

# Crippling vulnerability

a disability bioethics approach to the case of early autism interventions

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## Abstract

The relationships between neurodivergent and disabled communities, and healthcare practices are marked by ambivalence. While there is a history of harmful and discriminatory practices, the clinical encounter also holds beneficial and empowering potential for neurodivergent and disabled people. To address this ambivalence, this paper's central question is whether and how bioethical decision-making in healthcare settings can become more informed by critical insights from neurodiversity and disability studies. The bioethical debate in Western countries on early interventions for young autistic children will be the case animating my theoretical propositions. I provide a working definition of such a 'disability approach to bioethics' and review the obstacles in both mainstream bioethics and disability studies this approach has to overcome. Then, the ethical concept of vulnerability, its feminist reinterpretation and its potential for disability bioethics are introduced. Instead of using the concept in its traditional, problematic sense, I propose that vulnerability can be reclaimed, or crippled, by neurodiversity and disability movements to do the exact opposite: to trouble the demarcation between the vulnerable and the invulnerable, to stress structural injustices over individual deficits, and to justify solidaristic, empowering interventions over paternalist ones. Finally, this 'crippled account of vulnerability' will be applied to the case of early autism intervention.

## Keywords

Disability, neurodiversity, autism, bioethics, vulnerability

## Introduction

The relationships between neurodivergent and disabled communities, and healthcare practices are marked by ambivalence. On the one hand, there is a well-documented history of discriminatory and harmful healthcare interventions regarding neurodivergent and disabled people, which will be illustrated below (Chapman & Bovell, n.d.; Ouellette, 2011). On the other hand, healthcare practices also hold beneficial potential and provide necessary services. Neurodivergent and disabled people continue to seek and value clinical help, for example, to receive a diagnosis and thus formal recognition, to find support in navigating various social services or to obtain a remedy for impairing aspects of disability, such as mental health problems (Roche, Adams, & Clark, 2021).

To address this ambivalence, this paper's central question is whether and how bioethical decision-making in healthcare settings can become more informed by critical insights from neurodiversity and disability studies. To this extent, I will build on the parallel with feminist approaches to bioethics and propose a 'disability approach to bioethics'. Expanding on the work by feminist and crip scholars, I will argue that a universalised and politicised concept of 'vulnerability' offers much potential for such a disability-informed ethical approach. The ethical debate on early intervention for young autistic children will be the case animating the theoretical propositions.<sup>1</sup>

This paper is composed of four sections. First, the case of early autism interventions will be introduced as it is taking place in many high-income countries. Second, I will formulate a working definition of a 'disability approach to bioethics' and the issues in Western bioethics and disability studies this approach will have to overcome. Third, the merits and pitfalls of the ethical concept of 'vulnerability' will be discussed in the context of such a 'disability bioethics'. Finally, I will arrive at a 'crippled account of vulnerability' by applying the concept to matters of disability in general and the case of early autism interventions in particular.

### 1. Ethics of early detection and intervention for autism

In recent years, developing early, psychosocial interventions for autistic infants and their families has been among the top priorities of autism researchers in high-income countries. The aim of such interventions is to improve key social and communicative skills during critical, developmental phases in the first years of life. These improvements are expected to benefit autistic children's functioning and quality of life over time (Landa, 2018).

#### Opposing cure, affirming neurodiversity

Although a variety of autism interventions has always existed, particular autism interventions are marked by a history of controversy, e.g. Applied Behavioural Analysis (ABA). ABA-interventions for autistic children have been common practice in English-speaking, Western countries. Initially, ABA consisted mainly of 'discrete trial training' rewarding children when displaying 'normal' behaviour such as looking the therapist in the eye, while punishing them for displaying typical but often harmless autistic acts such as hand flapping. Autistic adults in North-America and Europe have strongly criticised ABA's means and ends as it would attempt to normalise or even cure autistic behaviour, and undermine autistics' autonomy and authenticity (Chapman & Bovell, n.d.; Dawson, 2004).

