

404 Not Found: Quantitative Methods in Disability Studies (Contribution to the Sage Handbook on Data & Society)

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Abstract: Disability is sometimes theorised as existing between the world (including social norms and infrastructure) and the person (who gets labelled disabled in a 'misfit' between the world and them). Disability is often enacted through data systems and infrastructures and the history of disability studies reflects a fight against such systems. In this paper, we examine the fraught relationships between disability studies and data science — from institutions and historical marginalisation to current practices of policing and surveillance. We critique the resulting preeminence of qualitative methods in disability studies as one impediment to translating disability studies to data scientists and to effective policy-making. We then address hopeful movements to crip data studies, looking at work on AI and disability bias, crip technoscience, counterventional research, and crippled data.

Keywords: crip technoscience, accessibility, cripistemology, quantitative vs. qualitative, data studies, disability



Introduction

Over the last half-century, Disability Studies (DS) scholars have managed to establish the field as a legitimate focus, with dozens of DS programs in the USA alone¹ — reflecting a strong North American presence, although major contributions also come from the UK and northern Europe, and increasingly from the Global South (Soldatic and Grech, 2014). What we denote here by ‘disability studies’ is not the study of disability as either a medical or social ill — as had been done since the 18th century at least (Linton, 1998). Instead we use it to denote a field which progressively came into being in the second half of the 20th century as scholars and activists — almost all of them disabled and disenfranchised — struggled to show the value of their own thoughts, lived experiences and even their very lives. One common rallying call of both DS and the disability rights movements was ‘nothing about us without us’, which is still reflected by the norms of the field. This raises the question of *who* can perform DS and what exactly are the borders of the field, questions we will leave aside in this article — although we have to mention that the corresponding debates are still ongoing (Block, 2017). One important element is the relatively recent development of crip studies which, inspired by queer studies, seek to challenge some usual dichotomies — such as that between disability and non-disability — and normativity’s role in society and in academia. ‘Crippling’ is then understood as adopting such a framework that questions the prevalent norms around disability — often in the pursuit of disability or design justice.² This process is particularly relevant when we consider how DS evolves in its interactions with other fields, and how other fields can learn from DS. Any analysis of the scientific practices within DS must carefully situate those within the political movements that engendered them. The fact that DS was built not just by scholars but also by activists, artists, and others has had a lasting impact on the field’s methodology. Indeed, different methods do not always lead to the same kinds of social truths, and no single method can be — politically or scientifically — effective or appropriate in all contexts (Feyerabend, 1975). For example, an analysis of the links between poverty and disability could employ advanced statistical tools not only to investigate the correlations but to control for

¹ For a partial list, see: <https://disstudies101.com/resources/academic-programs>.


² Disability justice centres the most marginalised disabled people in conversations about disability, and looks to cross-disability cross-movement solidarity. The term comes from the Sins Invalid disability justice artist collective, whose 10 Principles of Disability Justice can be found here: <https://www.sinsinvalid.org/blog/10-principles-of-disability-justice>. Design justice is a term that centres community-led practices in design, see Constanza-Chock (2020).

confounding factors (such as the complex relationships between education, employment and disability, as well as the fundamentally contentious determination of who counts as disabled). However, such methods might be superfluous in a context where other considerations take precedence, such as the fact that until recently, social security benefits in the USA were conditioned on having limited total assets (a maximum 2000\$ in an individual savings account) and income, preventing any durable escape from poverty.

Based on our previous work in this field — which is mostly focused on DS from a North-American perspective, a tendency which continues in this article — we had built up an intuition that the relationship between DS and data studies reflected a very particular epistemological choice in DS, built not just aside from quantitative methods but explicitly against them. This article makes a first step into investigating this particular epistemology. After giving some evidence confirming our initial intuition, we examine the historical and political roots that led to the rejection of quantitative epistemologies and show how this rejection — although it might have been historically necessary — could now be detrimental to the field, both scientifically and in the goal of effecting social change. We then compare the evolution of the field with that of similar fields strongly related to social justice and analyse which specific hurdles  has  clear before they can productively assimilate quantitative methods without sacrificing their emancipatory goals. We finish by going through multiple examples of crippling research and data studies.

1. Historical Roots

1.1 Quantitative methods in Disability Studies

Before we investigate the complex relationship that DS has  quantitative methods, we must provide definitions for the terms we use. Following Harris et al. (2014), we look at three major categories of evidence/data. The first category includes empirical evidence used in a quantitative fashion. This evidence can be collected by surveys, individual measures or through analyses of larger-scale databases (such as nationwide economic data), and is then treated numerically to ascertain the existence of effects

(discounting type 2 errors³) and their magnitudes. The second category uses qualitative methods to avoid the numerical treatments which often discard relevant but hard-to-systematise information, often through the use of in-depth interviews and (auto-)ethnographic practices. This aims to capture more complex effects and allows the exploration and elaboration of causal mechanisms — but not their validation — as well as a critique of pre-existing assumptions. Finally, the third category — which overlaps with the qualitative one — includes organisational and juridical literature which are the subject of theoretical and policy analyses, as with the USA social security benefits mentioned in the introduction. We must also add a fourth category of mixed methods, which involve both quantitative and qualitative aspects, such as survey data supplemented by in-depth interviews. When looking at the existing research on disability, even discounting research from the medical and public health fields (which are overwhelmingly quantitative), we can observe a strong presence of quantitative methods. Harris et al. (2014), in their investigation of 980 articles monitoring the impact of the American with Disabilities Act (ADA), show that 49% use quantitative methods, with an additional 11% using mixed methods, 24% for theoretical and policy analyses and 16% for qualitative methods. However, those include studies *about* disability, which do not properly belong to the field of DS⁴ (a field centred on ‘the socio-political-cultural examination of disability’) except as elements being analysed.⁴

