

Spatialités et temporalités du handicap II : une typologie systématique des taxes temporelles

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1. Paying the #CripTax

Introduced at least two decades ago (Weeber, 1999), the concept of *crip*^[1] tax has since been developed and expanded to analyse and denounce the many ways in which society imposes additional costs on disabled people. This *crip* tax is generally seen in a financial light, from the much higher cost of braille and audio books to the rare reimbursement of mobility aids. Social costs have also been decried, especially when it comes to restrictive disability policies that expect potential recipients to out themselves and have to explain — and prove — their status to receive assistance (Siebers, 2004). Although temporal costs have been briefly mentioned, they have received little formal study until now. This article focuses on this temporal part of this *crip* tax, and all the ways by which society imposes additional temporal costs to its members with various disabilities.

We aim to extend prior work on the peculiar spatialities of disability by studying the temporalities of disability (Blanchard, 2020A). This is related and inspired by the concept of “*crip* time”, which has been a subject of study for the past three decades, most frequently in activist circles (Zola, 1993). This “*crip* time” can be distended or discontinuous (Samuels, 2017), and can create strange futurities (Kafer, 2013). However, we will look at it not as a subjective experience of time as it is felt internally by people, to instead look at it more externally, from a more materialistic standpoint. More specifically, we will aim to give a formalisation and an analysis of the temporal costs of disability as they were shown in “A travelling *crip*’s temporal expenses” (Blanchard, 2020B). Although the typology introduced here has the goal of being general and applicable to many real temporal costs, we will focus on costs linked to moving around, not just in everyday life but also as a traveler.

The temporal costs introduced will create a form of hierarchy, with each new layer featuring costs that arise as a reaction to the problems shown in the layers underneath. We will look in turn at the six different layers, starting with direct physical costs that are direct consequences of the impairment as the bottom layer. Addressing physical issues created an array of protocols and systems that create new temporal costs : indirect physical costs, costs linked to the reduced autonomy of *crips*, and finally costs due to the organisational overhead. All of this in turn creates some new time sinks that form the top of the hierarchy, comprising costs due to both social interactions and psychological loads. For each layer, we will discuss the costs concerned and give relevant examples. We will also investigate how those costs are perceived by non-*crips*, as this perception — which is often distorted — is a fundamental element of the policies and behaviours that create the upper layers of temporal taxes. Let’s then start with the bottom layer: direct physical costs.

2. Direct physical costs

The simplest cost we can look at is the kind that stems directly from the impairment itself. For example, someone who uses crutches will seldom move as fast as someone who can run. Someone in a wheelchair can be just as fast, but it also depends on the type of wheelchair and whether they have to go uphill or not. This goes beyond the simple task of moving around, and also applies to tasks such as getting dressed or washing dishes. It also concerns some forms of communication slowdown, such as difficulties to type due to limited fine motor control, but also lower speech rates because of cerebral palsy, Parkinson’s disease or other impairments (Pinto *et al.*, 2010).

This is typically the type of impairment that is addressed by the traditional medical model of disability (Llewellyn and Hogan, 2000). If the only temporal costs were in this category, addressing the impairments themselves through therapy and prostheses could conceivably eliminate the issue. But we are currently only on the first and simplest level in the hierarchy.

This brings us to the perception of those direct physical costs, as they are easy to understand and might seem obvious to most people, disabled or not. However, the focus on this kind of cost and the cult of technology as a salutary *deus ex machina* affects this perception. First, it is overly optimistic and looks at the best of what is advertised today, with discussions often centred on exceptional cases like Oscar Pistorius (Swartz and Watermeyer, 2008 ; Burkett *et al.*, 2011), and stories that often follow and reinforce the supercrip^[2] paradigm (Schalk, 2016), making the cripp responsible for their own situation (Harvey, 2015). Second, it only looks at the technology's advantages, and not its drawbacks (from increased risk and painful procedures to eventual malfunctions). Finally, it ignores the unequal access to said technology, and all the administrative, financial, and social barriers that might prevent the cripp from using the technology (Harniss *et al.*, 2015).

We must be careful, as impairments do not just make some actions costlier, they can also make certain actions impossible. We do not include this kind of consideration into the direct physical costs, as it is not a temporal tax. This is mirrored by societal expectations: many would agree that it is not fair that a cripp requires more time to get around or to complete certain mundane tasks. However, if that person says that they want to perform an action that is rendered impossible by disability — at least in the non-cripp's perception — the discourse often changes to be about having reasonable expectations. For non-essential acts, a quantitative difference can be perceived as unfair and requiring correction to compensate. On the other hand, a qualitative difference would be attributed to a natural consequence of disability — seen as a binary and not a spectrum (Sherlaw *et al.*, 2014 ; Fritsch, 2013) — worth pitying the cripp but not worth doing anything to compensate. For example, someone with difficulties in walking long distances often warrants some small changes to their workplace — such as moving their office closer to the bathroom. Someone in a wheelchair would be perceived differently, with the very fact that they deserve an opportunity to work being questioned, even if the only required modification would be a small ramp to get inside the building (Bec and Constans, 2016). All these play a role in the next sections, as we discuss the costs linked to making those “impossible” tasks possible for cripps.

3. Indirect physical costs

The second kind of cost is related to the first, and is created mostly through the management of what would otherwise be “impossible” tasks. It corresponds to all the temporal costs that are directly caused by the use of alternative methods that allow cripps to perform mundane tasks.

