Cripping assistive tech design
How the current disability framework limits our ability to create emancipatory technology

Enka Blanchard

Abstract Recent advances in assistive technologies have blurred the lines between compensating for impairments — for disabled users — and augmenting capabilities — such as with cobotic systems. This article examines how assistive technologies generally seek to compensate for a single deficiency, as opposed to being more generalist tools meant to improve the lives and autonomy of (not necessarily) disabled users. It starts with a brief presentation of the different frameworks used to model disability in the social sciences, and how some of these frameworks could be used to boost creativity in the design of assistive devices. It then showcases a series of examples where innovative design ideas allowed for devices that go beyond trying to fix disability and instead liberate their users. The article concludes with a reflection on the ethical interactions between transhumanism and disability, as well as the possibilities created by new distributed design/construction networks affiliated with open-source/open-design models. This reflection can serve as a basis for a discussion about the necessary evolution of industrial practices in the design of assistive technologies, no matter whether they are designed to compensate impairments or augment capabilities.

Key words: User-centred design; Prosthesis; Assistive technologies; Disability studies; Transhumanism; Crip theory

1 Introduction: a wheelchair's purpose

What is a wheelchair's purpose?

The many answers to this question often use the imagery of compensation and rehabilitation: "giving access to what isn't accessible without functional legs (or balance, or a myriad other impairments)". However, if we turn away from the concept of impairment for a minute, a wheelchair's purpose is to maximise the user's

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autonomy and freedom to explore and participate in the world in a comfortable way. A more interesting question would then be:

Why don't all motorised wheelchairs include USB charging ports for phones?

There are of course technological, financial and logistical reasons[1] but they don't seem fully convincing when we consider how wheelchair users can be even more critically dependent on their cellphones. This article explores the possibility that this is not through a glaring flaw in designers' imagination but instead due to the main frameworks used when designing such products. This echoes van de Poel and van Gorp's reflections on *radical* versus *normal* design [51]. Using their terminology, even if a designer intends a radical reimagining of an assistive device's *design*, they might not adopt a radical reimagining of the device's *function*.

This article will focus on the assistive technologies for disabled users, and more specifically on power-wheelchair design[2]. However, the arguments below also apply to technologies seeking to redress *relative impairments* (such as the difficulty in orienting oneself without GPS), when compared to robots (which especially applies when trying to collaborate with them). After all, there are similarities between designing systems that require interaction between humans and robots [36], and between humans with mixed abilities [32]. Going back to the question on the lack of USB-charging wheelchairs, the product design of assistive technologies is enmeshed in the ways we tend to think about disability. Designers operating in traditional frameworks that see disability as a problem to be solved naturally tend to design compensations for the perceived deficiencies. To invent technologies that can be truly emancipating then requires acknowledging and questioning the assumptions ingrained in these frameworks.

The article starts with a quick introduction to the various models of disability that have been developed within the field of disability studies. This leads to a reflection on the methodologies of product design, followed by the concrete example of power-wheelchair design. Finally, we cover the relationships many users have with their devices and how they sometimes reclaim said devices, and finish with the links between these reflections and transhumanism.

2 Models of disability

The past forty years have seen the emergence of many theoretical frameworks to address the questions of disability in society. Based on a rejection of the previously established *medical model*, multiple theories were developed to address its limita-

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[1] There can also be legal and insurance reasons but the existence of wheelchairs with such extensions show that they are not insurmountable. On a technical side, adding this feature might increase the complexity somewhat — to handle the cable and the voltage difference — but the impact on the batteries would be negligible: few phones boast more than 20Wh batteries, whereas many wheelchairs' batteries exceed 1kWh.

[2] Manual wheelchairs have different external constraints on their design, *normal, non-radical* design can focus on technical constraints [34], although counter-examples exist [12].

tions and negative effects, one of the earliest one being the *social model* [40]. This was extended in many directions, such as the minority, cultural or relational models (all having anchoring in specific societies) [18, 31]. However, if these frameworks are by now well known within the fields where they originated and in activist circles, their impact outside the social sciences has been more limited. A very brief summary of the two central models seems appropriate before addressing the central question of this paper (a more complete introduction can be found in the first chapter of [21]).