When looking at DS⁴ specifically, the role of quantitative methods changes drastically. A first point of entry is to look at *Disability Studies Quarterly* (DSQ), the flagship journal of the Society for Disability Studies — principally because of its status as one of the most visible, longest-running, and well-known venues. With thousands of articles published over 42 years by a mix of scholars, activists, artists (often all three) as well as many others (Lindgren et al., 2014), DSQ would be the best positioned to claim to give a representative sample of contemporary thought in DS⁴ produced through the varied lenses of its many experts, albeit with a strong anglophone and North-American bias. Articles range from personal experience to policy recommendations, from poetry to phenomenological discussions. This variety naturally allows for more leeway than many fields of social science, but contributions engaging quantitative methods and data remain

3 A type 2 error is a false negative: the null hypothesis is presumed true when it shouldn't be.

4 Simi Linton explains that ‘Disability Studies [needs to be set off] as a socio-political-cultural examination of disability, from the interventionist approaches that characterize the traditional study of disability’ (Linton 1998, p.525).

surprisingly absent.⁵ For a motivating example, one can look at the DSQ online database containing the last 22 years of published papers in a searchable format. Of the 1549 total elements in the database (mostly articles, but also some editorials and reviews), only 115 mention the term ‘quantitative’ (similar results appear when searching for other terms like ‘statistical’⁶). What matters, however, is that of those, only 13 of that 115 correspond to actual quantitative studies about disabled people, including 8 which use mixed methods and some qualitative approaches. Moreover, 11 articles use the term in the context of a critique of quantitative methods, and 22 more only as a comparison to insist on the importance or superiority of qualitative methods. 3 studies look at large-scale economic data, and 11 use quantitative methods to study non-human subjects (quantitative representation in magazines or tv shows, building accessibility, article terminology, etc.). The other articles which are not reviews or editorials use the term ‘quantitative’ in other contexts or in the bibliography. One might then wonder how this strong inclination against quantitative methods came to be, and how it reflects a very particular epistemology — understood here as the way one produces legitimate knowledge about the world. This epistemology is not just partially reliant on unfalsifiable methods but is sometimes explicitly opposed to dominant norms of verifiability and reproducibility (Williams, 2020), although some scholars insist on the complementarity of the various approaches (Hahn & Hegamin, 2001; O’Day & Killeen, 2002).

1.2 A historically fraught relationship

We consider three main elements contributing to this particular epistemology that rejects quantitative methods: a historical-political reaction, a lack of access, and finally the possibility that such methods are not always the most efficient, especially in the historical contexts faced by DS scholars.

As stated above, quantitative methods are not foreign to the study of disability, and one could argue that such methods *created* disabled people as a specific social group that warrants both studying and specific policies. Indeed, as stated in the 2019 ‘Disability, AI,

⁵ One potential explanation would be that some journals become specialised in terms not just of subject but methodology — because of their editorial team, their reviewers, how they are indexed, etc... It is true that DSQ is more humanities focused, but considering its stated mission as well as its variety in terms of content and authors, this explanation seems insufficient here.

⁶ Using the keyword ‘data’ would not work as a cursory exploration indicates that it is most often used to denote qualitative data.

and Bias' report by the AI Now Institute: 'The history of disability itself can be read as the story of the ways in which various systems of classification (i.e., medical, scientific, legal) interface with social institutions and their articulations of power and knowledge.' Following Canguilhem (1943), early attempts to quantify human ability and performance led to the creation of a clinical norm in the Global North, this norm being interpretable both as the habitual average state of a body, and its ideal state. These early attempts allowed the establishment of a scientific basis for some of the worst horrors of the 20th century, including scientific racism and the eugenics movement. As such, it is not surprising that scholars who directly witnessed the atrocities organised around, and justified through, quantification developed a critique of the methods that were used to oppress and subdue vulnerable social groups.

These scholars' critique addresses three problematic aspects of this early quantitative work. First, the quantitative differences — which could stem from many different environmental sources — were often used to justify essential differences which negated the shared humanity of the studied subjects⁷ (O'Brien, 2011). Second, many of the initial studies — whose influence can sometimes still be seen, e.g. with IQ testing — rested on questionable methods and results (Washington, 2019). Third, any semblance of scientific neutrality or apoliticality was contradicted by the immediate biased use of such 'results' by their proponents to support eugenic policies — which was not just predictable but often an intended outcome for the scientists and policy-makers involved — such as with the *Buck v. Bell*⁸ case in 1927 in the USA and Aktion T4 in Nazi Germany.

This use of quantitative methods through motivated reasoning by people perceived as political adversaries cannot be relegated to a historical note on early 20th century racist-eugenic pseudoscience. In many ways, modern DS has evolved through a reaction to 'normal science' as performed by the medical establishment and its effects on different countries' policy-making, and more by critiques of data science as used by proponents of surveillance capitalism (Keyes and Austin, 2022). The development of the social model of disability shifted the debate by departing from the norm of

⁷ We explicitly assume here the fundamental position that all living humans have an equal claim to being considered human. This entails having their preferences equally valued as full-fledged members of society when trying to live their lives as they see fit.