In opposition to the pathological view of autism which underpins such normalising interventions, autistic researchers and self-advocates have gathered around the idea of neurodiversity.

The term neurodiversity was coined in the late 1990s by autistic sociologist Judy Singer (1998) and journalist Harvey Blume. Singer initially described the 'neurologically different' as a new political

category along with gender, race and class, building on existing ideas such as the social model of disability.

At this point in time, two central claims can be distilled from neurodiversity theorising<sup>2</sup>. First, the neurodiversity paradigm underscores the existence of natural and valuable diversity in human types of cognitive, emotional and behavioural functioning without immediately assuming a hierarchy among these ‘neurotypes’. Neurotypical people might be in the majority, but under this paradigm, they are not conceived as inherently superior to neurodivergent minorities such as autistics, ADHDers, Tourettics and others. This claim for acceptance of diversity drives the resistance against ableist research, clinical practices, and language use, focusing on prevention, treatment and cure (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2021; Chapman & Bovell, n.d.).

Second, neurodiversity proponents recognise distress and disablement experienced by neurodivergent people. Instead of attributing these disadvantages to individual deficits, though, they primarily point to structural processes of marginalisation and oppression. In reaction to these structural injustices, the neurodiversity movement manifests itself as an emancipatory, social justice movement. Proponents strive for a more just society in which discrimination against neurodivergent people in educational, healthcare, labour settings etc. is tackled, and privileges for neurotypical people are reformed into rights for all, irrespective of neurotype (Chapman, 2019).

The neurodiversity paradigm(s) can be seen as perspectives; either as lived experiences, ways of producing knowledge, ways of looking and talking back to power – of ‘queering’ the cognitive normative gaze

### Current debates on early autism programs

Moving back to this paper’s exemplary case, one can see that most interventions currently under development for young children with autism, move beyond contested ‘discrete trial trainings’. Behavioural techniques such as reinforcement are evidently still part of such programs, however, more recent interventions depart from the abstract, clinical setting where the child and therapist are sitting face-to-face. So-called ‘Naturalistic Developmental Behaviour Interventions’, or NDBIs, use daily, naturalistic settings instead to foster children’s development of socio-communicative skills. Often, parents are trained to conduct certain techniques, such as eliciting joint attention through eye contact in playful settings, while interacting with their child at home to increase practice time and generalise skills to daily situations (Sandbank, Bottema-Beutel, & Woynaroski, 2021).

Despite these evolutions, the controversy over these early interventions has not settled at all. In the fall of 2021 for example, autistic scholars and advocates raised concerns over a recent publication in *Pediatrics* reporting ‘a significant reduction in the severity of ASD behaviours’ through a parent-mediated, developmental intervention (Whitehouse et al., 2021, p. 8). Children involved were between 12 and 36 months and were at an elevated likelihood for autism. At the age of 3 years, 18 months after the intervention, significantly fewer children in the intervention group ticked off the necessary boxes to fulfil the diagnostic criteria of autism than the control group. In other words, the intervention diminished features of autism and, for some, led to a kind of ‘prevention’ of an autism diagnosis.

This publication led to an outcry on social media by autistic self-advocates (Neurodiversity Advocates, 2021). They felt harmed, collectively, by the ongoing conceptualisation of autism as an inherently pathological condition that needs to be prevented, or at least treated. Self-advocates would have rather seen an intervention in line with autistic priorities, such as improving mental health issues or quality of life in general. They also feared harm in a more individual sense. Children might lose access to services if they fail to obtain a formal autism diagnosis. Also, training children in normal behaviours

might lead them to ‘camouflage’, or hide atypical features in order to fit in. Reportedly, it is mainly autistic girls and women engaging in such camouflaging behaviours and bearing the associated costs on their mental health, such as anxiety, depression and suicidality (Cook, Hull, Crane, & Mandy, 2021). Lastly, power imbalances in the study design were questioned; i.e. were autistic people involved?

