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# ▶ To cite this version:

Valentine Gourinat, Paul-Fabien Groud. From the Persistence of Ableism to its Deconstruction in the Evolution of Collective and Individual Narratives around Prosthetic Amputee Bodies. Amnis - Revue de civilisation contemporaine, Europe/Amériques, 2023, 10.4000/amnis.8270. hal-04215249

HAL Id: hal-04215249

https://hal.science/hal-04215249

Submitted on 22 Sep 2023

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# **Amnis**

Revue d'études des sociétés et cultures contemporaines Europe/Amérique

22 | 2023

Du handicap aux variations humaines. Récits anciens, nouveaux récits

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### Electronic version

URL: https://journals.openedition.org/amnis/8270 DOI: 10.4000/amnis.8270

ISSN: 1764-7193

### **Publisher**

TELEMME - UMR 6570

Brought to you by Université Claude Bernard Lyon 1



### Electronic reference

Valentine Gourinat and Paul-Fabien Groud, "From the Persistence of Ableism to its Deconstruction in the Evolution of Collective and Individual Narratives around Prosthetic Amputee Bodies", *Amnis* [Online], 22 | 2023, Online since 10 September 2023, connection on 22 September 2023. URL: http://journals.openedition.org/amnis/8270; DOI: https://doi.org/10.4000/amnis.8270

This text was automatically generated on 22 September 2023.



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# From the Persistence of Ableism to its Deconstruction in the Evolution of Collective and Individual Narratives around Prosthetic Amputee Bodies

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# Introduction

- Given the extent of the physical trauma experienced, the stigma left on the body by the amputation, and the use of this particular object, the prosthesis, the amputee has long been part of the collective imagination1. From the wooden leg to the « bionic » hand, from the mutilated war soldier to the sportsman fitted with carbon blades, the figure of the « amputee » occupies a special place in the history of representations of disability<sup>2</sup> within Western societies (European and North-American3). After a transformation in the amputee's images from the 19th century onwards, a quick shift in these representations took place during the 20th century. The recognition of amputees (through the visibility and recognition of amputee soldiers) correlated with the development of the prosthetic field and physical rehabilitation medicine, has led to the production, over the course of the century, of new individual and collective narratives. At the beginning of the 21st century, a new techno-enchanted narrative emerged around the amputee figure, driven by surgical, medical and fitting progress and influenced by the mass media. As we shall see, while this historical development is far from uniform, it is nonetheless persistently affected by the filter of an ableist4 ideology that needs to be examined in depth.
- 2 Drawing on philosophy, anthropology, history and the information and communication sciences, this article analyses the development, from the 19th century to the present

day, of Western narratives around the figure of the amputee. The aim of this critical analysis is to decipher and study those narratives through the prism of the ableist norms and prosthetic fascination on which they were built and disseminated. Using a diachronic and iterative approach, this work will lead us to examine the ambiguous consequences of these narratives on contemporary representations of disability on a collective and societal scale. We will also look at the impact of these narratives on the life stories of amputees, while these narratives cannot be thought of in isolation from their performative dimension<sup>5</sup>. From a methodological point of view, the analysis is based, on the one hand, on a survey of archives and works on amputees from the 19th to the 21st century, and on the other hand on documentary monitoring of media content from the general press for the 21st century. It is also based on several ethnographic surveys (observations, videos, interviews with amputees, their relatives and healthcare professionals) carried out in France in rehabilitation centres, prosthesis manufacturing companies, an amputee association and in the homes of several of the participants in our research.

In this three-part article, we begin by tracing the evolution of collective narratives based on ableist norms with regard to the figure of the amputee soldier over the course of the 19th and 20th centuries. Our analysis then focuses on the first two decades of the 21st century, which saw the emergence and dissemination of techno-enchanted and ableist narratives around this same figure, with significant repercussions at both individual and collective levels. In the final part, we highlight the contemporary work of critically deconstructing this narrative and this prosthetic fascination within Western societies, particularly by the individuals concerned, in order to grasp its full scope and the current issues for amputees and, more generally, for people with disabilities.

# Narratives about Amputees and Prosthetic Devices in the Late 19th and 20th Centuries: from War Wounds to the Return to Work

Although the practice of amputation has been recorded since Neolithic era<sup>6</sup>, it was then only performed as a last resort, and was often refused by the people concerned, even when their lives were at stake<sup>7</sup>. It was not until the second half of the 19th century that surgical procedures evolved considerably (particularly in terms of anesthesia), and the idea of limb amputation became acceptable to both carers and patients8. Indeed, the medical and technical advances of the time (linked to the many wars that tore the period apart) made it possible to make stumps more functional and to restore some common activities thanks to increasingly sophisticated prostheses9. While medical documentation can be found throughout this period, the narratives and discourses of amputees did not really begin to be documented until after the Great War, when disabled veterans' associations began to emerge and relay the voices of those first affected. This concerned above all access to disability compensation rights, in particular by obtaining and increasing a disability allowance, which was the main concern of wounded soldiers at the time 10. It was also during this period that a certain structuring of the collective narrative around the figure of the disabled veteran began to emerge. Historian Sophie Delaporte explains that from the end of World War I:

While the 14 July parade, with its procession of war-disabled soldiers in the limelight, consecrated the nation's recognition of those who had suffered in their flesh to defend it, it also reflected a form of heroism of the wound received in war, and thus a certain valorization of the disabled.<sup>11</sup>