⁸ The *Buck v. Bell* case is the landmark decision by the Supreme Court of the United States that allowed compulsory sterilisation of those deemed disabled. A proposed explanation for the defense lawyer's poor performance was that he was a known supporter of eugenics (Lombardo, 1985).

fixing/curing/redeeming/saving the individual (Goodley, 2016). One goal of its proponents was to move the locus of disability away from the quantifiable material body and its performance, towards the complex social relationships and legal intricacies of disabled bodyminds⁹, which resist simple quantification. A gulf can then still be observed between critics of the medical-political establishment and those targeted by the critique, who sometimes ignore it altogether (Sanborn and Patterson, 2014).

As a field, DS then seems to consider quantitative methods as a flawed tool of power with a dark past that continues till the present. This includes the ways quantitative measures are still engaged in policy discussions of disabled people in ways that do harm, either by evoking disabled people as burdensome or costly or in how measures are deployed around welfare, access to maintenance and technology, activities for daily living, measures of quality of life, normative expectations of health/wellness, etc.

A second aspect reinforces these historically-grounded concerns: quantitative methods often require formal training, and are used as a central element of legitimate speech, notably by the medical establishment (Kidd, Spencer, & Carel, 2023). However, a significant part of research in DS is performed by non-academic scholars, often based on their own lived experiences both as disabled people and as artists or activists (Clare, 2017; Linton, 1998). Among the many explanatory factors, one stands out: disabled people have much lower educational attainment rates. For example, using USA Census data from 2021, we can observe that, whereas 31.9 million out of 265.6 million adults are disabled (12%), only 6.8% of PhD holders are disabled.¹⁰ The USA is not alone in this regard and France¹¹ (which has a different societal and academic approach to disability, see Kudlick, 2016) provides an even darker picture.¹¹ Whereas disabled students made up 1.3% of students registered for an initial degree, this proportion went down for

9 Margaret Price (2015) borrows the term 'bodyminds' from trauma studies. She explains: 'According to this approach, because mental and physical processes not only affect each other but also give rise to each other — that is, because they tend to act as one, even though they are conventionally understood as two — it makes more sense to refer to them together, in a single term.'

10 These figures were computed by the authors from the CPS Disability Supplement — July 2021, using columns PEEDUCA (Demographics - highest level school completed) and PRDISFLG (Disability - recode, disabled). Data available at <https://data.census.gov/mdat>.

11 The statistics between the two countries cannot be directly compared due to different local modes of evaluation of disability. For the USA, the categorisation into 'disabled' comes from multiple questions in the census. For France, it comes from the student who applied for disability assistance (such as extra exam time) at their universities. The system is also not fully exhaustive for doctoral students as the latter sometimes register for disability assistance as personnel and not as student.

advanced degrees; disabled students were registered in science, health, law and economics at lower relative rates than other fields such as humanities.¹² Out of 74.000 people registered in doctoral programs in 2015, only 120 (0.16%) were considered disabled.¹³ We are not implying here that academic credentials automatically make for better science, but rather that they help their owners get recognised as legitimate producers of knowledge who can perform systematised research (and publish and apply for funding to do so) and can influence policy (Ymous et al., 2020). There is also a body of work within DS that talks about academic ableism directly,¹⁴ which we can condense down to a few words: the ivory tower has stairs.

A third aspect should also be considered: DS' conversion to quantitative methods: they might not be the most appropriate or efficient tools. Many of the results and observations that were historically needed to advance the political project of DS — and the disability rights movement — did not require quantitative methods. When legal texts featured explicit discrimination, theoretical and textual analyses were sufficient. For example, USA disability history prominently features a critique of the 'ugly laws' which restricted disabled people's participation in society, in some places until 1974 (Burgdorf and Burgdorf, 1975). One such law was Chicago's ordinance, enacted in 1881 (Schweik, 2009) :

Any person who is diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in the city, shall not therein or thereon expose himself or herself to public view, under the penalty of a fine of \$1 for each offense.

12 This also raises the question of how to compare educational attainment when accounting for acquired disabilities which tend to attenuate differences in the long run. For example, 5.0% of doctors under 40 employed in the USA in science, engineering and health are disabled, whereas 9.4% of those 40 and above are disabled (data from NSF: <https://nces.nsf.gov/pubs/nsf21321/report/persons-with-disability>).

13 These figures were computed from 'Higher education & research in France, facts and figures', by the French Ministry of Education, Higher Education & Research. Data available at <https://publication.enseignementsup-recherche.gouv.fr/eesr/10EN/info.php>.

14 We can recommend Jay Dolmage's work in his book *Academic Ableism*, Margaret Price and Stephanie Kershbaum with their ongoing Disabled Faculty Study, and the many writers in the volume *Ableism in Academia* (2020).

Fighting such policies only requires establishing the humanity of disabled people — insofar as shared humanity is considered sufficient to obtain civil rights. This is one of the places where quantitative methods are least efficient — and where art, political coalition building, activism, advocacy, protest, and rhetoric can achieve much in terms of policy-making by changing public opinion.¹⁵ However, if many social justice movements initially strive for equality of rights, it often leads to a necessary fight towards an equality (or equivalence) of outcomes.¹⁶ Indeed, the latter does not automatically follow the former — as can be seen with the ongoing struggles against racial and gender inequalities.

1.3 Systemic prejudice and unequal outcomes

So far, we have not effectively compared the respective roles of the various scientific methods we mention, and how they can establish different truths, often in a complementary fashion. For example, auto-ethnographic exploration is useful to explore how we interpret phenomena and can establish the existence of some given human experiences — if not their universality. The qualitative methods used in DS and advocacy did visibly succeed in one important regard: they allowed the creation of a *community* (Pelka, 2012). Individual disabilities vary wildly and the set of material issues faced by disabled people is accordingly affected. However, through the use of complex narratives, some themes — especially those of exclusion and social rejection and stigma — emerged, linking those varied life experiences. The corresponding works also established the legitimacy of disabled thinkers as knowers with valuable social insights, and empowered some members of the community.