The simplest example concerns the many delays that wheelies are used to, with the most obvious being the fact that one has to take the elevator instead of climbing stairs — as that is a typical “impossible” task^[3]. This is innocuous, but often takes a non negligible amount of time, especially in public buildings or when one is going from floor to floor. It can also have a social aspect: if the wheelie is not on the top or bottom floor and the elevators in a building are used by many people, for example at peak hours. The elevator is then partially full each time it stops at the wheelie's floor, and there might not be space to get inside with the people already present. If the people

refuse to get out by letting the wheelie just take the next elevator, this can last almost indefinitely.

A related issue is that of forcing wheelies to take long detours, often to get to elevators. This is very visible in building complexes, especially ones linking old buildings^[4]. Crossing from one building to the next on an upper floor often involves a few steps, whereas the accessible way across sometimes requires leaving the first building — using the elevator — going through the street to the second building and up the elevator^[5].

There is an even more prevalent kind of detour that is hard to notice when walking around, but very much felt by wheelies. Although many Western cities are by now mostly accessible, the existence of an accessible path across the city does not guarantee the existence of a short accessible path^[6]. For example, one can generally cross a street more or less anywhere on foot, but the step to get onto the sidewalk prevents wheelies from doing so, making them depend on curb cuts. Although they are supposed to be standard, some cities feature particularly long stretches without them, forcing the wheelie to go around to find one, and then backtrack — from the other side of the street — to where they wanted to cross, sometimes for a few kilometres^[7]. Such detours are also very frequent in train stations and airports.

Detours are not always to reach the same places as abled people. Entertainment venues, for example, are seldom fully accessible (especially cinemas, theatres, or live music venues, see Griffiths and Hilder, 2014). However, recent regulations^[8] have forced many of them to create special accommodations for disabled patrons. Those seats, besides requiring special organisation^[9], often have restricted access and getting to them can involve going through labyrinthine paths (such as going through conservation and restoration rooms in museums, or through the scene shop or storage areas in traditional theatres). This kind of detour has a special significance, because it affects how the whole ordeal is perceived.

We have focused on disabilities caused by the lack of certain physical capabilities, but those indirect physical costs can affect crips with all sorts of disabilities. For example, assistive technologies often have secondary costs. Being allowed to type instead of manually taking notes can be a boon during one's studies, but some things are much slower to transcribe on a computer (for example, mathematics or hormonal pathways diagrams). For visually impaired people, recording audio and playing it back afterwards can replace note-taking (and not just in academic settings). However, listening to spoken word at its original speed is much slower than reading text (by a factor two to three in general).

As it happens, it is possible to increase the playback speed by an even greater amount while maintaining high levels of comprehension, with some training. But mainstream assistive tools often have built in arbitrary limits that prevent this (Bragg *et al.*, 2018).

All of this brings us slowly to the second central model of disability, the social model (Llewellyn and Hogan, 2000 ; Oliver, 2013 ; Gabel and Peters, 2004). The costs we see here are not direct costs linked to any given impairment, but instead costs that occur because of how societies decide to deal with the impairment. This will be mostly relevant for the next few sections, but we can already see some effects of addressing accessibility on an individual case-by-case basis instead of

promoting accessibility by default as with universal design (Smith and Presier, 2001).

On the perception side, unlike the direct costs which are well observed and elicit pity or concern, indirect costs are often ignored. When they are mentioned, they can make people uneasy, or even defensive, as those costs are a consequence of society keeping crips in mind (even though it is just as an afterthought). Because we are not living in *accessible by default* environments, any effort made to locally improve accessibility tends to absolve the people responsible for the state of things, even if the final situation is still far from fair. Reflections such as “you’re not going to complain, you still managed to get into the theatre, although you did miss the first 15 minutes of the play” do not stretch the imagination. Let’s take an example where the owners of a hypothetical theatre made the bare minimum changes to their venue to allow a crip inside (unlike some other venues, and despite being legally mandated to do so). According to popular opinion, the owners should be above complaints, even if the choices made in how the accessibility is implemented leave huge costs for the concerned crips.

Moreover, although non-crips can perceive the crips’ annoyance at being subjected to these costs, they can also consider that it comes with benefits, such as backstage access or the right to use a computer where others have to write by hand. This *special treatment* is central to the next category of temporal costs.

4. Limited autonomy costs

The *special treatment* that allows/obliges the crips to go through restricted areas always comes with a non-negligible cost: they are not allowed to do so alone. Here, we are not talking about restricted autonomy in general, and are instead focusing on a smaller facet of it. Specifically, the strong restrictions on autonomy that many crips face when interacting with a system (mechanical, social, administrative, etc.), which can increase their temporal costs. This is most visible when it comes to exploring space and moving around, with the basic principle being that crips should not be left alone, both for their own safety and because they should not be left unsupervised in restricted areas. This is especially true with children (Larsson, 2016 ; Shah, 2008).

This happens in all kinds of situations. For example, a school or a public building could have an elevator with a restricted access requiring a key. In the best situation, the crip themselves would have the key — especially if they are a regular user — but often enough they do not, having to rely instead on finding someone with the key. In many venues, crips do not just have to go through the detours, they also have to wait until they — or more probably the people at the entrance — manage to find someone whose job it is to help the crip, and who knows which way to go (and has the relevant keys). For a slightly different example, some recent public toilet services that impose a fee on users, such as 2theloo, feature a turnstile at the entrance. Although the turnstile can be bypassed if someone comes in a wheelchair, this requires the assistance of an agent — which requires finding the agent, hence a temporal cost.