- This narrative of the valorization of the mutilation largely involves the idea that the loss of their limb is a gift, a sacrifice for a « sacred cause » and, in so doing, « making sense of injuries in the ambiguous aftermath of the war required Union veteran amputees to mythologize their victory »12. This heroisation in the collective discourse seems rather paradoxical, however, if we consider how little social and financial consideration was given to soldiers, as denounced by disabled veterans' associations. In addition, this heroisation removes any reference to the pain, sorrow and suffering experienced by the first concerned, thereby erasing the whole dimension of vulnerability that could hinder the process of enhancing the image of the war wounded. Unfortunately, this has direct consequences for the population concerned, since « the denial of pain has undoubtedly helped to encourage amputees to withdraw into silence »13. Furthermore, despite the unacceptable social misery and psychological distress in which many war veterans were living<sup>14</sup>, they were expected to overcome their own suffering and situation, a necessary condition for their respectability. Earlier in the day, Phineas Whitehouse already assured his fellow veterans of the American Civil War that « With patient and persevering efforts, make the vest of that, and there is nothing to prevent you from becoming useful, respected and honoured citizens of our regenerated republic »15. Here we can already see the first snippets of an ableist socio-political dynamic (to be linked with the «discourse of enjoyment and performance »16 highly valued by capitalist ideology) that skews the collective representation of the disabled person, by giving only a carefully chosen partial image. This specific image is an integral part of the process through which the disabled's voices and experiences are stifled and suppressed, which in turn removes any sense of collective responsibility regarding the societal impact of disability.
- It was within this dynamic of thought, that emerged the sciences of functional rehabilitation, which sought to erase the « anomalies » of the mutilated body and bring it back into line with social norms<sup>17</sup>. Moreover, it was a direct response to the political objectives of maintaining (individual) productivity, particularly in terms of returning to work, in a context of economic reconstruction following the war. It was during this period that physiotherapy arose, a movement based therapy combining new paramedical methods (medical and orthopedic gymnastics, therapeutic massages and manipulations, electrotherapy, etc.). These new methods were aimed at people injured in the workplace, but also mainly at war wounded, who were sent to « recovery centres set up by the armed forces health service »18. Functional rehabilitation was formalized in earnest at the end of the Second World War, with the recognition in 1947 by the American Medical Association of this new medical discipline, now known as Physical and Rehabilitation Medicine<sup>19</sup>. At the same time, the constant improvement of functional prostheses has made it possible to regain a certain capacity and autonomy at work<sup>20</sup>. The idea, once again, is to be able to turn wounded people into productive individuals, through a return to employment. Throughout this century, a return to work has been at the heart of the narrative surrounding amputation and disability. Here again, it's hard not to see the ableist bias that runs through the representations and collective expectations that are addressed to amputees. As Patrick Fougeyrollas puts it:

The activity par excellence, as the central Western value concerning men, is productive activity, the capacity to work. 'Accident victims, recover your capacity to work' goes the maxim engraved on the inaugural plaque dated 1967 of the Quebec City rehabilitation centre built for its clientele by the Work Injuries Board.<sup>21</sup>

However, even if a return to work is an essential aspect of the collective discourse on disability and a desired and beneficial step in individual paths, the reality of professional reintegration for amputees is more complex, and highlights a certain paradox. Far from political ideals, individual wishes come up against possible discrimination by employers. For example, Dominique, 74, a traumatic transfemoral amputee in the early 1980s, who was urged to return to work and was keen to do so, felt the full force of the gap between the collective narrative and individual reality:

I was in the printing industry. I was capable of going back to work. [...] But then the boss said to me: « With your salary, I can pay back two people, so we'll come to an "arrangement" »... He fired me. $^{22}$ 

This approach, aimed at making individuals bear the burden of their own disability and urging them to return to a « useful » physical condition (while limiting their access to rights and employment), was also reflected in the evolution of disability policies right up to the beginning of the 21st century. The biomedical approach to disability, in force until the end of the 20th century, reflected a collective aim to normalize the individual by « correcting » him or her in order to adapt to the ableist environment<sup>23</sup>. It was not until the second half of the 20th century that people with disabilities began to stand up for their rights, in order to gain greater autonomy and, above all, self-determination<sup>24</sup>. While the figure of the war veteran remains a key figure in these social movements, it is gradually being overtaken by that of civilian amputees, who are increasingly numerous in the world of rehabilitation and more and more active in the public arena. While the profiles of amputees gradually changed at the end of the 20th century, the ableist bias that surrounded their collective consideration, and the construction of discourses around them, persisted.

# From the beginning of the 21st century to the present day: the story of an effective, fixed and enhanced prosthetic body

From the end of the 20th century onwards, developments in orthopedic devices radically transformed the prosthetic field and the experience of people with upper and/or lower limb amputations. The use of silicone made it possible to manufacture comfortable sleeves. New types and shapes of sockets are appearing, which are lighter, more resistant and adapted to each amputee. The use of new materials (carbon, titanium) and prosthetic technological devices equipped with microprocessors and electronic sensors has led to considerable advances in orthopedic devices. Their arrival on the public market and their reimbursement by social security (in France) offer amputees the possibility of being fitted with prostheses that enable them to perform everyday tasks more easily, more « naturally », and to regain a certain degree of autonomy. Not only healthcare professionals, but also amputees who have gone through this transformation phase—which has only accelerated over the years up to the present day—describe this pivotal period:

— Ambroise<sup>25</sup>: Things have evolved in terms of both substance and form. Patients are much better cared for before, during and after amputation. Then there are the advances in orthopaedic devices. The upper limb prostheses are increasingly sophisticated, and still very well reimbursed by French social security compared with other countries. And then, when I arrived here [at the rehabilitation center], 32 years ago [in 1989], there were 2 or 3 types of mechanical knee, there was no electronic knee, now there are different types of mechanical knee and half a dozen electronic knees. Things have "exploded", especially in the upper limbs. It's fascinating progress. Prostheses are more reliable, lighter, better performing and more aesthetically pleasing.<sup>26</sup>

— Franck<sup>27</sup>: What it's like to live with a prosthesis, especially now since the [electronic knees]... plus before I didn't even have a foot with a Carbon blade. I've experienced a lot of things... At the beginning, I didn't have any silicone sleeves either, they were made of leather. In the summer, it was crazy, they were all wet, they didn't have time to dry. [...] All that changed your life, it was like night and day.<sup>28</sup>

10 From the 2000s onwards, in conjunction with the emergence of these new prosthetic devices and the arrival of the internet, there was growing media coverage of amputees fitted with high-tech prostheses and/or original designs, particularly in Europe and the USA. The effect of these media figures is to produce new narratives and representations of amputees and disabled people in general. A paradigm shift is taking place in the media and in society, with amputees being shown and understood through the prism of performing and overcoming disability. This « contemporary prosthetic enchantment »<sup>29</sup> can be seen in the many images, videos and stories about the media's staging of a techno-body<sup>30</sup> based on a display of the performances of amputees fitted with prosthetic limbs and an unprecedented estheticization of prosthetic limbs.

The parasport movement has been a powerful vehicle for this enchanted and heroic narrative. South African athlete Oscar Pistorius, a 400m specialist who suffered a bilateral tibial amputation at the age of 11 months as a result of a congenital malformation, fitted with carbon blade running prostheses in competition, was one of the most talked-about media figures<sup>31</sup>. Between 2004 and 2012, under the media spotlight, his performances, which were close to those of athletes considered « ablebodied », fueled a major controversy about possible « technological doping ». As an analysis of the changes taking place at the beginning of the 21st century, the media coverage of Oscar Pistorius and, more generally, of the performances of disabled athletes at the London Paralympic Games represents a turning point in the visibility of people with disabilities in the media. It is the driving force behind a narrative of the heroic (disabled) athlete and a staging of a body/technology hybridization based on the ableist body norms current in industrial/capitalist societies: the athletic, muscular, technologized, high-performance, powerful body<sup>32</sup>.

The narrative in favor of contemporary prosthetic enchantment was also built over these decades on the media coverage of other amputee fitted with prosthesis figures with varying degrees of short-lived success. Aimee Mullins and Viktoria Modesta were/ are two amputee media figures who have made a name for themselves through a variety of artistic and publicity projects, and who are the bearers of a discourse and narrative in favor of prosthetics as a means of overcoming disability. Claudia Mitchell and Leslie Baugh are other amputee figures (re)presented as women and men who have become « bionic », following on from the 20th century ableist narrative of the soldier fixed by prostheses. They symbolize the capacity and power of (prosthetic) technology to fix the human body. Hugh Herr, double amputated following a climbing accident, is

an American engineer at the Massachusetts Institute of Technology (MIT) and designer of high-tech prostheses, but also one of the most representative media figures in the construction of this techno-enchanted narrative. Prophesying a near future where « it will be better to be an amputee than an able-bodied »<sup>33</sup>, he embodies the narrative of « enhanced man » advocated by the transhumanist currents in vogue in the 2010s.

From the prosthetic, athletic and high-performance amputated body to the claim that the body merges with prostheses, the media figures of amputees and amputees have helped to convey and exalt the narrative of a body fixed/enhanced by prosthetic devices. The dissemination of this exalted narrative is ambiguous as two analyses intertwine. The first underlines the consequent and beneficial impact that these mediatized individuals have had on society's image and collective representations of disability, in which the amputee body is made, said and shown to be a body with capacity<sup>34</sup>. Far from the crippled<sup>35</sup> and stigmatized<sup>36</sup> amputees, these figures lead to a redefinition of the boundaries, destined to become blurred, between disabled and ablebodied people. However, a second, critical analysis reveals the problematic nature of this techno-enchantment. This narrative is partly rooted in ableism, in which amputated bodies are acceptable and desirable since they are fixed and presented as overly-able<sup>37</sup>. Moreover, it reveals a significant gap between the narratives conveyed and embodied by media figures and the reality on the ground and the majority of the experiences and stories of those affected. Ethnographic observations and interviews highlight the vertiginous gulf between the prowess and narratives developed by media figures in favor of an amputated and prosthetic body—a « jigsaw puzzle » whose pieces could be changed without constraint-and the experiences of amputees fitted with prosthetic devices. This account masks the complexity of the profiles and daily experiences of amputees (managing the stump, phantom pain, sometimes difficult reconstruction of the body image) and people fitted with prosthetic devices (pain and difficulties in the stump/prosthesis relationship, fitting problems, limitations inherent in the amputee/prosthetic body). This can lead to numerous disappointments in the healthcare process and in the everyday experience of amputation and fitting<sup>38</sup>, which are palpable in the narratives given by amputees and their carers:

— Charles<sup>39</sup>: But come on, when... When you... type « prosthesis » on the... on the internet, what do you see? [Pi]storius doing, doing... [Pi]storius running. [...] But that's... aberrant! [Whereas using a prosthesis] is an obstacle course. It really is! [...] But I think it's ignorance. It's ignorance!<sup>40</sup>