The legal struggle against being considered second-class citizens is still ongoing — for people under guardianship arrangements and those with diagnoses of severe mental illness and intellectual disabilities, among many others. Beyond this struggle, a central object of contemporary critique is the systemic prejudice enacted by a multitude of institutions. The effect of each such institution can be limited, but they can combine to

¹⁵ Even when legislation establishes the right to equal access, for instance, disabled people have had to block buses until cities agreed to put lifts on them (like ADAPT protesters did in 1978 in Denver), or, in the cases of many access fails, provide testimony to get changes made.

¹⁶ We use 'equivalence' here as a way to address some critiques of the social model that underlined the advantages of the capabilities framework: what matters should not just be the 'utility' or 'welfare' but whether the individual manages to achieve certain objectives that they set for themselves, hence 'capabilities' (Burchardt, 2004).

create nearly insuperable odds. Because of this complex interplay, the causal relationships between policy and outcomes tend to dissolve — as does the chain of responsibility for particular outcomes. Any auto-ethnographic, oral history, or personal account of discrimination can be more easily dismissed as an anomaly by the institutions enabling such discrimination. Whereas purely qualitative methods can be useful for investigating causal relationships when those exist, they are generally powerless when it comes to generalising from the individual to the universal. A central issue remains: one cannot scientifically infer a systemic bias just from a (hand-picked) set of tragic personal narratives.¹⁷ Faced with technocratic systems and ‘evidence-based’ policy-making,¹⁸ simply asserting the humanity of disabled people is not enough¹⁹ to effect meaningful societal changes. Unlike for some earlier civil rights struggles, fighting for improved outcomes sometimes requires a focus on changing how resources are allocated. As things are today, the disabled community is already paying some costs that could have been alleviated by the use of quantitative tools. Let us take, for example, the British Department for Work and Pensions’ policies (DWP) from December 2011 till February 2014. Following a governmental ‘decision’ that there were too many beneficiaries of disability assistance and that one million people should be removed from the list,¹⁹ the DWP employed external contractors to efficiently reassess beneficiaries (Stewart, 2018). This ‘efficiency’ was not achieved, as the delays increased dramatically and only 13% of assessment reports met the required quality standard (Thomas, 2021), causing many people to be incorrectly categorised as ‘fit for work’, some of which consequently died, or were driven to suicide, from lack of resources,. Despite Stewart’s rigorous analysis of the political factors that led to the policy, she still bases some of her argument on the central figures of 2380 people dying after being found ‘fit for work’. This number by itself does

17 We have personally seen some colleagues defend this kind of epistemology and accept the inference of systemic aspects from personal experience. Although it can seem politically expedient, it creates an epistemological risk to legitimising such uses, as these methods can just as easily be used to defend oppressive theories and policies, or to argue that those in power suffer the most from discrimination (using choice examples instead of systemic analyses). There is a call within bioethics to develop measures of structural ableism, like those that exist for structural racism and sexism (Valdez and Swenor, 2023).

18 Although policies can be ‘evidence-based’, we should insist that they cannot be ‘evidence-driven’. Data analysis can improve the match between methods and ends, but cannot by itself establish what the ends should be. Following Hume (1739), data can tell us what *is*, which should never be confused with what *ought to be*.

19 To note, the target for the number of people to be removed from the beneficiaries’ list was apparently not even ‘evidence-based’ and corresponding to an estimate of how many were actually fit for work but was based on budget considerations (Stewart, 2019).

not reveal anything, as we do not have a control group or an idea of the mortality rate for the rest of the relevant population. Hence, although we do have numbers for how many people died, we cannot go from this statement to the establishment of a clear causal link and responsibility, which would have required obtaining more thorough data. The DWP itself, in its 2015 report answering the freedom of information requests, explicitly states as much in bold in the introduction: ‘Any causal effect between benefits and mortality cannot be assumed from these statistics’ (DWP, 2015). Addressing the limited use of quantitative tools in DS would allow different and potentially more efficacious critiques of public policies when the causal mechanisms become inscrutable. Although one cannot negate that quantitative methods have been used as a tool of oppression, a tool in itself does not always dictate its uses, although no tool is neutral (Eubanks, 2018; Noble, 2018). It is but a feature of power, and for DS to influence policy towards empowerment and beyond addressing immediate crises, it might be necessary to use such tools. The alternative is to cede ground — and legitimacy — to people for whom disability is an anomaly that has to be removed from society. Qualitative methods were historically necessary, optimised for the fights of the 20th century, and got us to the current status quo. We do not suggest abandoning qualitative methods, which still have a strong role. However, going further might require adapting some methodologies, following the lead of other social justice movements, merging contemporary critique with rigorous systemic analyses.


2. Disability, pride, and social justice futurities

2.1 Social justice and exclusions

Other social justice movements have faced some of the same problems that the disability rights movement is facing. Many movements have gone beyond fighting to be considered equally human and are fighting to obtain equality not just in rights but in facts (and outcomes). Whether we consider the evolution of social justice movements against racism or against sexism — to cite two of the main ones of the 20th century in the Global North — they have at least partially successfully transitioned to influencing policy-making for improved outcomes by addressing the shortcomings of purely quantitative research (Ben & al., 2023; Covarrubias & Vélez, 2013; Humbert & Guenther, 2020). It is not to say that there haven’t been successes in that direction for disability (such as the American with Disabilities Act in 1990 or the French Disability Law of 2005). However,

there remains the question of who is invited to the table when laws are drafted, and how those laws are ultimately implemented (Bagenstos, 2009).