The most egregious aspect of this temporal cost, however, occurs in interactions with transportation systems. Due to generally having the obligation to cater to all kinds of passengers, including disabled ones, airlines and train companies — among others — have special services dedicated to crips, which are by now generally outsourced to contractors (Morris, 2018). The first temporal cost appears as those services require one to be there in advance to be allowed to use it. Unlike a biped who can get onto a train as they want, the wheelie must come early and patiently

wait for someone to accompany them to the correct wagon. The first example comes from a comparison between the Taipei and Paris metros. In the first, a small bump at the end of the platform makes it on a level with the train, allowing wheelies to just roll in with no restriction on their autonomy. Although the wagons in France are built by some of the same companies (such as Alstom) they impose high autonomy restrictions (Noisette, 2017).

Wheelies have to come to a help desk and ask for assistance before being accompanied to the metro where the agent puts down a simple ramp from the platform to the train. It is also forbidden — at least according to security agents in informal interviews^[10] — to board alone as a wheelie^[11], as internal regulations do not allow the presence of more than two wheelies per train (in case of a fire). It would be possible to modify a few square metres of the platform to address this issue, which would cost much less than paying for an agent to work full-time just in case a wheelie arrives. However, controlling whether a wheelie is on board allows the observance of strict security regulations, at the cost of delays to get inside that can go as high as 45 minutes (to be able to reach the train driver by phone to ensure that there is still room for a wheelie, and to reach the destination station to ensure that someone will be on the platform to let the wheelie out of the train).

This can already seem ridiculous, but the unnecessary costs have many other examples, such as the ones due to the French national railway company^[12]. On top of potential delays due to the need to find available agents, it also imposes coming to the disabled office 30 minutes early if one wants their (mandatory) assistance^[13]. However, this assistance is only necessary because of arbitrary regulations: all fast trains — the main ones on which wheelies are allowed — have a small metallic ramp to get inside. Once inside, a small button activates a small hydraulic elevator for the single step inside the train. This could be operated by anyone, including a fellow passenger with no training whatsoever (it is a single button), but regulations impose that the button and the ramp are both inside locked cabinets.

The same kind of issues are also present in other forms of transportation, like air travel. Crips in airports generally have access to a special service that takes them directly to the gate, often going through priority queues at security and boarding the plane before anyone else. The same service then picks them up from the plane once landed. Although this seems like it would reduce temporal costs, those very services generally require users to show up 2 to 3 hours before the flight or be denied service (with stricter enforcement of such policies than for bipeds, see Wehrman, 2020). The crips are generally the last ones to come out of the planes (sometimes waiting more than half an hour for assistance to show up, as regulations prevent the cabin crew from helping). Moreover, they hardly ever have any control over their own mobility during their stay at airports^[14] (Yates, 2007). Following the logic of controlling where each crip is — in the case of fire evacuation — there are often constraints on crips. This is exemplified by the use in many airports of special wheelchairs with hand brakes not reachable from within the chair, or even small wheels that do not allow self-propulsion. Crips are also sometimes parked on a bench in a special room from which they are told not to leave (even to use the restroom), even in the case of layovers of more than six hours^[15].

This whole section on limited autonomy costs corresponds to a central part of the social model: none of the temporal costs shown here are directly caused by the impairment. Instead, they come from the will to make things more accessible while retaining a high degree of control over crips to make sure that rules (often pertaining to security) are respected, even when they are counter-

productive and have high costs (Damocles, 2019 ; Van Roosmalen *et al.*, 2011).

When it comes to perception, this kind of cost is nearly invisible to people not directly concerned. It also plays directly into the special treatment effect that makes it seem like an advantage instead of a cost. To illustrate this, in a recent trip going through Istanbul, the author had the (dis)-pleasure of meeting a British lady in a wheelchair who made snide remarks — on whether heavily disabled people should have the right to travel — after another disabled elderly passenger complaining audibly — as she had been injured by her handlers. After a small discussion, and thinking that the author might be in a similar situation due to their youth, the lady confessed that she was not disabled and had only signed up to enjoy the benefits of the special treatment. It took less than fifteen minutes of having to wait for assistance, being (slightly) roughly handled and then denied the authorisation to explore the airport or leave using a wheelchair before she loudly complained that their treatment of disabled passengers was terrible and that she would never try to simulate being disabled ever again as it was not worth it^[16]. However, before even being allowed to enjoy this special treatment, the *crip* has to deal with another kind of temporal costs, linked to the necessity to plan everything ahead.

5. Organisational costs

When making decisions on what to do, where to go and how to get there, nearly everyone pays some form of temporal costs just to plan ahead. The previously mentioned costs, however, make this a more critical task for *crips*. This section looks at the different additional temporal costs that arise from having to handle the specific constraints faced by *crips*.

First of all, the costs in the previous sections assume that the *crip* is recognised as such, and enjoys the support of the administration. National disability cards are often necessary to be allowed to use specific accessibility services in public transit or special seating in venues^[17] (van Dijk, 2018). Alas, the situation on this front is very unequal, and getting one's disability recognised by the state can be a challenge, especially since it is often linked to the right to receive disability benefits. In the USA, for example, this process generally takes a few months in the best cases. If the initial application is denied, however, getting a hearing can take more than a year (slightly old figures indicated between 314 days in Maine and 630 days in Nebraska, according to 2010 data, see Disability Benefits Center, 2010). Similar delays exist in many countries (in France, the expedited process — which generally does not give any right to financial compensations — already takes a few months (Hoareau and Brasseur, 2017). This administrative recognition seldom is a one-time event, and regular checkups are often needed to maintain this status, not to mention the fact that different organisations also require special procedures. Getting recognised as a disabled worker can sometimes depend on a process led by human resources, which can only be started after the *crip* already has the state recognition (and the process might have to be started from scratch if the *crip* changes who they work for).