The medical model is not so much a conscious creation as a theorisation of the default mode of considering disability in modern western societies. It views disability as a tragedy and as a medical problem situated in the individual — with no difference made between impairment and disability. The disabled individual is partially responsible for their health outcomes, especially if they do not follow the advice of medical professionals. The end goal of society's interaction with disability is to get rid of it — principally through cure, although institutionalisation and preventive eugenics are also considered. Assistive devices are meant to help the individual conform to society's expectations (walking, remembering, being fully autonomous). Researchers are expected to improve disabled people's livelihood — according to their notions of "improving" — but aren't encouraged to engage them as co-researchers or experts.

The social model (with its many variants and descendants) locates the disability not in the individual (who has an impairment preventing certain actions) but in society. Disability emerges from barriers created by society, which can be physical (the choice to build stairs and not ramps), but more often social (expecting people to be physically present for many activities), and often linked to discrimination and negative stereotypes (causing social isolation and economic dependence). Society's goal is to integrate impaired individuals through political, economic and educational policies. Researchers who address these issues are often disabled themselves and linked to disability activism circles (and trained in social science or humanities). This model is one of the most studied (and critiqued) and has links outside of the field, for example to Amartya Sen's capabilities framework [6].

Beyond the various models, this article is mostly inspired by crip theory, which is not so much a framework as a lens through which to see disability studies — mostly inspired by queer studies. One of its main elements is to critique the notion of normality and the abled/disabled dichotomy. In our present context of technological design, cripping can be interpreted as the move from trying to fix/fit the individual to the system using assistive devices[3] to instead finding how those devices can emancipate the individual [23]. Echoing more social concerns[4], the question of *who* is disabled — and hence the ideal target user — becomes secondary. Doing away

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[3] A pure social model approach would be not to use assistive devices but instead to change the expectations through policy-making, which is no always doable or desirable.

[4] The policing of who is and isn't disabled has been a point of friction between disabled activists and other groups (with the former arguing against all forms of policing), as concerns of "faking disability" are widely spread [13], which prevent many disabled people from using their rights in public for fear of being harassed [14].

with this question involves designing for all, and reducing the stigma about users of assistive technologies.

3 Designing with and for crips

Telling people (designers and engineers) to include the eventual users in a product's design process is nothing new, and neither is the push for universal design [45] (although there are limits to how universal a design can be, as conflicting access needs sometimes arise [32]).

Just by dint of legal and insurance considerations, putting an assistive device on the market when it hasn't been tested on its target population is probably (and hopefully) a thing of the past, despite testing being difficult, as the target users are often "protected populations" given special considerations in research [48]. However, the work of designing with and for users lies not just in the testing: there are multiple caveats that make user-centred design a non-trivial task when it comes to assistive technology [22]. A first question is whether the eventual users are involved at all stages[5] (including when initially setting the putative goals of the device and its specifications). Due to restricted access to both education and industry, disabled people form a small minority of designers, which often results in designers either foregoing involving disabled people altogether at this step, or "imagining" what the disability feels like.

Uninspired (or too-inspired) designs are a frequent source of both amusement and critique in disabled circles, with unrealistic wheelchairs receiving most of the flak, for example for having oversized wheels that do not allow any easy manual operation[6]. Well-meaning designers can also fall into traps, as with the tandem chair (Figure 1), which features both a design meant to avoid looking like a wheelchair and an additional seat for a companion [50]. The designer purportedly spent months in a wheelchair to figure out the main issues before coming up with his design (it is not evident whether this was entirely by choice but apparently so). However, there is a large difference between choosing to spend a while in a wheelchair — which can feel like a sudden limitation — and being in one for other reasons, where it can be liberating compared to the alternatives[7]. In this case the designer's main issue was how he was perceived by the public, something most crips learn to make their peace with (or fight against). It was not the fear of being stranded or harassed (major motivators in many crips' lives) but the fear of being perceived as disabled and correspondingly devalued which led to his design. The transient nature of the designer's wheelchair experience is precisely what made his takeaway irrelevant.

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[5] "Nothing about us without us" is still a central slogan of the disability rights movement [7].

[6] Many examples of such designs and corresponding flak can be found on https://twitter.com/LeafyQueerCrip/status/1185906442563309571.

[7] Hence the criticism of the term "wheelchair-bound" with the frequent reply "wheelchairs don't confine us, they liberate us" [27], before even addressing the fact that many wheelchair users only use them part-time [25].

This echoes the experiments denouncing ”disabled for a day” workshops where people get to try using assistive devices, which can end up worsening participants' opinion of disabled people [37].