The parallels between disability rights and other social justice movements have already been investigated by multiple scholars (Ralph, 2012; Clare, 2015; McRuer, 2009). But, rather than parallels, the salient points are the differences. For example, as stated by Ralph (2012) regarding the ADA: 'Perhaps even more disconcerting, "disability" coverage is the only civil right that legislates recourse to a medicalized definition for inclusion'. A central question is then: how do we explain the different evolutions between these movements, and does it stem from a fundamental difference between the social groups defined by race or gender and the ones defined by disability?

A first hypothesis would be to situate this difference in the fact that the disabled community is one whose central inclusion criterion is a shared exclusion from society. The contemporary social group externally defined as 'disabled' is more than heterogeneous and does not solely consist of people with observable, quantifiable material impairments (e.g., amputees or blind people). It also includes those whose impairments vary through time (such as with chronic diseases) and whom some would alternatively classify as disabled or non-disabled (like people going through cancer treatment, who count as disabled under most disability law, but some of whom may not be disabled after treatment). It finally includes those who may not always want to be counted as disabled for many complex personal and political reasons, such as the Mad and Neurodivergent communities. The Deaf community diverged longer ago and have their own rights movement, cultures, and history, often separate from and sometimes parallel to the disability rights movement (Gannon, 2012). However, this hypothesis ignores that the conception of a social group based on shared exclusion is also at the core of the social justice movements mentioned above. Historically, women and racial minorities are consistent social groups only insofar as they were both excluded from a society of white men.^{20,21} 

20 To quote Marcus Rediker (2007): 'no African consider themselves as "black" before getting aboard a slave ship. They were Dahomey, Fanti, etc. They *became* "black" (and the sailors *became* "white") during the Middle Passage, by the sole means of their common fate.'

21 A common critique of non-intersectional feminism (and 'white' radical feminism) is the essentialisation of women as a monolithic group based not just on a shared exclusion but on a common women's experience (which rarely takes into account the lives of women who are also members of other marginalised groups). See the #DisabilityTooWhite on twitter, a hashtag created by Vilissa Thompson, for examples.


2.2 The problem of pain

A second hypothesis would be that, unlike mainstream disability politics, a central concept underlying other social justice movements was that the distinctions that formed the norm were mostly arbitrary. Not only were the different social groups claimed to be equivalent in dignity, but also in most relevant measures (such as working ability). Concerning gender and sex for example — which should not be oversimplified into binary categories (Fine, 2010) — the current scientific consensus is that although there are some material differences, they should have next to no bearing (and no predictive power) on both day-to-day life and how people should be treated socially or legally. However, the arbitrariness of the difference seems harder to claim when it comes to disability. Contemporary research has indeed shown that the social model, despite accounting for many of the obstacles faced by disabled people, ultimately ignores some material realities. Central to this evolution is the problem of pain: even a society where ableism would be eradicated would still have to contend with the fact that certain bodyminds go through life experiencing chronic pain — some of which resists medication.

This problem of pain is central to our considerations as many schools of thought are centred on the goal of avoiding pain. For most philosophical traditions that acknowledge it, pain either lowers individual welfare (in many forms of utilitarianism) or makes it so that no amount of pleasure could counterbalance it (see Benatar, 1997, for his analysis of the asymmetry between pain and pleasure and its impact on questions of disability). Going from these individual welfare considerations to the exploration of how to compare societies is the central object studied by the field of population ethics, which asks in what ways one potential future society is better than another (and hence, how to guide choices that could affect which society we live in). In most frameworks considered within population ethics, replacing a disabled life by a non-disabled life is a net positive. Despite the field's many problems (Arrhenius, 2012), such a view is still reflective of both popular opinion and public policy with its use of quality-adjusted life years (Orr and Wolff, 2015). If an ideal society is one without (non-consensual) pain and one where every being maximises their capabilities, it cannot feature disability (in its naive interpretation). This is

reflected in contemporary society's imagined futures: the ones that are not dystopian seldom feature disability, at least until some recent fictional works by disabled writers (Sjunneson-Henry et al., 2018). This difficulty to imagine a disabled future is not without consequences. Indeed, in many ways this lack of future not only reflects the present but guides it. The goal of many 'charity' groups that focus on disability is, essentially, to make disability a non-issue, either by curing disabled people or by preventing their being born through genetic research and testing. This is notably the case for Autism Speaks — one of the main organisations dedicated to autism — which has received harsh criticism from autistic advocates for favouring eugenics as well as not having any autistic person serving on its board for a long time (Broderick, 2010). Despite the idea's absurdity,²² this perceived transient nature of disability as a social concept lives on and continues being an obstacle on multiple fronts. First, it reinforces this idea that a disabled life is inferior and might not even be worth living.²³ Second, it affects our policies in the short-term: why would society fundamentally change its practices (architectural norms, healthcare, universal sign language education) to address social 'ills' that would not be relevant anymore in at most a few generations? In the context of 'evidence-driven' policies based on quantitative methods with the goal of optimising certain metrics for a given effort/budget, costly fundamental societal change are rarely worth the investment (for the decision-makers).