Once their status as a *crip* is established, the *crip* can fully appreciate the different temporal costs coming from organisational issues. The first type comes from the lack of choices. This might seem counter-intuitive, as choice paralysis is generally a time sink, and having limited choices help in this regard. However, the problem is that the lack of choice translates into a lack of easy backup

plans. When flying to a city in a foreign country, the average traveller can be relatively certain that they will find an easy way to get from the airport to where they are staying. A wheelie, on the other hand, knows they have to check the accessibility of public transit, and make a list of adapted cab companies, although this might not be enough. Each solution also has a high chance of failing (due to broken equipment, untrained or misinformed interlocutors, or simple refusal to serve clients with “special needs”). This means that organising any activity outside of one’s habitual environments requires making a comprehensive list of backup plans, as improvising as issues happen is seldom doable, which is a significant temporal overhead.

There is one main hindrance that makes this improvisation much harder: protocols that limit the freedom to explore and to make impulsive decisions. As it happens, the accessibility services mentioned earlier do not only require the crip to show up early, but also to book in advance through custom booking systems. It is harder to decide to go on an impulsive train trip when the companies require crips to book between 2 days and 2 weeks in advance or be denied service (House of Commons Transport Committee, 2013). These custom booking systems create multiple problems, as they are generally added as an afterthought. This means that they seldom allow online booking, and often require calling a — sometimes unreachable — call centre. Moreover, if the crip has a special request that is not related to the disability but falls into a second special case (even if is quite common like having a layover or flying with a pet), they might not have a way to handle both^[18]. Most importantly, the procedure is often arbitrary and seemingly random. Still on the subject of flying, security rules can change, not just between airlines and airports, but also depending on who is the person in charge that day.

Going through security checks can then take anything from 5 minutes (by going through a priority queue) to 2 hours (still on the priority queue, just being unlucky), and the crip needs to be more than passingly knowledgeable about their own impairment and any medical device they are travelling with, to answer eventual questions.

All this creates a second type of organisational cost: due to the intricacies of navigating this system and the specialised questions that can be asked at any point, the crip generally cannot delegate such tasks to other people (or only to very close friends or family members who are used to it). Not only does this remove the option of paying for other people — such as travel agencies — to do it, but it also means that additional constraints appear when travelling for work (especially in academia). On top of the organisational difficulties linked to crip travel, the crip might have to fight their employer for the right not to use the standard travel agency^[19] — as trusting it would have a high chance of leaving the crip stranded somewhere upon realising that the travel agency forgot to mention they were disabled for one leg of the trip.

Perception-wise, but those costs are generally ignored, or worse. Due to the presence of those special services, there can be an assumption that crips can easily use them at no cost, no matter their impairment. And although people are sometimes aware of the limited number of available choices, they rarely understand the extent of it, and that the lack of fallback plan makes it necessary to be organised. This incomprehension can make them doubt the crip, which is the source of another type of cost, analysed in the next section.

6. Social interaction costs

The next category of temporal costs is probably the most diverse and could warrant another typology by itself, but we will try to give a quick presentation of it. It corresponds to all the additional social interactions that come as consequences of the effects already shown: people trying to help or refusing to help, people doubting the crip's specific needs or even disbelieving them when they say they require to organise in advance.

The first issue here is the constant interruptions faced by crips when out in public. Just being outside as a crip is often considered by non-crips as an invitation to offer help (Cahill and Eggleston, 1995). There are many reasons for this, but three central ones come up. First, the difficulties in accessibility linked to the physical costs mentioned above mean that people believe they can be useful and a good person by offering to help (Cahill and Eggleston, 1995). Second, the cultural tropes around the lack of autonomy and the common representations of crips as eliciting pity (although this is slowly changing) reinforce this phenomenon (Clare, 2001 ; Tsai and Ho, 2010). Third, crips are not generally welcome to visibly inhabit public spaces (Chouinard, 1997). Not only have there been some laws regulating this issue and limiting the crip's right to be in public (in the USA for example), strong cultural taboos and shame towards disability in general persist to this day (as in multiple East Asian countries, see Tagaki, 2016 andav Tsai and Ho, 2010). This absence from public space means that people are not used to seeing crips around, and often perceive that something is wrong (or the crip would not be there) (McFarlane and Hansen, 2013). All together, it makes the act of just sitting in a wheelchair outside a building or in a park a tiresome one, as the crip is interrupted every few minutes by someone asking if they need help.

Worse than the cost of being interrupted by someone asking to help, however, is the one caused by people trying to help without even asking the crip, which is still commonplace enough that there have been multiple campaigns to address it (Kavanagh, 2018).

What makes it even more exhausting is that the offenders here have the impression of helping (even though in a misguided way), which means that it takes time to get them to stop. There are two main options in such a situation: tell them it is not necessary and ask them not to help, which can take a long time — people often insist that it is not a bother — or tell them directly that what they are doing is bothersome and not helping. The second strategy isn't even necessarily faster, as it exposes the crip to harassment and/or verbal violence, as people can get extremely upset at being denied the opportunity to help (Mason-Bish and Kavanagh, 2019).

