

What's in a name, a gender, a crip?

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Identity

“As far as I can remember, I have always known I was a man”. “One day it hit me and it just clicked, and I realised that I was transgender”. Those sentences together make up most of the commonly heard experiences of realising one is trans. They are not, however, universal, as I know full well.

I am a **crip**. More than being woman, man, or any other gender, my identity is tied inextricably to my experience of disability, from the earliest age. An experience of disability that often masqueraded as something else. An experience of never being condemned to one's condition, but always in the process of healing, towards a new being, a new identity that would leave behind the impairments of the past. But my life cannot be spent in pursuit of this impossible ideal.

I am a **queer**. I claim that word, and all it represents. The otherness of crip is intermingled with that of queer. The rejection of easy-made categories of assimilation, and the knowledge that community can sometimes be found among those who are othered. But this community is divided and under attack by those who should be closest to us, and I am tired of this fight.

I am a **scientist**. I harbour a distrust of my own impressions and ideas. I seek to generalise and to establish, if not causal links, then at least statistical inferences. My own life experiences only seem relevant insofar as they give me tools and frameworks to look at the world around me, to understand some of it. But I am faced with issues that seem unique, and I cannot see my experiences reflected anywhere.

I am an **activist**. I see injustice and prejudice and wonder how to change it. I choose now to be visible and to confront those who would want me to hide my identities. I try to be a shield: by welcoming debates with those who deny my existence, I try to draw their attention to me rather than those who have more to lose. I confront myself and question my own motives more often than not, and I've been doing it for most of my life. But there is a fine line between awareness and denial.

I am a **Jew**. I still do not know what that means. I come from a family that preached assimilation and cut off its roots. I come from a family with privileges. I come from a family that has suffered, and still holds many taboos. I am in search of a history that does not exist anymore. I am the product of communities that have seen their numbers erased on purpose by many governments' policies. I know the risk of sticking out from the group. But I do not trust the group, any group.

Those six paragraphs are not unrelated. They are six central pieces of a puzzle that I am still trying to put together. Some of them have been with me for close to three decades. Some made it much harder to find the other pieces. This text is my first try at putting to paper long-standing reflections. It could not have been written two years ago, and future me

probably wouldn't be able to write it, as I am changing that person by this very act, hopefully for the best. I put it out here because I have rarely had the opportunity to see myself reflected in common crip and queer narratives, which made my soul-searching only slower and tougher. Hopefully, this can inform others to make their own paths somewhat easier. Let's then start from the beginning and look at the pieces independently before focusing on their interplay.

Pieces of the puzzle

Crip is the first, in a way, and it will also be among the last. It's the first, in that it's always been present. It's in constant evolution, as disabilities seldom come alone. It will be among the last, as accepting the word took me more than twenty years. But another word comes first to the fore: handicapped. Although they are translations in any case¹, and culture seldom translates accurately, it is the word used at the time. It is not so much the conscious experience of being excluded as that of excluding myself.

Handicapped brings me back to early years, before age ten, and to kids – myself included – playing around in pretend fights by putting my leg braces on their arms as if they were weapons. Of feeling included by the very visible artefacts of my exclusion. Handicapped brings me back to the hope that I might be healed, if only I trust the doctors and my parents, and follow their orders. It brings me to doubt and fear as the surgeries that are supposed to finally make me better are perpetually delayed. And then, as they finally happen, it brings me back to pain and renewed hope. False hope, and it was always a given. Hope nonetheless, that it will get better eventually, I just need to work hard at it.

Handicapped brings me back to years spent in and out of hospitals, where the screams of children in pain will stay with me to the end. It brings me back to the morphine ever in my system as I developed my own set of mental methods to keep functioning through the fog and through the pain. It brings me back to a will to fight. Not fight for people like me, not fight to end any problem besides my own, nothing so noble. No, it brings me back to a will to fight the detestable word itself. It brings me back to hating the condition I am in, denying it, and putting all my strength in proving that I am stronger than it is, that I can escape my status. That I can reach that damned holy grail: being normal. Handicapped is me focusing on myself by denying my reality, encouraged by those who could not accept it nor their potential responsibility in it. Handicapped is here and will stay here, crip will come much later.