2.3 Crip pride

We can then ask whether DS  usual to engage with quantitative approaches, especially when it comes to disabled bodyminds, could be related to an aversion to any theory that features utilitarianism — which underlies evidence-based policy-making. Unless disabled lives are considered to be as worthy as non-disabled lives, accepting quantification means giving credence to theories which advocate for the eventual eradication of disabled people. There are, thankfully, some arguments to be made against this position. First, this perceived inferiority of disabled life is increasingly challenged, thanks to

²² This is discussed in the conclusion to Shew (2023), where the author discusses how we can actually expect a more disabled future — through climate change's impact on insect-borne diseases, environmental pollution, normal ageing expectations, or through new viruses — to even an off-planetary future where, indeed, everyone is disabled in space (and will be disabled by space).

²³ In the USA, an online poll on 1000 adults indicated that 52% of them would rather die than lose the ability to live an independent life (Sibonney, 2008). Despite the shortcomings of online polls and the importance of the question's phrasing on the answers, this still indicates that this idea is far from alien to the public.

reflexions which trouble the notions of curing²⁴ slowly making headway (Clare, 2017), and challenges by communities like the autistic self-advocacy community (groups like ASAN and AWNN²⁵). Another facet is the emerging study of transability, or the desire to acquire a disability — which remains contentious within the disabled community (Baril, 2015). If being disabled becomes something that can be socially desired, it fundamentally challenges the notion of disabled lives not being worth living. Despite these arguments, many disabled people still believe that disability entails inferiority — just as other marginalised communities have, sometimes through centuries of internalised oppression — even when the peculiarities of their bodyminds give them rare opportunities (Rembis, 2013; Letz, 2022). Most importantly, following other social justice movements, is the emergence of *crip pride* celebrating not just the dignity and inherent value of disabled lives but also disabilities themselves in how they change the bodymind in ways that should not automatically be considered negative. Any version of DS that seeks to utilise quantitative methods without fearing the dangers of a descent into utilitarianism then needs to assert the equal value of disabled lives, not just in terms of dignity but in terms of utility (in the utilitarian sense). This radical pride is already performed by certain subgroups, such as the Deaf community. But crucially, the latter has historically generally rejected the disabled label, asserting their pride as a community separated more by cultural than material differences. This is reflected by Deaf studies often being considered outside of Disability Studies.

We have examined some of the fundamental obstacles to the use of quantitative methods in DS, which radical *crip pride* could address. But how? The next section will focus on the application of such frameworks to data-driven methodologies.

3. Crippling Data Studies

Although the previous sections examined the emphasis on qualitative work within DS, some new projects go against this trend. A number of interdisciplinary DS scholars and community members offer new methods to incorporate data into the project of DS. They


²⁴ In France, a short film was once shown at a medical conference in the Parisian public hospital network (APHP) in the early 2000s. This film featured a young lady with a form of cerebral palsy who was offered a treatment that would fully cure her disability and who refused to do so. Private communications with a doctor present at the time reveals that the doctors in the public were baffled by the idea at the time.

²⁵ The Autistic Self-Advocacy Network (<https://autisticadvocacy.org>) and the Autistic Women and Nonbinary Network (<https://awnnetwork.org>), among other groups.


use concepts like disability justice, epistemic justice, and a recognition of past data harms, not just to reform data projects, but to imagine how data science can be reclaimed toward crip-led futurities.

3.1 Crippled Projects



Kelly Fritsch and Aimi Hamraie begin their 2019 'Crip Technoscience Manifesto' with the following words:

As disabled people engaged in disability community, activism, and scholarship, our collective experiences and histories have taught us that we are effective agents of world-building and -dismantling toward more socially just relations. 

They explain how crip technoscience often positions disabled people as not-already makers and tinkerers, which is a terrible misconception. They explain how we need a crip technoscience that values disabled people as knowers and makers from the start. They talk about the practice of technoscience — and here data science would be included — as always and already a political practice.

Though not specific to data sciences, their four 'commitments' to crip technoscience should inform any data studies project wishing to do justice by disabled people. The four commitments are: centering of disabled people as designers/makers, acceptance of political friction as inherent in this work and willingness to engage with access as friction (a space where things are contested), interdependence as a political technology, and disability justice. They explain: 'We position the crip politics of interdependence as a technoscientific phenomenon... Crip technoscience borrows the tools of feminist hacking and coding blasphemy against liberal theories of disability rights and rehabilitation imperatives, as well as against the technological essentialisms of disability scholarship.' Where traditional approaches have often left disabled people outside where it pertains to doing and making (Blanchard, 2022), a crippled data studies agenda would keep the four commitments in mind.

How do we 'crip' data science? The Crip Technoscience Manifesto offers theoretical backing, but what does this look like in practice? What does data look like in crip hands and hooks? What kinds of data, different from that studied in traditional data science, are crip technoscientists making, gathering, and shaping?

One approach to crippling a research space can be found in the counterventional research agenda being created by Rua Williams, a critical DS researcher. Counterventional research inverts the usual sense of expertise in scientific research: instead of researchers setting the parameters of design or consultation for disabled participants, Williams sets up research where disabled participants — in their case, autistic people — are brought in and direct researchers on the parameters of what they want to see designed and how they want projects to go.  Much of this research is in the works, but the model Williams uses is designed to give disabled participants control of the direction and character of the research — and indeed the outcomes are, in part, expected to be with the researchers themselves. Part of the interest in putting disabled people in charge is to make other participating researchers experience surprise and recognise (and internalise) disabled expertise as an important facet of any project aimed at disability. The intervention is on the researchers themselves in this model, not just the research participants. It's an attempt to address some of the asymmetries of research (and participant-experienced epistemic violence and injustice, more below) that Williams has encountered as an autistic researcher. 