In a related fashion, the individuality of the crip (or of their disability) is often denied. Many non-crips apparently seem to believe that there are only a dozen different impairments (such as “being blind” or “using a wheelchair”, with no distinction on the reason why the crip is using the wheelchair) (Fritsch, 2013 ; Siebers, 2004). This leads to some ridiculous discussions — often in public spaces and with strangers — insisting that their cousin/aunt/friend has the exact same issues, before even asking the crip what they have (which, although an intimate question, nearly always follows^[20]). Besides the temporal cost of answering or deflecting such questions — with insistent interlocutors — there is a second issue that sometimes arises. The interlocutor might suggest a novel treatment, often based on alternative medicines, that they “guarantee will work, it did for their friend” (Plaise, 2018). The crip's options in such a case are limited, as the fact that they deserve respect, and potentially assistance, depends on their fulfilling the image of the good disabled person that will do absolutely anything not to be disabled anymore. The problem is that, what is a one-time occurrence for the person proposing a solution — no matter how misinformed they are^[21] — can be a daily occurrence for the crip, with unsolicited personal advice being offered

by everyone: from colleagues and friends of the family to service workers (Stebler, 2011 ; Blahovec, 2017).

The well-meaningness behind it also prevents the crip from legitimately lashing out, despite the very real mental and temporal costs (Cahill and Eggleston, 1994).

On a lighter note, a related cost happens in relation to what could be called the “disabled toilet law”. The law itself corresponds to a temporal cost, and goes as follows: in any public building big enough to have multiple bathroom stalls side-by-side including one for disabled people, the latter will be occupied. By which we mean that if a single stall is occupied, it will be this one, because most people — crip or not — will use it in priority, as it is “more comfortable”^[22]. Thus, the crip will nearly always have to wait, which is a negligible cost but can be an annoyance due to its frequency. What can be costly, both temporally and psychologically, is the interaction that follows when a non-crip comes out of the stall, sees the crip, and starts apologising at length — while staying in the way.

All the social costs so far have been linked to people interacting with the crip because of their reaction to the disability, but a frequent reaction is also to disbelieve the crip’s disabled status. There is a common experience of people not believing that one’s special needs are actual needs, or that one’s pain is simulated, from the government to medical professionals, and potentially including almost anyone with power over the crip^[23] (Siebers, 2004). A very visible example of this was the fight that crystallised over the plastic straw bans in multiple countries. This was an initiative that meant to address the environmental damage made by the automatic distribution of single-use plastic straws with drinks in most eateries. It suffered from multiple issues, and was based on an ecological framework that prioritises individual instead of collective action (Haggerty, 2019). Straws being necessary for many crips to drink, there was a strong backlash from the community, which was met by successive arguments. The first concerned the availability of alternative straws (made of paper, metal, bamboo, silicone), which ignores the fact that none of the alternatives were simultaneously safe, usable and reasonably priced. The debate then moved on to having plastic straws available, but only for crips. This puts the locus of effort on the crip, and requires them to disclose their disability to get a drink. This requires time, as the crip needs to get waiters to believe them, which can involve a thorough discussion on whether they really need the straw (Ho, 2018).

Looking at how these costs are perceived by the general public, we end up with mostly adversarial reactions, and complaints about them are very often badly received. As directly telling someone not to help when they are trying to assist you is already a source of harassment, complaining about receiving unsolicited help is similarly rarely seen in a good light. This means that those costs are very rarely discussed except within the immediate social circles of the people directly concerned. Avoiding those subjects and keeping it bottled up can be tiring, which brings us to the top layer of this hierarchy, which addresses psychological costs.

7. Psychological costs

Psychological costs are more closely related to other forms of #CripTaxes, but they have a few important temporal components which we will quickly cover.

First, all the previous types of costs contribute to the stress of being a crip, which means that the

crip needs time to recuperate and lower their stress levels. Having to face adversity and justify one's situation and right to exist in public is both exhausting and a stress factor. It also requires mental preparation before being able to gather the energy to face the potential challenges. This is especially true if the crip has PTSD, which is a frequent occurrence, partially because of the omnipresence of denials of autonomy and non-consensual touching^[24].

The time costs of exhaustion and stress are also potentially compounded in two ways for crips. First, some crips have issues — such as hypersomnia (Vernet and Arnulf, 2009) — that prevent them from efficiently recuperating during their sleep, thus paying a double cost.

Second, even if the crip has some time, they might be out of energy and not able to use this time for anything (whether working, enjoying oneself or even resting). This is especially true among people with chronic pain and chronic fatigue, and is an effect often described by proponents of the spoon theory (or spoonies) (Miserandino, 2003).

On a completely different front, there are also extended periods of doubt that arise from wondering whether to disclose one's disabled status. For example, a crip could have trouble walking long distances and use a wheelchair in public. If that crip goes shopping and wants to reach a high shelf, they are often faced with two possibilities: try to find some assistance (which takes time and can be humiliating), or stand up to get it themselves. Although the latter is simpler and faster, it also involves the “risk” of being caught, accused of faking a disability, and potentially harassed (Siebers, 2004 ; Harris, 2014). Those costs are often kept in mind, which increases the mental load of the crip, along with their stress level.

Perception-wise, we come to the issues of showing weakness and being considered useless by society (which was still a relatively frequent occurrence a few years ago). Discussing those costs can be dismissed as navel-gazing or playing the victim card in an exaggerated way. A second issue that affects spoonies in particular is the limited patience from their social circles, who keep expecting them to get better. Discussing those issues regularly can then drive people away as it stands at odds with common narratives of healing and getting rid of one's problems, which leads to a social cost (Clare, 2017 ; Rothman 2019).