Scientist comes next, as an inevitability more than anything else. It starts with a different way to see things. Is that linked, one way or another, to a potential neurodivergence? Maybe. I do not know what the answer to that question would bring to me. It is not something I know, something I wish to know, or something I need to know. And in any case, my

¹ France has two main words for disabled people: “handicapé” (handicapped) and “invalide” (invalid, closest to “disabled”). The first is now used more frequently, including in official documentation, but the second used to be the standard. Until recently, cards which showed that the owner had a state-recognised disability (which offers right to assistance and priority in certain settings) were called “invalidity cards”. They are now “mobility-inclusion cards”, with a special “invalid” category in some cases (Bugada, 2017).

handicapped status is established to the powers that be, so nothing else is needed on that front.

Scientist starts out with curiosity; it becomes an identity with a trauma. A promise that I will get better, I just have to wait until the liberating, salutary, surgery. A twelfth birthday passing with the solution ever delayed, always out of reach. A knowledge that my disease is rare, and that many similar ones end in early death. A feeling that my body is slowly giving up, tasks becoming harder, week by week then day by day. And then a horrible realisation: the optimal strategy for patients' survival in this case involves keeping their spirits up, even by lying. Emerge, then, two possible worlds in which I might be. In the first, all is well and I am worried for naught. In the second, my fate is already sealed: probably a few months, maybe a few years, of seeing my body decay. Worse than the decay, the second world has everyone around me reassuring me that we are in the first world – it is after all, in everyone's best interest for me to believe that. And the conclusion of this thought: there are only three ways to find out which world I am in: dying, people confessing and telling me that I will die soon, or getting the surgeries. As long as I am waiting for those, the second world is always a strong possibility.

A promise to myself then: avoid being this powerless at all costs. Make such a situation impossible in the future: be present at all medical appointments, hit the books, become more knowledgeable than the decision-makers. Make it nigh-impossible to be lied to. And in the meantime, pay the dues: more than a year spent wondering if it's the last, and if everyone around me is lying for my own good.

Doctors do not like insolent patients. They do not appreciate when it is implied that they might have made a mistake costing you many months in the hospital and years of pain. They prefer assuming the patient is just too sensitive². Knowledge is useful, but authorities can too easily brush it aside, and the hypocrisy is visible. They can't be trusted, and independence is entrenched as a goal, with a second promise to myself: avoid doctors whenever possible. Years later, upon looking back, it is still impossible to know the extent of the damage done to the body, let alone to the mind.

Hitting the books pays off. Self discipline is strong, and the power that is sought is on its way, piece by piece. Being stuck at home pushes me to alternate between studying and working out, despite the doctor's recommendations (with, if I'm honest, as healthy an amount of video-games as had any French kid with free access to a computer back then). The machine works efficiently, and everything can be attained if one has enough willpower. Daily therapy goals are systematically met, my intellect is getting me into one of the schools I desire, the future is bright. I find a partner, and normalcy seems near.

But the blessing that gets me this far is also a curse: lying to myself only lasts so long. All the daily goals are met, sure, but they never translate into the long-term ones. This analytical brain can no longer accept the dissonance, and all hell breaks loose when the mental edifice crumbles. Despite the failure, the inevitability stays. If not knowledge, then what? Using my

² It was at the time quite standard in France to discard any mention of *complex regional pain syndrome* – one name for what I ended up having twice for a few years each – as it reflected badly on the surgeon's skill. Being a disabled kid only made it easier for them to ignore my complaints. This issue is sadly still prevalent (Lunden *et al.* 2016).

talents will lead to depression, but wasting them is not an acceptable option. Constructing my identity then becomes a work-in-progress, never to be achieved.

Activist comes quite late. I still have a mild aversion to the word itself, informed by early participation in some circles where power is still claimed and abused, just by different groups. I am never confronted directly in my youth, my ideas are not truly challenged, but mostly because I don't dare voice them. They are solid ideas based on reason and common sense. They are also wrong and based on a very biased vision of history. It is just luck and curiosity that make me read the right texts to start questioning my assumptions. Going against the famous quote attributed to Churchill³, every year that passes sees me going further in deconstructing and refuting what my upbringing made me believe, as the good cultural product of neoliberalism that I was.