Another approach to crippling data can be found in the work of Martina Svyantek (2021), who was initially motivated by the gap between the fact that many university planners and architects talked positively about accessibility in master planning sessions, but then showed little understanding of it in their presented plans. Using library resources, university archives, official documents, she tracked keywords around disability from 1990 to 2015 with collections every five years to plot it out — both at her home university and at two other universities in the USA. Recognising the dearth of good data about how many and what types of disabled people exist within an institution over time — especially given issues with diagnosis, stigma and risk with disclosure, and more — Svyantek explains her work is 'to collect and analyze the documents produced at institutes of higher education as a workaround' (p.70). The methods she developed in order to perform 'institutional counter-surveillance' are broadly applicable to other places, and represent a way of tracking and monitoring how institutions talk about disability versus what they enact in terms of policy. Her methods offer a way to gather data about disability and accessibility over time through data and documentation that exist about campus resources and plans instead of focusing on people, who may or may not be documented as disabled and whose individual records would be private. She explains: 'Observing documents from institutions of higher education is not about locating

Disability within people or society, it's about *locating inaccessibility in the systems and structures that surround them*—a stance that reiterates my own relationship to this work while utilising a Critical Disability Theory perspective' (p.84). The apparatus she develops is meant to avoid tracking individual disabled people over time, and instead track the inaccessibility they encounter. This is a form of crippled data production in a quantitative mode that sits in opposition to usual measures of disability on campus, which often rely on self-reports, private data, and quota numbers that often don't accurately reflect anything about *structural* institutional changes toward access, and instead often draw from how many people need accommodations.

Although we lack the space to provide in-depth coverage of each interesting crippled research project out there, we think it important to mention other crippled perspectives of research: AI projects by blind researcher Cynthia Bennett, tactile access projects by Chancey Fleet, data visualisation by Crystal Lee, the work of the Nakamura Disability Lab, and various DISCO network projects (Elvasky et al., 2022; Lee, 2022; Nakamura, 2015-2022; and DISCO, 2022²⁶). There are also new tools to help people assess whether their programs align with disability justice. The Disability Justice Audit Tool²⁷, created by Leah Lakshmi Piepzna-Samarasinha and envisioned with Stacey Park Milbern, helps assess the goals of organisations and how they arrange their business. This tool does not provide or make quantitative data. However, it offers good questions to consider prior to or in process with different lines of research, products, and arrangements. The audit tool asks about the features of an organisation with relation to disability and disability justice, including its history, relationships, knowledge, and politics, and the tool asks board and advisors to take stock of what they offer and know (in terms of accessibility, community, and internal policies). It also offers education on disability justice in a way that primes groups to orient differently.

3.2 Barriers to Crippling Data Science, besides the usual suspects

26 The DISCO Network consists of the following labs and PIs: Black Communication and Technology Lab, PI: Catherine Knight Steele; Future Histories Studio, PI: Stephanie Dinkins; Digital Accessible Futures Lab, PI: Remi Yergeau; Humanities and Technoscience Lab, PI: Rayvon Fouché; and the Project on Rhetorics of Equity, Access, Computation, & Humanities Lab, PI: André Bock.

27 <https://www.northwesthealth.org/djaudittool>.

Projects that situate disabled people as more central in research — by catering to disabled modes of communication/feedback and by centering disabled experts to ensure ‘nothing about us without us’ happens — often arouse more scrutiny from institutional review boards and ethics review. Rua Williams has had to explain, as an autistic researcher, why recruited autistic participants would need alternate forms of communication and, more importantly, how such participants could be reliable witnesses about their own experiences. They explain at one point (Williams, 2022):

I interview autistic adults over text message. I have to fight with my IRB sometimes about how, yes, that's allowed, and I use Signal, like it gets encrypted. But they [tell me] you're confused about it. And, no, I can get rich ethnographic data from a week of talking to somebody over text chat that I cannot get from an hour of making somebody sit in front of a camera and talk to me... Complex explorations into what is effective communication for your population is a really important aspect to consider when you're doing this kind of work.

There are also quality issues regarding data collection about disabled people, partially because of the way samples are collected — both in qualitative and quantitative research — from participants who sometimes struggle with normative expectations and ableist modes of communication and participation. Some participants might also quit after reading a survey's demographic section, especially if it features ableist language. The recruitment processes also sometimes favour certain demographics with undiagnosed disabilities, which skews the data (Blanchard, 2022). Surveying parents and caretakers also gives a warped perspective, even before considering the potential conflicts of interest.

By default, institutional review boards often regard disabled people as uniquely vulnerable, while also not appreciating differences in communication styles, technologies, and modes of data gathering that may be necessary to properly engage participants. Disabled researchers face a never-ending series of obstacles and microaggressions to be able to publish and practice as scientists, especially when they work on topics on which they have personal experience. Instead of being viewed as

having a unique window into the subject²⁸, disabled researchers often get to hear other colleagues and peer researchers talk about research subjects — people who are like them — in stereotyped and demeaning ways.

One important article that spells out the epistemic violence encountered by disabled STEM researchers is coauthored by seven researchers (including Williams and Bennett) who share their experiences as disabled people in their fields — with the lead author going by Anon Ymous, since the consequences of speaking up about these experiences can be professionally costly. The piece, entitled, “‘I am just terrified of my future’: Epistemic Violence in Disability Related Technology Research’, speaks to the personal experiences of the seven authors, but also names the pervasive epistemic injustice they are faced with as they try to their work. They write:

We read about ourselves as disordered, as an emotional, financial and overall burden to the people around us, as incapable of forming social relationships, undesirable, less than, limited, incapable, as fundamentally lacking—echoing the worst nightmares of our internalized ableism... (Ymous et al., 2019)

They name the harms in the way research is positioned *against* disabled people, and how participating in these systems is draining and degrading. In what is surely an example of what these authors offer, the publication, which is not known for point-counterpoint style offerings, *solicited a rebuttal to their paper*, shared directly after its text that repeatedly uses ‘disabled scholars’ in scare-quotes and italics and suggests that because these scholars have made it in the academy that they are not truly disabled.