— Jean<sup>41</sup>: There are a lot of traumatic amputees who decide to do sport after an amputation because they've seen videos of so-called enhanced amputees. Even if the desire to practice sport is a driving force in rehabilitation and in post-amputation life, these images make our work in rehabilitation difficult, because we have to remind them that there is no such thing as an enhanced amputee. It's sometimes difficult to get this message across to patients who want the latest high-tech prosthesis they've seen on the internet straight away.<sup>42</sup>

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With the myth of the enhanced human being in the background, the (over-)media coverage of high-tech prostheses and the performances of media figures are a source of contradictory injunctions. Held up as a (ableist) model to be followed, this narrative around the fixed/enhanced body leads, in contrast to the enchanted narrative, to profound disenchantment and disillusionment for some amputees, with significant effects on their healthcare and life paths.

# Deconstructing ableist paradigms and injunctions: the contemporary development of new individual and collective narratives

- The previous two parts highlighted the way in which stories about amputation and prosthetic limbs are driven by values of performance and power. From the amputee soldier to the bionic man and the top-level sportsman, these are all figures who embrace ableist norms. This vision of the disabled person who surpasses him/herself in order to be assimilated into the world of the able-bodied and, more broadly, into the dominant norms<sup>43</sup>, amply echoes the figure of the « supercrip », described by Eli Clare<sup>44</sup>. Supercrip is a way of performing disability, promoting the values of surpassing oneself, competitiveness and individuality<sup>45</sup>, with the aim of normalizing disability in able-bodied society. In so doing, supercrip « reinforces the superiority of the nondisabled body and mind »<sup>46</sup> and perpetuates the hierarchical mechanisms of ableism, by discrediting forms of disability that do not seek to correspond to these values. The rights and place of disabled people in able-bodied society are evolving and changing, but the values inherent in ableism remain very strong and tenacious.
- However, criticism and alternative approaches have gradually emerged in recent years. The politics of difference, described by Charles Taylor, advocates equal recognition of all ways of being and universal dignity<sup>47</sup>. By deconstructing ableist values, people who do not correspond to the dominant norm, or minority identities, should be able to be recognized for what they are and celebrated in their differences<sup>48</sup>. A new narrative then gradually emerges, on this critical basis, in a contemporary context that tends to renew the image we have of the amputated body or its prostheses and to become aware of the need for recognition of identity diversities<sup>49</sup>. This narrative is one of negotiation, or even more, resistance<sup>50</sup> to the dominant ableist norms. For a long time, disabled people, and even more so disabled women, have been excluded from narratives of beauty, whose collective criteria seem incompatible with disability<sup>51</sup>. The recent emergence of the « body positive movement » is encouraging us to question these norms and change these narratives<sup>52</sup>, calling for a more inclusive acceptance of beauty<sup>53</sup>. Kelly Knox, a young transradial amputee, puts this approach into words on the website of Alternative Limb Project, a company that manufactures prostheses with a subversive aesthetic:

I want to change the way society perceives disability—showing disability can be cool, fashionable, beautiful and powerful... it's like my body is a canvas and when wearing an Alternative Limb, I become the art. $^{54}$ 

With regard to amputees more specifically, our different fields of investigation have enabled us to highlight the rapid evolution in the ways in which amputees make their bodies visible. Just a decade ago, most of the people we met in functional rehabilitation, medical consultations or ethnographic interviews were trying to hide their amputation behind realistic or discreet prostheses, and to blend in with the able-bodied<sup>55</sup>. During our last survey, it was striking to see that a significant proportion of the people we met were now trying, on the contrary, to make their prosthesis visible by decorating it with colors or patterns, or by leaving it without any covering<sup>56</sup>. In this case, it is no longer a question of hiding one's condition, as long as it is not considered to be shameful or disgraceful. Like Moussa, a 22-year-old double tibial amputee as a result of Covid-19, who has chosen to leave his prostheses visible:

I want to put an identity with the prostheses, I didn't want to tell myself that I'm hiding, I don't really like to say hiding my « difference »... But rather my « particularity » we'll say. I want to show it off, expose my particularity.<sup>57</sup>

Further down the line, some people claim that this approach is a genuine attempt to normalize disability in the face of ableist injunctions, like Claude, 50, a tibial amputee as a child following a road accident, who encourages the visibility and reappropriation of the prosthesis as a tool for self-assertion:

From the moment you start using this object and looking at it as an attribute, like a tattoo for example, you start accepting it on yourself, because it can also become a weapon, it allows you to stand out from others [...] and you start accepting it, and above all you start showing it off, you start showing yourself off, so you start asserting yourself. 58

But while this type of narrative is becoming more and more common these days, it still seems difficult to break away completely from ableist paradigms and expectations. One of the side effects of this more « positive » visibilization of disabled or different bodies is the forced construction of a narrative with heroic connotations, used as an example or collective model. This trend, greatly accelerated by the development of social networks, is known as « Inspiration Porn »<sup>59</sup>. A relatively recent phenomenon, it highlights stories associated with the supposed courage to live as a disabled person, and features « fantasies of survival [...] with personal stories from disabled people touching the non-disabled user deeply, motivating them to share this trope »<sup>60</sup>. In the same vein as the « supercrip » figure, the aim here is to make people believe that the disabled condition is being normalized, while still keeping it separated from the ablebodied condition, and valuing or retaining only those traits that correspond to collective ableist values. This is only an apparent subversion of the ableist system, hidden behind the veil of benevolent inclusion and openness to different bodies.