Jew never comes into play. It also never leaves. It is the subject of jokes in my youth, a subject of bewilderment later. It cannot be religious, cut off from any roots I could have had. It is, in the end, mostly defined by the reactions from my peers. By seeing those who would judge me on that alone, or would doubt my loyalties because of it. People around me span the whole range of opinions on the question, and the more I learn the less I know what to make of it.

And then, just before **crip**, finally comes **Queer**, at least in its first form. I would like to say that I never had misgivings about my own orientation, but it took me a few years to recognise the reality of desires that had been the subject of jokes at the dinner table for most of my life. On the other hand, I quickly notice that homosexuality can be just as discriminatory towards those who do not care about gender⁴. And after years of exploring this and seeing the extent of abuse in many communities, often from the same hands, I still do not know how I feel about the gender of my partners.

Pieces interacting

The first **opposition** comes between **crip** and **scientist**, what is perceived as the body and the mind at the time. At first the choice is easy, as the hours of therapy and pain still leave me enough time to keep up with my peers. Ambition in the face of increasing competition removes this possibility, and I am then stuck on a wild pendulum. Working out all day prevents me from thinking, and feels like wasting my life. Reading and writing all day lets my body wither, which I can't afford. No balance has been found so far, and I am on the eighth swing as I am writing this text.

The first time the pendulum swings back, it hurts. So much so that the grieving process is, in a way, still ongoing. I can pinpoint the moment it starts down to the second. I see it now as I saw it then: a wheelchair's rear wheel deciding to explore the world on its own, leaving me

³ The quote "He who is not republican at twenty compels one to doubt the generosity of his heart; but he who, after thirty, persists, compels one to doubt the soundness of his mind" has been attributed to many but can actually be traced to 1874 at least, either to Anselme Polycarpe Batbie or to Edmund Burke (Claretie, 1875), with the meaning of "republican" differing quite a bit from its more recent interpretation.

⁴ For more information on how the French queer community in general suffered from biphobia and dealt with it at the time, see (Welzer-Lang, 2008).

precariously balanced on two wheels, alone in the middle of a street crossing. I remember the help I got and the strenuous ride to where I was supposed to have my first important exam of the year, all the while holding the wheel in place with my arm. I remember managing to walk the last few hundred metres, sitting in the classroom seemingly unscathed and proving that, once more, willpower could triumph over adversity. I remember being unable to focus, repeating the earlier scene on a loop in my head. I remember my first bout with anxiety and how I tried to fight it⁵. I remember how every effort I made worsened my struggle until depression was the word of the day, of the week, of the months that went by.

Redefinition is what gets me unstuck. Slowly acknowledging that disability is a part of me, and has always been. Trying not to hate it as much as I did. Accepting that, just like everything else, goals can change, and that who I am is just as changeable. And, in the process of removing this set of blinders, noticing a few others and exploring a world that was not meant for me. A weird world of nights ending long after sunrise, spent wandering in the streets or in squats, where this redefinition of who I am happens continuously.

I haven't truly grieved the ideal of normalcy yet. I use a scooter, not a wheelchair, and the image it projects is one I am trying to be proud of. Handicapped, yes, but not like the others, not limited by it. This will have a large impact on the following years. It is a new promise in a way. Yes, I am disabled, but I swear that I will act as if that wasn't the case, and supercrip⁶ ideals find another unwitting adept. This is what leads me to try spending half a year in Chennai, India (which is not the smartest decision of my career⁷). I pay for it with a few years of PTSD, which I handle with the help of my partner. I don't learn my lesson, and accept teaching jobs and conferences in hard to reach places, from Kosovo to Taiwan. No hardship can deter one who's made a promise not to learn.

I get used to joining the groups I meet in the streets, from the white collar workers on a drunken night out to the golden youth thrown out by their parents. Sometimes, that includes the bands of roaming suburban youth that come to the capital to be visible, sometimes by wrecking the bikes and cars of the privileged Parisians who often ignore them from their ivory towers⁸. Despite the insults I receive sometimes, and the comments on how I'm just lazy for using a scooter, I am not passing as "normal". I see it in how they react to my presence, but mostly in the eyes of people I meet in potentially romantic settings. I am not a

⁵ One aspect in which being a scientist helped a little is that it allowed me to easily come up with one method to sometimes prevent panic attacks as they are starting: computing powers of 2, 3 or 5. This quickly becomes unmanageable and requires one's entire memory and focus, which can be slightly useful in the cases where the stressor disappears automatically after a certain time.

