in making technology universally inclusive, and even the feeling of discomfort with diversity by society.

Although it has to be said, the world of design already took action to address this issue. Since 1997, it suggests a way to design the environment and items that do not preclude anyone's enjoyment. This branch is called Universal Design and aims to include the broadest range of people into society making areas and objects accessible, equally.

Empathy is another factor to consider in the inclusion process to end biases and misconception against disability by familiarising with diversity. Besides, promoting the growth of empathy through specific techniques and tools would offer the possibility of reaching a more comprehensive range of creatives that would interact with the issue, increasing the solutions' variety, provided from different backgrounds and skillsets. The "empathy-building" process, albeit already adopted from the Design industry, raised concerns about how it has been done so far. In fact, it ended up treating the final user as a spectator, rather than including them in the design process, which is precisely the opposite of what recent studies have demonstrated effective: an approach that involves (or inspired "by solutions adopted by") disabled people in facing gaps, often provides more creative results to problems that were considered unsolvable even from expert designers (who never considered to interact with the subject).

The involvement of creatives, designers and artists brings new added value to the cause: the aesthetical aspect of the prosthetic that turns the stigma of diversity into an icon that acclaims uniqueness and individuality, but that, again, can be a

controversial matter when you aim to be part of the "normality". To the opposite side of the aesthetic prosthetic, there is the functional one. Technology helps the cause making the possibility to gain, or regain, regular physical and mental functions. Fewer impairments would also mean a potential reintegration into society. Thanks to the pop culture, using a noticeable technology blended to a human body does not bother anyone (anymore). In some cases, it is even considered appealing.

However, there is another aspect that technology can cover to help inclusion, and that is through the building of empathy using Virtual Reality as a tool to reproduce experiences of other people's feelings and challenges by which, awareness and familiarisation can grow, favouring so the process of acceptance. Moreover, this technique might involve people who supply daily-use tools, equipment, and public spaces (such as designers, engineers, architects, makers) to start a mental process of inclusion by developing a design enjoyable for all the human requirements, universally. Once experienced "personally" the issue of disability.

In fact, it is demonstrated that a role embedded into Virtual Reality is perceived as a first-hand experience because it involves and surrounds the subject, causing empathy, which can affect the behaviour precisely because it is felt like a personal experience.

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