Over this article, we have tried to give a first typology of temporal costs that affect crips, and how they interact with each other. Although some of those costs are caused by the impairments themselves, the vast majority comes from the policies implemented to address the initial issues. Policy decisions that ignore the desires of the relevant communities, arbitrary regulations and the body policing in public spaces by a general public afraid of “mooching” can in practice create even greater costs for crips. Most of the examples we've shown are about temporal costs related to crips exploring and interacting with their environments, often centered around people with physical impairments. That said, this typology should be applicable more generally in more varied contexts. We must then finish this article by leaving the reader with three main questions. Are there common temporal costs that do not fit in this typology? Is there an alternative systematisation of temporal costs that would give further insights about their relationships? Finally, can similar typologies be developed to systematise other forms of costs related to the #CripTax, such as financial costs?

Bibliographie

Bec, Ghislaine and Constans, Carine, 2016. [Le handicap au coeur de la stratégie globale du CNRS](#), CNRS.

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- Blahovec, Sarah, 2017. « [Your Unsolicited Health Advice Isn't Just Irritating. It's Damaging](#) » Huffpost.
- Bragg, Danielle, Bennett, Cynthia, Reinecke, Katharina, & Ladner, Richard, 2018. « A large inclusive study of human listening rates » in Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, 1–12.
- Blanchard, Enka, 2020A. « [Crip spatialities and temporalities I : discreet crips in a discrete world](#) » EspacesTemps.net , Works, 2020.
- Blanchard, Enka. 2020B. « A travelling crip's temporal expenses » submitted for publication, preprint available [on the author's website](#).
- Burkett, Brendan, McNamee, Mike, & Potthast, Wolfgang, 2011. « Shifting boundaries in sports technology and disability: equal rights or unfair advantage in the case of Oscar Pistorius? » *Disability & Society*, 26(5), 643–654.
- Cahill, Spencer E., & Eggleston, Robin, 1994. « Managing emotions in public: The case of wheelchair users » *Social Psychology Quarterly*, 300–312.
- Cahill, Spencer E., & Eggleston, Robin, 1995. « Reconsidering the stigma of physical disability: wheelchair use and public kindness » *The Sociological Quarterly*, 36(4), 681–698.
- Chouinard, Vera, 1997. « Making space for disabling differences: challenging ableist geographies » *Environment and Planning D: Society and Space*, 15, 379–390.
- Clare, Eli, 2001. « Stolen bodies, reclaimed bodies: Disability and queerness *Public Culture*, 13(3), 359–365.
- Clare, Eli, 2017. *Brilliant imperfection: Grappling with cure*. Duke University Press.
- Damocles, Caelan, 2019. « [#FlyingWhileDisabled](#) Twitter.
- Fraser, Jayme, 2019. « [New federal requirements show airlines damage thousands of wheelchairs each year](#) » USA Today.
- Fritsch, Kelly, 2013. « [On the Negative Possibility of Suffering: Adorno, Feminist Philosophy, and the Transfigured Crip To Come](#) » *Disability Studies Quarterly*, 33(4).
- Gabel, Susan, & Peters, Susan, 2004. « Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability » *Disability & Society*, 19(6), 585–600.
- Gardré, Solène, 2020. « [Rochefort?: une locataire expulsée à cause de son handicap](#) » Sud Ouest.
- Griffiths, Graham, & Hilder, Liz, 2014. [Surveying UK Live Music Accessibility for Deaf and Disabled People](#). Attitude is Everything.
- Haggerty, Meredith, 2019. « [We were all right to hate the plastic straw ban. And we need more legislation like it](#) » Vox.
- Harniss, Mark, & Raja, Deepti Samant, & Matter, Rebecca, 2015. « Assistive technology access and service delivery in resource-limited environments: introduction to a special issue of *Disability and Rehabilitation: Assistive Technology* » *Disability and Rehabilitation: Assistive Technology*, 10(4), 267–270.

-
- Harris, Scott Jordan, 2014. « [Despicable Memes: How “miracle” jokes and inspiration porn demean disabled people](#) » Slate.
- Harvey, Clare, 2015. « What’s disability got to do with it? Changing constructions of Oscar Pistorius before and after the death of Reeva Steenkamp » *Disability & Society*, 30(2), 299–304.
- Ho, Vivian, 2018. « “People need them”: the trouble with the movement to ban plastic straws » *The Guardian*.
- Hoareau, Virginie, & Brasseur, Anne-Lise, 2017. Synthèse des rapports d’activité 2017 des maisons départementales des personnes handicapées.
- House of Commons Transport Committee, 2013. Access to Transport For Disabled People-Volume I: HC 116: Fifth Report of Session 2013-14, Report, Together with Formal Minutes, Oral and Written Evidence (Vol. 1). The Stationery Office.
- Kafer, Alison, 2013. *Feminist, queer, crip*. Indiana University Press.
- Kavanagh, Amy, 2018. « [Just Ask Don’t Grab Campaign](#) » [caneadventures.blog](#), accessed on 25/11/2019.
- Larsson, Naomi, 2016. « Out of sight: the orphanages where disabled children are abandoned » *The Guardian*.
- Llewellyn, Ann, & Hogan, K., 2000. « The Use and Abuse of Models of Disability » *Disability & Society*, 15(1), 157–165.
- Mason-Bish, Hannah and Kavanagh, Amy. 2019. « [Private Places, Public Spaces](#) », accessed on 25/11/2019.
- McFarlane, Hasel, & Hansen, Nancy, 2013. « Zones of exclusion » in *Geographies of Privilege*. Routledge.
- McRuer, Robert. 2006. *Crip theory: Cultural signs of queerness and disability*. New York : NYU press.
- Miserandino, Christine, 2003. « [The Spoon Theory](#) » [butyoudontlooksick.com](#), accessed on 25/11/2019.
- Morris, John, 2018. « [Scapegoating: Airlines, Contractors & Disabled Passengers](#) » *Wheelchair Travel*.
- Noisette, Thierry, 2017. « Le métro parisien, l’un des moins accueillants pour les fauteuils roulants » *L’OBS*.
- Oliver, Mike, 2013. « The social model of disability: Thirty years on » *Disability & Society*, 28(7), 1024–1026.
- Peet, Lisa, 2019. « Hunters Point Library Confronts Accessibility Issues » *Library Journal*.
- Pinto, Serge, Ghio, Alain, Teston, B., & Viallet, François, 2010. « Dysarthria across Parkinson’s disease progression. Natural history of its components: dysphonia, dysprosody and dysarthria » *Revue Neurologique*, 166(10), 800–810.
- Plaise, Max, 2018. « [Able people explain things to me](#) » *Spooniehacker*
- Rothman, Lauren, 2019. « [How My Chronic Illness Showed Me Who My Real Friends Are](#) » *Huffpost*
- Samuels, Ellen, 2017. « Six ways of looking at crip time » *Disability Studies Quarterly*, 37(3).