⁶ Using Schalk's terminology, this would correspond to a glorified supercrip ideal. For a discussion on the differing uses of this term, see (Schalk, 2016).

⁷ The fact that I survived in this environment led me to believe that, in a way, I could handle anything (by putting my mental health on the line), which led to all kinds of trouble afterwards (Blanchard, 2020).

⁸ They were upset at many things, in a time where tensions were even higher due to recent governmental repression against them. I was, in a way, partially a member of the group that they were legitimately upset at. I also made use of a weird privilege at the time: by having a masculine passing, I mostly avoided the threat of sexual violence. But by being the quintessential non-threatening dishonourable target (a cripple unable to defend themselves), that also prevented most physical violence. The last bit was making sure I only talked to groups, where no-one would dare initiate the violence (because I was the wrong type of target). I would use this kind of privilege later to limit the risk of violence when being gender-nonconforming in public.

threat, I am not a man; I am at best someone to talk to. And I see the men, and how they act to talk, to me and others, and I take pride in not feeling like one.

The second **opposition** comes. This time it is between scientist and queer. I have a number of people around me who challenge the usual gender binaries. Some transition, others don't. I feel a kinship with them, and like some, I am angry at the world. Angry that, at the time, I do not know a single trans person who hasn't been raped at least once, generally by a partner or a friend. That is something else I share with them. But I am not trans. How could I be? After all, they all seem to have known for a while. Sure, I feel massive amounts of dysphoria⁹, but that is just because of my disabled body, isn't it?

The scientist comes back to meddle, with a dozen years of experience since it first dealt with those dilemmas. If one of the main indicators of transidentity is dysphoria, and that disability induces it, there is no way to know the source of mine. No way to differentiate crip and trans in my current experimental framework. I have an effect, two causes, and no idea how much each contributes.

The framework and the questions it allows are wrong, I need new ones. If a magic spell would give me a body associated with the other sex, I think I would immediately accept. But isn't it because I represent this new body as abled in my mind as well? Just give me any other body and I'll be happy, I say to myself. Restricting the scenario to disabled bodies makes answering harder and raises tougher questions. Still, I can explain my desire to change by a greater compatibility with the social expectations of a different gender. In this context, I'm still tending towards the affirmative answer. But this is just a mental experiment with no relevance to my reality, after all.

It is time for the third **opposition**, between activist and queer. I have changed since earlier, and am slightly ashamed of what I used to believe. I have not yet fully realised that I was the product of a well-made system, and that it is partially through luck that I rejected it. And I am now confronted with my potentially belonging to another minority. The problem is that I don't know whether I "deserve" to be part of it. I have been among the oppressors and defending their values for too long. I am surrounded by people who suffer because of who or how they are, and in a way it often becomes a badge of honor. I do not believe that this is something I share, or rather, I cannot prove it, mostly to myself. I doubt my own legitimacy, and this lasts for more than a year.

The legitimacy riddle cannot be solved with the a prioris I have. But I notice some patterns in the communities I mostly follow online. Arguments then targeted at bisexuals are now reused against asexuals¹⁰. Just as right-wing politicians attack queers with the tools of the state, trans-exclusionary radical feminists manage to convince a new generation that the words our

⁹ Dysphoria, generally shorthand for *gender dysphoria*, is a state of distress linked to inadequation between one's perceived and assigned gender. It is often linked to *body dysmorphic disorders*, which can interact in multiple ways with disabilities (Phillips *et al.*, 2006). For details on the word "transidentity", see (Alessandrin, 2018).

¹⁰ For more information on the parallels between the two in terms of exclusion and othering, as well as an analysis of the general debate over the queerness of asexuality, check (Canning, 2015) and (Szuba, 2018).

cultural ancestors fought for shouldn't be used¹¹. The fight for “they” is starting to be visible, and battle lines are drawn, between the respectability of a word used this way for seven centuries and that of “absurd” neo-pronouns with no linguistic basis. Everywhere then, the word of the day is gate-keeping.