Further on, while ableist injunctions seem to be gradually being resisted by the people concerned, the narratives and images of amputees are not immune to other forms of dominant injunctions. The amputees currently covered by the media and set up as a collective model, although seeking to challenge and go beyond the ableist vision, remain firmly anchored in the promotion of young, white, beautiful, smooth and hygienized profiles<sup>61</sup>. We might think here of Viktoria Modesta and Tilly Lockey, contemporary icons of the amputee body fitted with atypical prostheses, whose committed discourse and militant stance have been analyzed by Léna Dormeau and Amélie Tehel<sup>62</sup>, who emphasize the underlying need for exemplarity in both their approach and public image. While their commitment is to change the image of disability, they still never show themselves without their prostheses, paradoxically hiding their bodies while advocating the recognition of different bodies. It therefore appears that even the claimed dynamics of resistance to ableism remain limited and constrained in their application. However, while we are showing here the limitations that still underlie this system, we should nevertheless remember that more and more of the people concerned are now taking the public stage, putting forward their own stories and sharing their narratives with the community. Some examples are the young French Nelia Keciri and the American Kristi Loyall, who present their post-amputation journeys transparently on social networks<sup>63</sup>. This is a significant and beneficial contemporary consequence of all these dynamics of resistance to the ableist hegemony, which are sometimes still in their early stages.

# Conclusion

- From the end of the 19th century to the present day, the stories told about (and by) amputees fitted with prosthetic devices are part of a historical process of change. As we have highlighted throughout this article, the ideological filter of ableism is at the heart of the construction of collective narratives in the 20th century around the figure of the amputee soldier « fixed » by prosthetic devices. From this figure of the soldier to that of « bionic » amputee women and men « enhanced » by prosthetic devices, the first two decades of the 21st century marked a turning point with a transformation of collective narratives, combining techno-enchantment and physical performance, disseminated via the growing media coverage of remarkable figures of amputees fitted with prosthetic devices. In opposition to and in addition to this dominant narrative, other individual and collective narratives are emerging and spreading. As part of a process of empowerment, they are deconstructing these heroic and techno-enchanted narratives and encouraging people to free themselves from the influence of ableist norms. The emergence of these new narratives is an ongoing process, paving the way for a paradigm shift and a change of normative model within contemporary Western societies (more specifically in Europe and North America).
- 22 While a necessary shift is underway, the ethnographic work carried out in close proximity to amputees nevertheless invites us not to overlook the diversity of their individual narratives, and to be careful not to essentialize them or categorize them in a simplistic, dichotomous way. Between collective and individual narratives, the relation to ableist norms remains ambivalent and oscillates, depending on the individual, to varying degrees, between rejection and aspiration. The path of life before and after, and the particularity of having been «able-bodied» before facing the life ordeal of amputation, must be taken into account, and for some people also give cause to think about their identification with and attachment to the dominant ableist norms. Between the importance of the critical discourse of deconstruction and the variation in the trajectories, experiences and stories of the amputees we interviewed, it is the complexity of reality and its current mutations that come to light. It is in this sense that we believe amputees fitted (or not) with prosthetic devices to be a particularly rich socio-anthropological analyzer, as they give us so much to think about, to question, and to build new frameworks, based on the refusal of hegemonies, the highlighting of plurality and inclusivity.

# **NOTES**

- **1.** Gabaude, Florent, « Représentations du corps prothétique de la Renaissance à aujourd'hui », Les Cahiers du MIMMOC [Online], n° 26, 2021.
- 2. Sticker, Henri-Jacques, Corps infirmes et sociétés. Essais d'anthropologie historique, Paris, Dunod, 2005.