3.3 Data Harms

Crippling data science is not just about having more disabled researchers or having more accessible technology or universal design on one’s agenda. Beyond involving disabled experts in conversations about research and data, it is making sure control of data remains with communities impacted and that data is not used ‘against’ disabled people,

²⁸ Another issue affects researchers in certain countries where minority studies are not well established, as in France. Researchers close to their fields of study are heavily scrutinised, based on the presumption that this closeness brings bias — not realising that bias is omnipresent and that the best a researcher can aim for is acknowledging and controlling for that bias — which means questioning the objectivity of a ‘default position’.

given the history at work. It means engaging with disabled identities and in cross-disability communities, attending to the larger political context of disability to avoid perpetuating the harms that disabled people, as subjects of technoscience, have often been subjected through classification systems and surveillance.

One key feature we see in crippled projects is that authority stays in the hands of disabled researchers, communities, and participants. Another key feature is with how data is generated, managed, and used: who are the authors, curators, keepers, etc, and how are things stored and managed. We also see, justifiably, ongoing concern around privacy and against surveillance. The 2019 AI Now Institute report on 'Disability, AI, and Bias', reviewed some areas of bias produced by already-deployed machine learning and AI, especially around race and gender. The authors explain:

Those who have borne discrimination in the past are most at risk of harm from biased and exclusionary AI in the present. And when these discriminatory logics are reproduced and amplified by AI systems, they are likely to be read as authoritative, the product of sophisticated technology. Beyond biased data, additional risks are presented by the significant power asymmetries between those with the resources to design and deploy AI systems, and those who are classified, ranked, and assessed by these systems.

Many disabled people are 'managed' through systems of healthcare already, and much more at risk of the lack of privacy afforded in institutional settings. Even where privacy risks are lower such as with public transit, some of the institutions intended to increase disabled welfare are in practice built not to favour autonomy but to exert control over disabled lives (Blanchard, 2020). With additional data generated by our technologies, many are at risk of the sort of continued policing and curtailment of autonomy seen in earlier eras for disabled people. Too often, a false scarcity with regard to resources for disabled people is given as justification for what technologies they are allowed to use, what healthcare they can get, what spaces they are given access to.

A consistent trend that we witness in crippled research is a desire to 'counter' certain ways of normal technoscience. There's a desire to put the tools of research back upon the researchers, and the tools of policy in terms of technoscience back toward reforming policy. A crippled data science has to be one that not only puts crips in charge, but allows crips to subvert regimes of data that serve to constrict, incarcerate, and police disabled

identities. In this vein, we should be looking to surveil institutions that have surveilled disabled people, and to count and monitor things within the infrastructure rather than individual disabled people or limited categories of disablement. We also see a great desire to take advantage of public data and force transparency upon the institutions that govern our lives, with a huge value placed on publicly-shared information and publicly-accessible research.²⁹ We should be seeking data science that combats ableism, values the crip, and reduces rather than redirects systems of oppression.

4. Conclusion: beyond controlling disability

In the introduction, we decided to set aside the question of *who* can perform disability research. Since then, following ‘nothing about us without us’ we have detailed the importance of involving crips at all levels in disability research. One question then seems natural and even central: *who counts as crip?*

We reject the relevance of this question. If the history of disability is in good part one of control through various institutions, let us not forget that the public played a big role. The gatekeepers of disability are strong, and nearly never disabled. They are the righteous crusaders harassing the person with cerebral palsy on a reserved parking spot because their disability is not visible. They are the ones who yell at the amputee with a discreet prosthesis on the subway before realising their mistake. They are the people who require full disclosure of any disability status before letting people live their lives. They enforce rules, ostensibly to protect a vulnerable minority’s interest but at a significant cost. Well-meaning ignorance is the reason why many disabled people fear going outside (Mason-Bish and Kavanagh, 2019). More crucially, the scarcity that motivates these rules is often artificial or a result of the control mechanisms: these can be more costly than a system that would guarantee autonomy without controlling who deserves assistance.

Regimes of suspicion and biocertification (Samuel, 2014) are not liberating: their effects are first felt by the most vulnerable or the ones who depend on passing to survive. Research projects should not be evaluated based on the identities of their authors—

²⁹ Publicly-accessible here should not just be understood as overcoming the financial paywalls but also by formatting the outcomes of this research — to be compatible with screen-readers for example — and to make it as understandable as possible by those it affects.

these matter, naturally, but should not be determinant: ableist work can be criticised for its ableism without considering who wrote it. Moreover, being disabled gives no guarantee that one's work is free from (internalized or lateral) ableism³⁰. No crip can speak for all crips after all. Our objective is not to have a quota of disabled researchers in every research project on disability. We instead want to underline that this is an opportunity to perform better research and to open new questions by involving and empowering people who have had little opportunity to be heard and whose agency has not been allowed to develop to its full potential.

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³⁰ One's work sometimes has a strange influence on one's status within the community, such as with Tom Koch's (2008) critique of (disabled) British disability researcher Tom Shakespeare in an article titled 'Is Tom Shakespeare disabled?'

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