The absurdity of it all makes for an easier decision. Once again I come to claim queer, only this time it takes some political meaning. I side with those who would keep the one word that unites us. And so, I stop gate-keeping myself, and try exploring the intricacies of non-binary genders. The umbrella term “non-binary” itself is tempting, but this happens even as the word makes its first real public appearance in French, and as it becomes a subject of ridicule¹². I do not choose one in particular, staying in the fuzzy comfort of undefinition. Dysphoria was undiagnosable with any accuracy, as it had multiple potential causes. On the other hand, one thing is indisputable: the distinct pleasure and validation I feel when people around me start ungendering me – which I'd later learn is called euphoria. And that is all the proof I needed. Validation feels good, but it raises more questions than it solves. The scientist's job is far from done. I still question my own legitimacy, but I try to avoid those questions. I have a bigger one to face: what should happen to my body?

This is the site of the fourth **opposition**, between crip and queer, and it brings back the pain of the first opposition. I am aware of the medical details of confirmation therapies and surgeries, and have been following their development for a decade – even the ones concerning other sexes and genders, maybe in a bid to make self-denial easier. I have also considered hormones for a while, albeit in a different setting. Testosterone could be a boon to me health-wise. As I've had little time and energy to devote to legally getting this kind of supplement, I have avoided it until now. But things have changed and testosterone blockers might also be on the table now. And with them, some new questions that might also have no answer.

Dilemmas

I am given a choice between two avenues of action. The first will improve my body, at the expense of my gender feelings and my dysphoria. The second will do the opposite.

Scratch that. I am given a choice between three possibilities. The first two are as before, but are not guaranteed to work and have different chances of success. The third option is to wait until I can make an informed decision, but not eternally: the effectiveness of treatments will diminish with every passing year.

The activist argues: I am trying to have an impact on the world, how am I to fight if I sabotage my own health? The scientist replies: Look at the people in the statistics, look at the

¹¹ The reweaponisation of a word that had been among the first to be reclaimed, the debates surrounding it and the role of trans-exclusionary radical feminist in it have recently been documented and analysed in (Feraday, 2015) and (Szuba, 2018).

¹² This happened during the summer of 2018 as the queer activist Arnaud Gauthier-Fawas was interviewed in *Arrêt sur images*, a French radio show, on June 29th, the day before a pride march. The interviewer misgendered them and they answered that they were not a man but we're non-binary, despite having a masculine presentation (Assouline, 2018). This got ridiculed so much that the video is still in the top three YouTube results in France when searching “non-binary” eighteen months later.

depressions and suicides. Am I special enough to think I'm immune? I know by experience that it's not the case. And if not, how can I work efficiently while fighting my own mind and hating myself?

Is it selfishness to want to feel at home in one's body? Is it hubris to think it might be necessary to sacrifice yourself? It's a complex optimisation problem with moral arguments in all directions, and none of the probabilities of success are even known.

The arguments go beyond this. I am well aware that my own brain generally avoids thinking about impossible situations to avoid unnecessary pain. But I have also known all my adult life that a complete medical transition is not possible, as it goes against some of the strongest promises I made to myself as a teen. Hence the second rhetorical question: is my decision that I am non-binary – informed by deep feelings, surely – contingent on me being disabled? Is the identity I claim a consolation prize, given by a brain that knows that seeking a transition to a binary gender would be doomed from the start, would only bring suffering?

I haven't quite reached the end of the introspection. I am well aware that it is hard to work on something without becoming emotionally invested in it. I also know – or at the very least, I feel – that my appearance is not something I will ever be satisfied with. The optimal strategy to avoid suffering is then to avoid doing anything that could improve my situation, as that could make me care. And so I have been avoiding all ways to feel better, in an attempt not to feel worse.

My whole life has seen me being deprived of power over my own body and appearance. From the lack of autonomy to the medical recommendations that I abstain from all exercise. From the need to buy garments that prioritise my movements to the people attentively watching my weight¹³ (and phrasing it as a critical health issue I was responsible for, despite my having next to no control over it¹⁴). It is limited in scope, but exploring this is one of my first attempts to take possession of my own body. And the freedom is scary but exhilarating.

Administratively, I also wonder about making changes. The name is an obvious one, but the country where I live does not make it easy¹⁵. It is still productive, as the coming-out process is how I end up writing this text, originally intended as an F. A. Q. before it got too intimate. The gender is weirder, as changing to the other binary marker makes no real sense. My country does not recognise third genders (yet). This is one of the few places where the Jewish experience plays a role. Being on a small centralised list of individuals with a special particularity that often makes them a target raises all kinds of alarm bells.