In their counterreaction, the study’s authors made a valuable argument regarding the risk of missed diagnoses, in favour of needs-based services over category-based ones. In reply to the other points, though, the counterreactions were more oppositional. First, they claimed to adopt neurodiversity and participatory schools of thought, although their publication did not mention this. Also, they claimed this bottom-up reaction from the autistic community might ‘discourage young scientists from wading into autism research’ and ‘thwart ongoing treatment studies and future investment’. Last, some argued that therapies for ‘desperate families’ of ‘low-functioning’ children would be paused as a result (Askham & Dattaro, 2021, pp. 2–3). This latter attempt to break up the autistic community into so-called ‘low-functioning’ autistics in desperate need of professional help and ‘high-functioning’ self-advocates ignoring these needs, is seen by many as anti-neurodiversity rhetoric (Van Goidsenhoven & Vanaken, 2021).

### The ethical stakes of early autism programs

Clearly, bottom-up resistance evokes tensions in autism research, with two apparent camps in the ethical debate. On the one side, much of mainstream academic literature assumes that developing these early autism programs is the right way forward. Consequently, current discussions in the field mainly involve questions of operationalisation and implementation, i.e. which intervention methodologies are most effective, at what age should they start, what is an optimal cost-benefit ratio etc. Neurodiversity critiques, on the other side, may make us infer that clinical interventions for autism should always be considered a no-go, as the focus should be on removing societal barriers outside of these clinical settings.

However, the ethical discussion on early autism interventions deserves better than a debate on whether these interventions are *inherently* right or wrong. More valuable ethical questions would inquire whether and how such early interventions can avoid or lessen existing harms for the heterogenous group of infants on the spectrum and their families, without causing additional harm; how early autism interventions can be an opportunity to redress structural injustices without reproducing current, unjust power asymmetries.

A proper bioethical analysis of this case holds the potential to answer these questions and contribute to the debate in two ways. First, a robust ethical underpinning may strengthen the political claims of the neurodiversity movement and anticipate co-optation or authority-based counterreactions like the ones illustrated above. Second, a bioethical analysis might help build alliances with autism researchers and clinicians. Autism professionals intend to lessen or avoid harms for autistic people, which is a strong, ethical commitment which they share with neurodiversity advocates. In a similar vein, principles of doing well, promoting justice and respecting autonomy are both critical principles for healthcare professionals *and* for neurodiversity proponents (Chapman, 2019). Bioethical arguments and terminology might thus help bridging both camps.

Up to now though, bioethicists nor neurodiversity scholars haven’t engaged much with each other’s fields (Hens, Robeyns, & Schaubroeck, 2019). The fairly recent entry of neurodiversity studies into academia might explain this lack of crossover. However, when we look at the more established interactions between bioethics and *disability studies*, it seems that time in itself does not suffice to arrive at a fruitful crossover. The next section will analyse which current tensions need to be overcome to arrive at a proper disability approach to bioethics.

## 2. Disability bioethics

Neurodiversity theorising shares some critical aspects with the academic and activist disability movement. Both aim to reconceptualise disorder into difference, as discussed above, and take up the struggle for social justice for those who differ from able-minded and able-bodied norms. Neurodiversity proponents have highlighted the experiential and theoretical links between being autistic and being physically, sensory or intellectually disabled. Although daily realities might differ, some claim a shared affinity between disabled and neurodivergent people as both live their lives in a minority body-mind in a society where able bodies and typical minds are still the norm (Chapman, 2019; Rosqvist, Chown, & Stenning, 2020; Singer, 1998). Below, I build on this shared affinity by drawing parallels between bioethics' interaction with disability, and a neurodiversity-informed, ethical analysis of early autism interventions.