- **3.** The decision to focus our study on European and American societies is justified by the resonance effect that exists between these two geographical and cultural zones, as well as the concordance in the evolution of prosthetic technologies.
- **4.** Ableism is defined by Fiona Campbell as a « network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human. Disability then is cast as a diminished state of being human ». Campbell, Fiona, « Inciting Legal Fictions: "Disability"s' Date with Ontology and the Ableist Body of the Law », *Griffith Law Review*, vol. 10, n° 1, 2001, pp. 44.
- **5.** Winance, Myriam, « Pourriez-vous être politiquement correct lorsque vous parlez des personnes handicapées ? Sur la force du discours dans le champ du handicap », *Handicap Revue de Sciences humaines et sociales*, n° 97, 2003, pp. 54-70.
- **6.** Friedmann, Lawrence W., « Amputations and Prostheses in Primitive Cultures », *Bulletin of Prosthetics Research*, vol. 10, n° 17, 1972, pp. 105-138.
- 7. Sellegren, Kim, R, « An Early History of Lower Limb Amputations and Prostheses », *The Iowa Orthopedic Journal*, vol. 2, 1982, pp. 13-27.
- 8. Kirkup, John, A History of Limb Amputation, London, Springer, 2007.
- **9.** Vesselle, Benoît, « Amputation et appareillage du membre inférieur pendant la Révolution et l'Empire », *Histoire des sciences médicales*, tome 48, n° 3, 2014, pp. 327-338.
- 10. Delaporte, Sophie, « Le corps et la parole des mutilés de la grande guerre », Guerres mondiales et conflits contemporains,  $n^{\circ}$  1, 2002, pp. 5-14.
- 11. « Si le défilé du 14 juillet, par la mise en avant du cortège de mutilés de guerre, consacre la reconnaissance de la nation à l'égard de ceux qui ont souffert dans leur chair pour sa défense, il traduit également une forme d'héroïsation de la blessure reçus à la guerre, et par là, une certaine valorisation des mutilés. » *Ibid*, p. 6.
- **12.** Jordan, Brian Matthew, « "Living Monuments": Union Veteran Amputees and the Embodied Memory of the Civil War », *Civil War History*, vol. 57, n° 2, 2011, p. 141.
- **13.** « La négation de la douleur a sans aucun doute contribué à favoriser le "retranchement" des amputés dans le silence. », Delaporte, Sophie, *op. cit.*, p. 13.
- **14.** Jordan, Brian Matthew, « "Living Monuments": Union Veteran Amputees and the Embodied Memory of the Civil War », *op. cit.*, pp. 121-152.
- **15.** Whitehouse, Phineas, « Letter to 'Soldier Brothers'« (dated May 20, 1865), *The Soldier's Friend*, June 1865; Quoted in Jordan, *op. cit.*, p. 130.
- **16.** Dardot, Pierre, Laval, Christian, La Nouvelle Raison du monde. Essai sur la société néolibérale, Paris, La Découverte, 2009, p. 438.
- 17. Sticker, Henri-Jacques, Corps infirmes et sociétés. Essais d'anthropologie historique, op. cit., p. 146.
- **18.** Monet, Jacques, « Naissance de la kinésithérapie et de la physiothérapie. L'émergence des instituts de rééducation (1880-1915) », Journal de réadaptation médicale: pratique et formation en médecine physique et de réadaptation, vol. 30, n° 4, 2010, p. 168.
- **19.** Brégain, Gildas, *Pour une histoire du handicap au XX<sup>e</sup> siècle. Approches transnationales (Europe et Amériques)*, Rennes, Presses Universitaires de Rennes, 2018, p. 101.
- **20.** Fourny, Philippe, *Homo erectus : le combat d'une profession*, Paris, Le Cherche Midi, 2011.
- 21. « L'activité par excellence, comme valeur occidentale centrale concernant les hommes, est l'activité productive, la capacité de travail. "Accidenté, récupère ta capacité de travail" dit la maxime gravée sur la plaque inaugurale datée de 1967 du Centre de réadaptation de Québec construit pour sa clientèle par la Commission des accidentés du travail. », Fougeyrollas, Patrick, « L'évolution conceptuelle internationale dans le champ du handicap : enjeux socio-politiques et contributions québécoises », *Perspectives interdisciplinaires sur le travail et la santé*, n° 4-2, 2002 [Online], p. 3.

- **22.** « Mon métier, j'étais dans l'imprimerie. J'étais capable de pouvoir reprendre mon métier. [...] Mais seulement le patron me dit : "Avec votre salaire, je peux rembourser deux personnes, donc on va 's'arranger'"... Il m'a licencié. » Interview conducted in May 2021.
- **23.** Paccaud, Laurent, Baril, Alexandre, « Corps dérangeant, corps dégenré : performer la féminité supercrip dans le milieu du powerchair hockey et du blogage », *Recherches féministes*, vol. 34, n° 1, 2021, pp. 161-179.
- **24.** For more details, see the historiography written by Gildas Brégain, Pour une Histoire du handicap au  $XX^e$  siècle. Approches transnationales (Europe et Amériques), op. cit.
- 25. 62 years old, physical medicine and rehabilitation (PMR) physician.
- 26. « Ça a évolué sur le fond et la forme. Les patients sont beaucoup mieux pris en charge avant, pendant, après amputation. Puis l'appareillage a beaucoup évolué. Et c'est de plus en plus sophistiqué comme prothèse aux membres sup et toujours très bien remboursé par la sécurité sociale française par rapport à d'autres pays. Et puis, à mon arrivée ici [en centre de réadaptation], il y a 32 ans [en 1989], il y avait 2 ou 3 types de genou mécanique, il n'y avait pas de genou électronique, maintenant il y a des types de genoux mécaniques différents et une demidouzaine de genoux électroniques. Ça a "explosé" surtout au niveau des membres supérieurs. C'est fascinant comme progrès. Les prothèses sont plus fiables, plus légères, plus performantes, plus esthétiques. » Interview conducted in February 2021.
- 27. 47 years old, traumatic femoral amputee for 23 years.
- 28. « Comment on revit avec une prothèse, surtout maintenant depuis les [genoux électroniques] … en plus avant je n'avais même pas un pied avec une lame de Carbone. J'ai eu l'expérience de beaucoup de choses quoi... Au départ, je n'avais pas non plus de manchon en silicone, ils étaient en cuir. L'été, c'était de la folie, ils étaient tout trempés, ils n'avaient pas le temps de sécher. [...] Tout cela, ça a changé la vie, c'est le jour et la nuit. » Interview conducted in February 2013.
- **29.** Gourinat, Valentine, Groud, Paul-Fabien, Jarrassé, Nathanaël, «L'ambivalence de l'enchantement prothétique contemporain », Gourinat, Valentine, Groud, Paul-Fabien, Jarrassé, Nathanaël (dir.), *Corps et prothèses*, Grenoble, PUG, 2020, pp. 189-209.
- **30.** Musso, Pierre, « Le technocorps, symbole de la société technicienne », Munier, Brigitte (dir.), *Technocorps. La Sociologie du corps à l'épreuve des nouvelles technologies*, Paris, Les Editions Nouvelles François Bourdin, 2013, pp. 121-144.
- **31.** Marcellini, Anne, Vidal, Michel, Ferez, Sylvain, De Léséluc, Eric, « "La chose la plus rapide sans jambes". Oscar Pistorius ou la mise en spectacle des frontières de l'humain », *Politix*, vol. 23, n° 90, 2010, pp. 139-165.
- **32.** Groud, Paul-Fabien, « L'analyseur institutionnel Oscar Pistorius : un entrelacement fallacieux entre altérité du handicap, technologie prothétique et corporéité (handi)sportive », *Illusio*, n° 14-15, 2016, pp. 570-595.
- Richard, Rémi, Marcellini, Anne, Pappous, Athanasios Sakis, Joncheray, Hélène, Ferez, Sylvain, « Construire et assurer l'héritage des Jeux olympiques et paralympiques. Pour une inclusion sportive durable des personnes vivant des situations de handicap », Movement & Sport Sciences Science & Motricité, n° 107, 2020, pp. 41-52.
- **33.** « Hugh Herr, l'homme réparé grâce aux prothèses biomimétiques », *Journal de 20h de France 2*, 23 mars 2015.
- **34.** Andrieu, Bernard, *Le Corps capacitaire. Une performativité du vivant*, Nanterre, Presses Universitaires de Paris Nanterre, 2018.
- 35. Sticker, Henri-Jacques, Corps infirmes et sociétés. Essais d'anthropologie historique, op. cit.
- 36. Goffman, Erving, Stigmate, les usages sociaux des handicaps, Paris, Edition de Minuit, 1975.
- **37.** Dolezal, Luna, « Representing Posthuman Embodiment : Considering Disability and the Case of Aimee Mullins », *Women's Studies*, vol. 1, n° 46, 2017, pp. 60-75