-
- Schalk, Sami, 2016. « Reevaluating the supercrip » *Journal of Literary & Cultural Disability Studies*, 10(1), 71–86.
- Shah, Sonali. 2008. *Young Disabled People Aspirations, Choices and Constraints*. Routledge.
- Sherlaw, William, Lucas, Bernard, Jourdain, Alain, & Monaghan, Nigel P. 2014. « Disabled people, inclusion and policy: better outcomes through a public health approach? » *Disability & Society*, 29(3), 444–459.
- Siebers, Tobin, 2004. « Disability as masquerade » *Literature and Medicine*, 23(1), 1–22.
- Smith, Korydon, & Preiser, Wolfgang, 2001. *Universal Design Handbook*. McGraw-Hill.
- Stebler, Kristine, 2011. « Insider Perspective: The Story of Kristine Stebler » in *Psychosocial aspects of disability: Insider perspectives and strategies for counselors*.
- Swartz, Leslie, & Watermeyer, Brian, 2008. « Cyborg anxiety: Oscar Pistorius and the boundaries of what it means to be human » *Disability & Society*, 23(2), 187–190.
- Tagaki, Masakuni, 2016. « Research Development from Acceptance to the Meaning of Acquired Disability in People with Impaired Mobility in Japan » *Japanese Psychological Research*, 58(S1), 85–109.
- Tsai, I-lun, & Ho, Ming-sho, 2010. « An Institutional Explanation of the Evolution of Taiwan's Disability Movement: From the Charity Model to the Social Model » *Journal of Current Chinese Affairs*, 39(3), 87–123.
- van Dijk, Charlotte, 2018. « Case Study — The European Disability Card » in *Co-Production and Co-Creation*. Routledge.
- van Roosmalen, Linda, Karg, Patricia, Hobson, Douglas, Turkovich, Michael, & Porach, Erik, 2011. « User evaluation of three wheelchair securement systems in large accessible transit vehicles » *Journal of Rehabilitation Research & Development*, 48(7).
- Vernet, Cyrille, & Arnulf, Isabelle, 2009. « Idiopathic Hypersomnia with and without Long Sleep Time: A Controlled Series of 75 Patients » *Sleep*, 32(6), 753–759.
- Wechsler, Kathy, 2010. « [Stand Up and Go with Mobile Standers and Standing Wheelchairs](#) » Muscular Dystrophy Association.
- Weeber, Joy E., 1999. « What Could I Know of Racism? » *Journal of Counseling & Development*, 77(1), 20–23.
- Wehrman, Jessica, 2020. « Emotional support animals could be banned from planes under DOT rule » *Roll Call*.
- Yates, Karen 2007. « Understanding the experiences of mobility-disabled tourists » *International Journal of Tourism Policy*, 1(2), 153–166.
- Zola, Irving Kenneth, 1993. « Self, identity and the naming question: Reflections on the language of disability » *Social Science & Medicine*, 36(2), 167–173.

Note

- ^[1] Following Robert McRuer, we will use the term “crip” to denote any arbitrary person with a disability

(McRuer, 2006). “Wheelie” will denote someone who regularly uses a wheelchair, as opposed to “bipeds”.

^[2] The supercrip analysis states that there are generally only two options when talking about disabled people in public. The first is centered around either pity, with the crip being entirely dependent on others. The second is focused on being an inspiration (with the crip overcoming their disability and achieving independence through sheer will), precluding any option of presenting the crip as just someone un-exceptional.

^[3] There exists some wheelchairs that are made to climb stairs, but they tend to be high end models, with prices that until recently ran in the tens of thousands of euros (which are rarely reimbursed through health insurance (Wechsler, 2010)).

^[4] Old buildings are by no means the only ones with accessibility issues. A good example is the Hunters Point library in New-York City, which cost 41 million dollars and was celebrated as a work of innovative architecture. Although construction started in 2015 and finished in September 2019, multiple floors inside the library can only be reached by stairs (Peet, 2019).