Even if we assume that the target population is actually involved, the question of representativity is not fully resolved. Pre-design studies or even focus groups can be influenced by leading questions which can restrict the eventual feedback's scope [11]. A second concern is that many devices developed within the medical model can be useful to certain individuals, but are considered irrelevant by the majority of the disabled communities. To give just two short examples, recently developed gloves that recognise signing in American Sign Language (ASL) drew the ire of both activists and researchers as they make many simplifying assumptions on ASL [24, 53], but also because they seek to integrate Deaf users by helping them speak (which would precipitate the disappearance of Deaf culture) [19, 46]. Closer to our previous example, stand-up wheelchairs that allow their users to assume a standing position (while being strapped in) are also criticised for similar reasons [4], even as their complex engineering raises questions about the right to repair and the freedom to modify one's own devices [16].

Moreover, taking only the users most readily available for usability testing and goal-setting can lead to major biases — although this is not the most helpful critique, hard-to-reach populations are often true to their name. Cripping assistive technology means making it usable not just by its ideal recipients (patients regularly followed by the medical system, able to use the device as intended, in appropriate conditions and with regular care) but also by all the ones who fell through the cracks of the system. To give a critical example, American HCI researcher Ted Selker tells a story of an experiment on assistive technology for dyslexic users, where the control group performed much worse than the principal one [41, 42]. After a short investigation, the explanation was revealed to be that the recruitment method for the control group (offering a small sum of money via flyers in NYC) had attracted a population that was mostly composed of homeless people who overwhelmingly had disabilities (including dyslexia) for which they were receiving no assistance.

The problems mentioned above can be handled by appropriate methodologies, but some similar problems have no easy solution. Let's consider for example the case of designing wheelchairs for autonomy.

4 Designing for autonomy

When discussing power-wheelchair autonomy, one of the first considerations is battery life and related issues. This has attracted a lot of work, from more efficient batteries to mobility devices with removable batteries (which are often too heavy[8] to be changed by their users). A central goal (showcased in many advertising leaflets) has been to increase the wheelchair's maximal range [39]. However, this still generally

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[8] Due to both airline regulations and economical reasons, lithium batteries are rarely used, and it is not rare for the power supply to represent more than 60% of the device's weight.

assumes that crips move from their homes to their destination and back (a reasonable assumption in practice [15], which alas is a factor of decreased autonomy as it prevents the crips from exploring their environment as they see fit [2]). As such, the wheelchair chargers are often both bulky and heavy, making longer trips much harder. A potential solution would be integrating the charger into the device itself (with a standard plug coming out on a retractable cable), or at least allowing a space to store the charger on the device — but this is nearly never done[9].

However, this is only one small part of the question of autonomy. A much more critical one is the double question of fault-tolerance and maintainability. Wheelchairs are often treated as non-critical personal use devices, despite their role (a broken mobility device can leave its user entirely stranded at home). They seldom integrate measures that could greatly increase mean time between failures, such as having redundancies on the moving parts with lowest MTBF, like potentiometers on mobility scooters[10]. Moreover, due to intellectual property protections, the electronics on such wheelchairs can require expensive proprietary equipment to diagnose, maintain and repair. With the increased industrial concentration and complex logistical chains, this means that a user with a broken potentiometer can be left stranded for multiple months[11]. The end result is that to guarantee their autonomy, some crips have to force redundancy at a higher level, by owning multiple mobility devices — which few can afford. Maintainability is still a mostly ignored concern, but it is central to this extended interpretation of autonomy.

The point where this question gets thorny is when we get to the potential (mutual) reliance on other people. Going back to the tandem wheelchair (Figure 1), it makes two major assumptions which led to criticism. First, it assumes that a central goal for disabled people is not to appear disabled — by getting rid of the "wheelchair stigma" — which many activists take offence to [35, 9]. The second assumption is the potential need for a companion warranting the second seat (which is central to the chair's design). This was criticised as both assuming a need for assistance and creating the image of a "disabled taxi" where the disabled user is valued only through being useful to others — a sensitive point when the value of disabled lives is often questioned [26], sometimes to the point of eugenics. The USB-charging wheelchair can also provide a service to others — and many would be glad to help their friends by serving as a massive mobile battery bank. Crucially, however, this feature is first in service of the users' autonomy. The need for assistance criticism is more complex, as it relates to current debates about the role of both disability and assistive devices in public spaces. Due to how disability is currently viewed

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[9] One of the author's acquaintances had managed to integrate into their wheelchair a device to charge it on public stations for electric cars.