### Defining disability bioethics

The field of bioethics and the disability movement have clashed several times over the past decades, particularly on life-or-death issues such as prenatal selection or assisted suicide for disabled people. Despite these tensions, some feminist ethicists have explicitly integrated a disability perspective in their work and vice versa (e.g. Kafer, 2013; Kittay, 2019). However, most attempts at cross-pollination between bioethical and disability thinking are still taking place in the margins of the respective fields. Consequently, a more systematic 'disability approach to bioethics' is still far from being established as an acknowledged line of academic inquiry, particularly when compared to the now well-established 'feminist approaches to bioethics'.

Interestingly, a handful of interdisciplinary scholars have started to define the contours of such a disability approach to bioethics, or 'disability bioethics' in short (e.g. Ouellette 2011; Scully 2008; Garland-Thomson 2017; Stramondo 2016). My working definition is the following: disability bioethics are approaches to bioethics conscious of the empirical and theoretical insights offered by disabled (and neurodivergent) ways of living. The approaches conscientiously apply those insights in its questioning, methodology, theory and ultimately in its recommendations to ameliorate the state of affairs for disabled people.

My proposition is that the ethical concept of 'vulnerability' offers an interesting, theoretical framework for disability bioethics. Before discussing this in depth, I look at the challenges in both bioethics and disability studies, which the proposition needs to overcome to make a valuable contribution to a disability bioethics approach.

### Issues with bioethical thinking on disability

Bioethics is often defined as a strand of applied ethics studying ethical problems emerging from advances in biology, medicine and technology. A relatively frequent critique of mainstream, Western bioethics though, is that it has turned into a docile facilitator of business-as-usual biomedical research and practice, rather than being its critical watchdog, as in the early days of bioethics (Brody, 2009). As such, bioethics has been reproducing some of the same structural injustices pervading the rest of society. This critique already inspired the development of feminist and queer approaches to bioethics and applies to matters of disability as well.

American legal scholar Alicia Ouellette examines this latter critique in her book *Bioethics and Disability* (2011). She discusses an extensive set of controversial, bioethical cases involving disability. Ouellette concludes that heavy-handed claims of a new eugenic logic in Western bioethics promoting the eradication of disabled people are overstated. She does find convincing evidence, though, for an ableist bias in bioethical thought:

Babies are left to die because they are born with disabling or potentially disabling conditions. Healthy growth is stopped and functioning organs are removed from children with disabilities when such interventions would never be allowed for nondisabled children. Parents are charged with child neglect for failure to cede to social and medical pressure to use medical technologies to cure traits in their children deemed defects by medicine but a valuable human variant by their parents. (...) Fertility specialists deny services based on assumptions about the ability of persons with disabilities to parent. Doctors unquestionably accept as reasonable decisions by adults with disability to die regardless of the surmountable social problems faced by the patient (2011, p. 319).

### Issues with disability thinking on bioethics

In disability studies and activism then, there are some problematic aspects as well hindering a fruitful, interdisciplinary crossover with bioethics. The issues I identify are threefold.

First, ethical arguments are often not made sufficiently explicit in disability scholarship (Scully, 2008). Much of the disability literature aims to complexify disability as a phenomenon and to read disabled lives through multiple viewpoints (e.g. Goodley & Runswick-Cole, 2012) as a critique to unidimensional views of disability as mere tragedies in need of a cure. However, by focusing on complexity over reductionism, the style and language of disability scholarship differs markedly from the analytical approach in much bioethical research. Much bioethical literature aims to disentangle dilemmas into bite-sized elements to ease the application of ethical theories and principles, before arriving at concrete normative recommendations. Such explicitly formulated, normative positions are rather scarce in disability studies. Disability scholars seem to be somewhat wary of defending norms whatsoever, possibly because the deconstruction of norms in society is core to the field, albeit oppressive, ableist ones. Nevertheless, main objectives in disability studies such as challenging ableism or empowering disabled people are without any doubt normative activities themselves. Viewed this way, the lack of bioethical terminology and traditional, ethical theory in disability scholarship is remarkable (Garden, 2015).