^[5] The author’s worst personal experience of this involved going down an elevator, then around the building, through a passageway of a second building into a third building with an elevator going to the ground floor — as the first elevator did not — then into a courtyard, through a tunnel under the second building, through a second courtyard, under a tunnel under a fourth building, through a third courtyard, into the fourth building, up the elevator there, and then around the upper floors of the fourth building. The total distance was about 300 metres, and involved three elevators (taking approximately 10 minutes). The distance on foot, however, was about 15 metres, including a few steps. This path had to be taken multiple times a week for a whole academic year.

^[6] For an analysis of the spatial discontinuities linked to exploring space as a crip, see Blanchard (2020A).

^[7] To give just two real examples, Saint Petersburg featured a boulevard along the Neva with at least 1500 metres without any way down, and sidewalks that were close to half a meter higher than the central part of the road (at least until a few years ago). There is also a stretch of the Boulevard de la Pétrusse in the center of Luxembourg City that goes for nearly a kilometre, with at least five pedestrian crossings, none of them featuring a curb cut in 2019.

^[8] To give two examples of such regulations which were voted decades ago but took a while to fully apply, there are the *Americans with Disabilities Act of 1990* in the USA and *Disability Discrimination Act of 1995* in the UK.

^[9] Booking them can take months (Griffiths and Hilder, 2014), but this will be covered in Section 5.

^[10] The relevant regulations and reports on accessibility are often internal documents that are not released to the public, sometimes despite massive public campaigns.

^[11] In such a case, one could of course ignore the security agents, but risks being denied access in the future. Considering that crips are often visible and memorable, the benefits of getting access once are seldom worth the long-term risks.

^[12] The focus in this section is on French public transit, but similar problems can be seen in many places, from New York City to Lausanne or Berlin.

^[13] This is sadly not an exaggeration: in one instance, the author arrived 29 minutes in advance at the Marseilles train station and was denied service, even though many agents were available.

^[14] This is rarer — although not unheard of — in airports in the USA and Western Europe than in Russia, Turkey or the UAE, where it is still commonplace.

^[15] For wheelies going through Dubai airport, there is trick spread around by fellow crip academics: pretend that a nearby person (any stranger whom you met in the plane, and ideally one going to the same destination as you) is your aide, and that you are a smoker, which generally forces the handlers to leave you the use of a wheelchair instead of parking you on a bench.

^[16] This is one of the main reasons why the idea that people are “over-using” disability assistance or faking disabilities is perceived as ridiculous by many in the community: the advantages are far from compensating the costs — even if we only consider the costs of using the disability assistance and not the costs of the impairment itself.

^[17] There are of course wide differences in enforcement of such rules. Someone in a wheelchair or who looks visibly impaired can often manage to convince interlocutors to let them use the disabled facilities easily without a card, whereas people with invisible disabilities are under a much stronger scrutiny, and are not always believed even when they have the proper state recognition of their disability (Siebers, 2004 ; Gardré, 2020).

^[18] As a silly example of this, paying for a plane ticket from within the USA often requires an American credit card, and passengers with European credit cards are then redirected to special websites or call centres. This procedure is not compatible with the second special service that handles disabled passengers, and as of early 2019, multiple airlines (including American Airlines and Delta) had no way for a crip with a European credit card to book plane tickets from within the USA, either online or by phone. The last possibility would of course be to come to the airport itself, but besides not being sure whether it would work, that is precisely the act that is extremely costly to crips (Blanchard, 2020B).

^[19] Even if the crip wins this right not to use their employer’s travel agency, this can lead to a financial crip tax as getting reimbursed becomes more complicated and can take longer.

^[20] In a display of irony and statistics, within a few days of writing this paragraph, the author got addressed by a person in the street. Their second question was about the author’s disability, which turned into a heated discussion when the author answered that those were personal matters and not a great question — with the passerby being offended and insisting that it was a display of genuine interest and thus should always be welcome.

^[21] A critical subject is the disability itself, where remedies of all sorts are peddled by many people (as the remedy worked on their friend). There are multiple issues with this. First, time is finite, and trying out every possible remedy is not reasonable. Beyond the question of time, there is also the high mental cost of believing in the potential cures only to be disappointed again and again, negating the “what’s the worst that can happen” argument (the person proposing generally does not realise that such miraculous cures can be proposed on a weekly or even daily basis). Finally, it is very hard to handle these conversations as refusing a potential cure — even if it is snake oil — will probably upset the person proposing it, as it can be seen as a demonstration that the crip does not care for themselves, which is often seen as a severe moral flaw.

^[22] This is in fact quite variable, and a common joke asks the difference between an accessible and a common stall, the answer being “the sign on the door”.

^[23] Even when there are legal obligations, people might not believe the crip when they insist on defending their rights. A good example of this in the USA is that commercial planes have a closet to store foldable wheelchairs near the front of the cabin, to avoid them being mishandled in the cargo hold (which happens on average in 1.6% of trips Fraser, 2019). Even when a crip tells the cabin crew that they are legally mandated to put the wheelchair in the closet, they are most often met with doubt or

incomprehension, and not listened to (Damocles, 2019). This is also linked to an organisational cost: some crips have to become very knowledgeable about planes and airlines and pay attention to the plane model when they books, as to ensure that the cargo hold can fit their chair.

^[24] A recent project by Drs. Mason-Bich and Kavanagh focuses on those experiences of non-consensual touching in public. Titled “Private Places, Public Spaces : how disabled women and non-binary people experience non-consensual touching”, it is a very informative, if harrowing, collection of personal experiences (Mason-Bish and Kavanagh, 2019)

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