- **38.** Gourinat, Valentine, « La prothèse comme promesse de réparation du corps amputé : du discours à l'expérience », Lindenmeyer, Cristina (dir.), L'Humain et ses prothèses : Savoirs et pratiques du corps transformé, Paris, CNRS Editions, 2017, pp. 155-170.
- Gourinat, Valentine, Groud, Paul-Fabien, Jarrassé, Nathanaël, Corps et prothèses, op. cit.
- **39.** 73 years old, transfemoral amputee following a staph infection.
- **40.** « Mais attendez, quand... Quand vous... tapez "prothèse" sur le... sur internet, qu'est-ce que vous voyez ? [Pi]storius en train de, de... [Pi]storius en train de courir. [...] Non mais ça c'est... aberrant! [Alors que] c'est le parcours du combattant. Vraiment! [...] Mais je pense que c'est de l'ignorance. C'est de l'ignorance! » Interview conducted in July 2016.
- 41.59 years old, physiotherapist.
- 42. « Il y a beaucoup de personnes amputées traumatiques qui décident de faire du sport après une amputation parce qu'elles ont vu des vidéos de soi-disant hommes amputés augmentés. Même si la volonté d'avoir une pratique sportive est moteur de la rééducation et dans la vie post-amputation, ces images rendent cependant difficile notre travail en rééducation, car nous sommes obligés de leur rappeler que l'homme amputé augmenté n'existe pas. Il est parfois difficile de faire passer ce message auprès de ces patients qui souhaiteraient avoir de suite la dernière prothèse high-tech vue sur internet. » Interview conducted in June 2019.
- 43. Goodley, Dan, Dis/ability Studies: Theorising Disablism and Ableism, Routledge, 2014.
- 44. Clare, Eli, Exile and Pride: Disability, Queerness, and Liberation, Duke University Press, 2015.
- **45.** Paccaud, Laurent, Baril, Alexandre, « Corps dérangeant, corps dégenré : performer la féminité supercrip dans le milieu du powerchair hockey et du blogage », *Recherches féministes*, vol. 34, n° 1, 2021, pp. 161-179.
- 46. Clare, Eli, Exile and Pride, op. cit., p. 2.
- **47.** Taylor, Charles, « The Politics of Recognition », Gutmann, Amy (ed.), *Multiculturalism : Examining the Politics of Recognition*, Princeton University Press, 1994, pp. 25-73.
- **48.** Loja, Ema, Costa, Maria Emília, Hughes, Bill, Menezes, Isabel, « Disability, Embodiment and Ableism: Stories of Resistance », *Disability & Society*, 2013, vol. 28, n° 2, pp. 190-203.
- 49. Gutmann, Amy (ed.), Multiculturalism: Examining the Politics of Recognition, op. cit.
- **50.** Thomas, Carol, Female Forms: Experiencing and Understanding Disability, McGraw-Hill Education, 1999. Loja and al., op. cit.
- **51.** Garland-Thomson, Rosemarie, «Integrating Disability, Transforming Feminist Theory », *NWSA journal*, 2002, pp. 1-32.
- **52.** Sastre, Alexandra, « Towards a Radical Body Positive : Reading the Online 'Body Positive Movement'«, *Feminist Media Studies*, 2014, vol. 14, n° 6, pp. 929-943.
- **53.** Cohen, Rachel, Irwin, Lauren, Newton-John, Toby, Slater, Amy, « #bodypositivity : A Content Analysis of Body Positive Accounts on Instagram », Body Image, 2019, vol. 29, pp. 47-57.
- **54.** https://thealternativelimbproject.com/in-depth/kelly\_knox/
- **55.** Gourinat Valentine, « Vivre avec une prothèse de jambe : hybridité sociale et malentendus identitaires », Hintermeyer, Pascal, Le Breton, David, Profita, Gabriele (ed.), *Les Malentendus culturels dans le domaine de la santé*, Nancy, PUN, Editions Universitaires de Lorraine, 2016, pp. 303-313.
- **56.** Dalibert, Lucie, Gourinat, Valentine, Groud, Paul-Fabien, « Visibles et invisibles : approche socio-anthropologique des stratégies et pratiques de dissimulation et de monstration des corps amputés appareillés », Kondratuk, Laurent (ed.), *Monstration, dissimulation, mouvement du corps dans l'espace public*, Presses Universitaires de Franche-Comté, 2023.
- 57. « Je veux mettre une identité avec les prothèses, je ne voulais pas me dire que je cache, je n'aime pas trop dire cacher ma "différence"... Mais plutôt ma "particularité" on va dire. Je veux l'exposer, exposer ma particularité. » Interview conducted in February 2021.
- **58.** « A partir du moment où cet objet, on arrive à l'utiliser et à le regarder comme un attribut, comme un tatouage par exemple, donc on l'accepte sur soi, car ça peut aussi devenir une arme, ça