[10] From discussions with technicians tasked with repairs, it appears that on certain mobility scooters models, acceleration potentiometers can account for up to 50% of all failures.

[11] A real-life example would involve a wait of two weeks to get a technician to visit, followed by a week to transport the device to the only workshop in the country and get a diagnosis there, followed by a multi-week wait to obtain a missing part from the only factory still producing them — in a faraway country — after a merger led to multiple factory closures, followed by the repair itself and the delivery, totalling between 2 and 3 months.

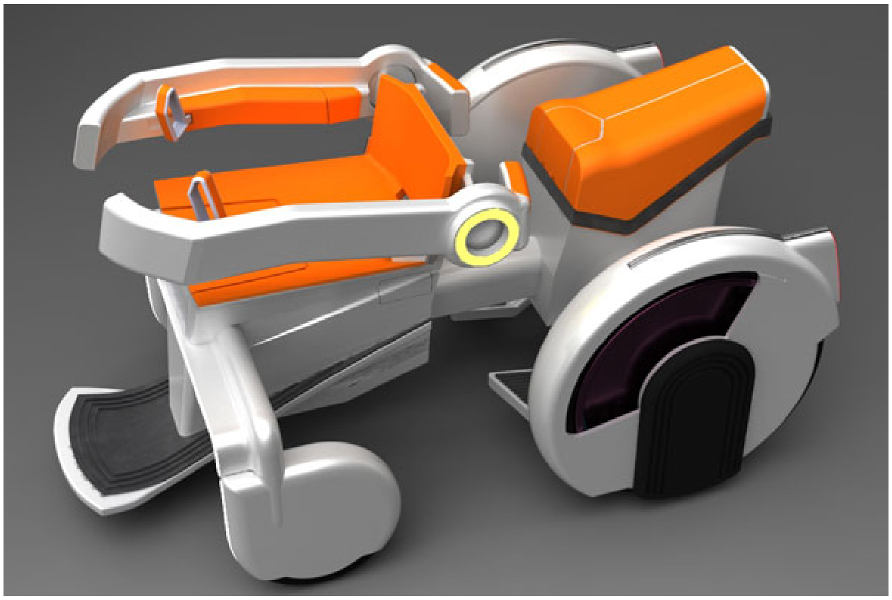

Fig. 1 The Tandem chair. Copyright Alexandre Pain and Yanko Design. Reproduced under fair use/French Intellectual Property Code, article L.122-5-3°a).

in many Western societies, people perceived as disabled can be non-consensually "assisted" in disastrous ways [33]. As such, the simple presence of an element that could indicate a need for help is often seen as an invitation. This is typically the case for wheelchair handles and many manual wheelchairs favoured by disabled activists feature no such handles. In a creative reconfiguration of her assistive device, one activist installed spikes on her wheelchair handles (as removing them is not always feasible), which triggered many negative reactions from non-disabled people [5]. This example serves as both a reminder that there is no "ideal" assistive device, just like there is no representative wheelchair user — some often need assistance and will want handles, others will fight against their presence. Autonomy sadly does not allow one-size-fits-all solutions. Without being discouraged by this, let us now showcase a few examples where users creatively reconfigured their devices, or where inspired designers managed to extend the realm of possibilities.

5 Recuperation, reconfiguration and design outside of the box

By necessity, many crips are also makers, and learn to modify their environment to suit their needs (sometimes with the help of others such as the e-nable program[12]) [23]. A common practice is to transform one's devices or prostheses into

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[12] See https://enablingthefuture.org/.

works of art and going beyond their purely functional design by painting them or making sculptures out of them. This challenges their roles as sites of shame and allows the owner-user to appropriate the device (which generally has a positive impact on their mental health) [52]. They can also serve as pieces that have both an activist/aesthetic role and a functional impact for their users. Fellow researcher Ashley Shew has the habit of putting googly eyes on her prosthesis, which "stare back" when stared at, making observers realise that they are currently staring and hence affecting their (un)social behaviour (Figure 2).

Fig. 2 Ashley Shew's foot prosthesis collection, featuring googly eyes and/or art. Reproduced with permission from the author.