All of this goes through my mind, even as I try to ignore the elephant in the room: it's been close to a decade since I last saw a doctor, a consequence of my independence and the

¹³ I owe to Dr. Zinaida Benenson a very interesting exchange on the role of fatphobia and ableism in the context of security metaphors. In the field of usable security, the use of disabled people as a metaphor for non-experts with difficulties to use the technical systems is frequent and problematic. Similarly, users who are warned about issues but refuse to act on them and are blamed for it (even as they rarely have all the tools they need to comply) often use obesity metaphors.

¹⁴ Naturally, the same doctors who had forbidden any physical activity wanted me to build muscle mass and avoid putting on weight while keeping a balanced but normal diet.

¹⁵ Until 1993, changing one's first name required extensive legal battles and was quite a rare occurrence (except in specific instances, such as the francisation of foreign names for immigrants who elected to change). For a comparative treatment of names between common law and civil law, see (Guinchard, 2008).

strained relationships of my teenage years. The seeds of a medical phobia were sowed then. I have spent a decade nourishing them with the stories of my fellow crips and queers, as well as a generous serving of papers focused on the sociology of medicine. It does not make seeing a doctor any easier. As I write these lines, the situation is still far from resolved, but I might have finally found the help I needed.

Crip

Crip, as I said earlier, comes last. It comes slowly as I am surrounded by my kin, of heart and mind if not of blood. It is intermingled thoroughly with queer. The scientist has won some concessions, and I am looking at what can be done, without outright eliminating the options that might be detrimental to my physical health. The activist has also won some things, and I have decided to be who I am publicly and visibly. I go to my first conference as an outspoken non-binary person¹⁶. That side goes over relatively smoothly, but the locale is far from accessible. I speak about being queer, and also about being disabled. I go to a second conference and am struck by the lies about the accessibility of the US system, as narrated to foreigners. I realise that I'm now spending most of my time talking about those subjects, from teaching military researchers how to make their labs more inclusive to queer people, to mentioning to other attendees the small obstacles that keep disabled people away. I believe I might be having a small but positive effect so I decide to learn more about the latter, to refine my thoughts. I've read many blog posts, but it's now time to look at the more formal side, from McRuer to Clare¹⁷.

I recognise the supercrip in me and am conflicted. I cannot continue tolerating the places and organisations that try to keep me away by their inaction. But boycotting them is not just ineffective, it's also career suicide and would bring an end to my attempts to teach about the different groups I belong to. Participating while being loud about the issues seems a decent compromise in the short term. But it doesn't address some inner problems. I've learned that it might be good to take possession of my body and presentation, to alter it – to fit some ideal that cannot avoid societal influences – but I'm also seduced by a critique that situates the problem in how people treat me¹⁸.

I do not know where this all leads, pretending otherwise would be silly in a world as fluctuating as ours. I do know a few things, though. I am **queer**, and I am **crip**, and those

¹⁶ The risk was limited as I knew the organisers, who were aware of my identities. One thing worth mentioning is that having to field questions on queer subjects was something of a novelty, but cannot be directly compared to fielding questions about disability as those do not register anymore after a few decades of practice.

¹⁷ Those two books, “Crip Theory: Cultural Signs of Queerness and Disability” (McRuer, 2006), and “Exile and Pride: Disability, Queerness, and Liberation” (Clare, 1999) offered a first treatment of some of the subjects discussed here. There is still a rather limited body of work on the interactions between transidentity and physical disabilities, unlike other forms of disability and neurodivergence (as in Strang *et al.*, 2018, Noonan and Taylor Gomez, 2011, and Duke, 2011). One central exception is the work of Alexandre Baril (Baril, 2015 and 2018).

¹⁸ This line of reasoning has been treated more eloquently by Alexandre Baril, with references to the fat movement, in his conference titled “Personnes trans et handicapées : vivre à l'intersection du cisgenrisme et du capacitisme” at UQAM on 2019-10-08 (Baril, 2019).

adjectives are here to stay, hopefully until their meanings dissolve through acceptance and lack of relevance.

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