permet de se démarquer par rapport aux autres [...] et on arrive à l'accepter, et surtout on arrive à le montrer, on arrive à se montrer, on arrive donc à s'imposer. » Interview conducted in July 2010.

**59.** Young, Stella, « We're not Here for Your Inspiration », ABC Ramp Up website, 2012, http://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006

Young, Stella, « I'm not Your Inspiration, Thank you Very Much » TEDx- Sydney online video, 2014, http://www.ted.com/talks/

stella\_young\_i\_m\_not\_your\_inspiration\_thank\_you\_very\_much ?language =en#t-539335

- **60.** Haller, Beth, Preston, Jeffrey. «Confirming Normalcy: 'Inspiration Porn' and the Construction of the Disabled Subject? », Disability and Social Media, Routledge, 2016. pp. 63-78.
- **61.** Dalibert, Lucie, « Remarquables mais non (re-)marqués : Le rôle du genre et de la blanchité dans les représentations des corps technologisés », *Poli-Politique de l'image*, 2015, vol. 10, pp. 50-59.
- **62.** Dormeau, Léna, Téhel, Amélie. « "Je suis le prototype": femmes bioniques et "empuissancement" subalterne ». *Recherches féministes*, 2021, vol. 34, n° 1, pp. 255-272.
- 63. https://www.youtube.com/channel/UCB4B4VIEdEdOkWVsE86v84w https://www.instagram.com/onefootwander/?hl =fr

# **ABSTRACTS**

This article traces the evolution of the image of the amputated body fitted with prosthetic devices in collective and individual narratives from the early 20th century to the present day in European and North American societies. As these narratives are persistently permeated by an ableist lens and ideology, they are not devoid of socio-political issues and consequences for the people concerned. Based on these narratives, this paper proposes a socio-anthropological analysis of their historical development and their impact on representations of disability, insofar as they are a tool for transmitting social and collective values. More specifically, the aim is to question the fascination with prosthetics and the culture of the high-performance amputee body, which are vectors of ableist injunctions and ideals. The aim is also to highlight the complexity and variety of individual approaches in the face of persistent and collective normalisation over time.

Cet article retrace l'évolution de l'image du corps amputé appareillé dans les récits collectifs et individuels de la fin du XIX<sup>e</sup> siècle à nos jours dans les sociétés européennes et nord-américaines. Ces derniers étant traversés de façon persistante par un filtre et une idéologie validistes, ils ne sont pas dénués d'enjeux socio-politiques et de conséquences sur les personnes concernées. Se basant sur ces récits, cette contribution propose une analyse socio-anthropologique de leur évolution historique et de leurs enjeux sur les représentations du handicap, en tant qu'elles sont un support de transmission de valeurs sociales et collectives. Cette réflexion vise plus spécifiquement à remettre en question la fascination prothétique et le culte du corps amputé performant, vecteurs d'injonctions et d'idéaux validistes. Il s'agit aussi de montrer la complexité et la variété des approches individuelles, face à une normalisation collective et persistante inscrite dans le temps.

Este artículo trata de la evolución de la imagen del cuerpo amputado protésico en los relatos colectivos e individuales del fin del siglo XIX hasta hoy en día en las sociedades europeas y

norteamericanas. Dado que estos relatos están impregnados de forma persistente por un filtro y una ideología validistas, no están exentas de cuestiones sociopolíticas y de consecuencias para las personas afectadas. A partir de estos relatos, este artículo propone un análisis socioantropológico de su evolución histórica y de su impacto en las representaciones de la discapacidad, en la medida en que son un medio de transmisión de valores sociales y colectivos. Más concretamente, se trata de cuestionar la fascinación por las prótesis y el culto al cuerpo amputado de alto rendimiento, vectores de preceptos e ideales validistas. También se pretende mostrar la complejidad y la variedad de los enfoques individuales frente a una normalización colectiva persistente en el tiempo.

# **INDEX**

**Mots-clés:** amputation, prothèse, validisme, récits collectifs et individuels, normes **Palabras claves:** amputación, prótesis, validismo, relatos colectivas e individuales, normas **Keywords:** amputation, prosthesis, collective and individual narratives, ableism, norms

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