The modified devices themselves are not always works of art but can be tools to create them, as with Jessica Tang's flutes made from crutches [20]. Crutches are good targets for reconfiguration, as they allow for many potential uses beyond helping one's balance : adding a pouch to one can help carry small items (such as phones), and — just like canes — they are often used to push, bring closer or grab small items that are slightly out of hands' reach.

The latter use has actually managed to get an impact outside of maker circles to inspire industrial designers to create canes that double as functional grabbers[13]. But — despite seldom doing it in a fashion that would be called cripping — there

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[13] See for example https://reachergraspercane.com/.

is one professional field which has made most progress in thinking in terms of new possibilities: biomedical engineering. The first such "object" is the audio induction loop, which is generally meant to compensate for a hearing impairment but in reality gives users an extra sensory apparatus: being able to directly perceive certain electromagnetic signals as auditory information. Recent research in ocular implants has similarly studied the possibility of using thermal imaging to improve people recognition despite using very limited visual resolution, although this remains a recent experimental technique [17, 10].

Beyond the strict confines of disability — and issues directly linked to disability — the questioning of the normative framework in transgender medicine gives us a last example. Until very recently, gender confirmation surgery — also called sex reassignment surgery — had as central objective of getting an individual as close to possible to an "ideal" version of either binary set of genital organs (and secondary characteristics). Some surgeons[14] are now creating procedures adapted to non-binary people and to those who for any reason do not want to get close to this binary, by asking people what their ideal would be like and then trying to adapt or create the appropriate procedure (some of those procedures are known as penile-preservation vaginoplasty, labiaplasty without vaginoplasty, or nullification).

6 Perspectives: crips in industrial transhumanism

As shown in the examples above, thinking out of the box when designing assistive devices invariably takes researchers and designers away from "fixing" humans into "expanding/improving" humans, and hence well into the realm of transhumanism. This means that we have to address many ethical questions, especially when it comes to biomedical engineering. This is a complex endeavour well beyond the purview of this article. Thankfully, many answers can be found in a long history of scholars — crip or not — both using disability to address transhumanism and the role of crips and their devices in industrial futures [49, 38, 47, 29]. Some also question the role of disability in the many thought experiments used on the subject [43].

However, even as we avoid the question and direct the reader to other works, we must be careful in the framing of the issues. Trying to emancipate crips through assistive tech design should not be interpreted as entering a fraught field where we must think about the dangers of foregoing the status quo. Or rather, the status quo should be understood as already far from an imagined state of nature, as current and past biopolitics are far from neutral on the subject of disability [3, 1, 30, 8]. Influenced by the medical model, most of our visions of the future tend not to feature any form of disability, unconsciously assuming its eradication, through either eugenics or "fixing" [28] — although exceptions do exist [44]. The questions must be asked, but just as we examine the frameworks that constrain our creativity when it comes to

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[14] Such as Dr. Heidi Wittenberg of Mozaic Care (https://www.mozaiccare.net/). The procedures are recent enough that finding peer-reviewed resources on them is still difficult in 2021.

developing emancipating technology, we must wonder if exploring the frontiers of "beyond human" is not justified when the alternative is often seen as "sub-human".

Getting back to assistive tech design, how can we go forward? Stating that we need to expand our creativity and involve disabled users more thoroughly is not an actionable plan that differs from recommendations made over the last two decades. Thankfully, there are more concrete steps that can be taken. First, an immediate priority is to generalise thinking about assistive technologies in terms of maintainability and tolerance-to-faults. As said previously, these are at best secondary concerns in wheelchair design today, but this problem also affects most types of assistive technologies (from cochlear implants to diabetic glucose monitors[15]). Both aspects are important: even if the device is maintainable, a low MTBF makes the user in need of regular assistance if they can't maintain it themself. Reciprocally, a resistant device can push its user to take more risks, and bring it to places where spare parts are hard to obtain. This is especially true when designing assistive devices for sale in low-and-middle-income countries, where the ability to fashion replacement parts locally would be privileged. This finally brings us back to the e-nable network mentioned in the previous section. Such networks bring together designers, users, and owners of fablabs and other workshops, providing a great model to further develop open-source and open-hardware systems — which generally emphasise maintainability by default. Using those, creating emancipatory assistive technologies and putting them in the hands of all who need them becomes an achievable goal.

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[15] For glucose monitors, there is in fact one "redundancy" in that users whose device fails still have their own sensations to alert them if something's wrong, albeit with higher risks.

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