Second, the oft-cited 'models of disability' leave little room to criticise clinical research and practice constructively. Social, minority politics and cultural models of disability provide theoretical tools to argue for the removal of social barriers to equal participation, for disability rights legislation and for diversified cultural representations. Of course, these models served to dismiss normalising clinical practices, but next to that, they've often left bioethicists and clinical practitioners wondering how disability studies relate to their daily work. Meanwhile, disabled people continue to seek clinical advice, be it for diagnostic and thus formal recognition purposes, to find help navigating services or to obtain a remedy for impairing aspects of disability (Roche et al., 2021). These models of disability don't seem to engage much with these practices that are important for disabled people and happen to be at the core of bioethics' interest.

A third issue with disability thinking arises on the central role of 'independency', one of the few concepts with an ethical connotation in the disability movement. Western disability rights groups, such as the Independent Living movement, protested the lack of self-determination under institutionalisation and claimed their position as full-fledged citizens who should have decision-making power on how to organize their lives. In an early critique of the medical model of disability, the Independent Living-analysis pointed to the child-like and disempowering dependence on institutions, professionals and relatives as a key problem for disabled people. 'The concept of care,' as some have put it, 'seems to many disabled people a tool through which others are able to dominate and manage our lives' (Wood, cited in McCrary, 2017, p. 378). Instead of being reliant on these forms of

governmental, medical and familial care, reducing social barriers, consumer control over personal budgets and the hiring of personal attendants became key steps in the struggle for 'independence'.

Organising around the ethical ideal of independence comes at a cost, though. Among others, feminist philosopher of disability Eva Kittay (2019) points out how the ideal of independence is an excluding one, as some disabled people will never be independent as they are in continuous need of support. Independence as the central claim to rally behind, thus, risks drawing new binaries within the disability movement. For example, in the earlier discussion of early interventions for autism, we have seen these binaries popping up when researchers argue that the claims of 'high-functioning' autistic people hamper 'low functioning' autistics to access interventions. On the contrary, Kittay favours embracing *dependence* rather than chasing behind the neoliberal agenda of individual responsibility and productivity, modelled on able-bodied views of personhood. 'Bringing this understanding into the lifeblood of society can be a precious contribution bestowed upon us from the community of disabled people' (2019, p. 163).<sup>3</sup>

To wrap up this section, one can say that a disability approach to bioethics clearly has several issues to overcome. It must deal with ableist biases in bioethics, and it has to translate disability insights into normative and ethically underpinned arguments departing from the flawed ideal of independency and addressing the essential ethical domain of clinical research and practice. The following section will introduce the ethical concept of vulnerability as a promising theoretical contribution to a disability approach to bioethics.

### 3. Vulnerability revisited

Vulnerability is often understood as a state of being in which one is at risk to be wronged. At the same time, one is limited in capacity to overcome this risk. Since it concerns a conditional, forward-looking state, i.e. the potential harm or injustice has yet to arrive, vulnerability implies a call to action to prevent harm from happening. This way, 'vulnerability' differs from 'dependency' as it is not merely a descriptive but also a normative term.

Traditionally, 'vulnerability' featured in Western research ethics to indicate one's inability to give a valid informed consent. To avoid coercion or hard paternalism, special precautions were formulated to protect vulnerable groups, such as children or intellectually disabled people, in the form of more favourable benefit-risk ratios or even outright exclusion from research. Over the years, lists of vulnerable groups continued to grow though, to include a vast amount of people such as people living in poverty, ethnic minorities, chronically sick people, elderly persons, pregnant women, the institutionalised etc. (Rogers, 2013).

This labelling approach to vulnerability led to two strands of criticism. First, some say 'vulnerability' became too *broad* in the sense that, according to the expanding lists, almost anyone can be labelled 'vulnerable' simply by being part of a certain identity category (Luna, 2009), fixing people in a political position of powerlessness and lack of agency (Butler, Gambetti, & Sabsay, 2016). Second, the overly *narrow* interpretation of vulnerability in bioethics has been criticised as well, as it would only refer to autonomy-deficits such as the inability to give informed consent. Beyond autonomy-deficits, unjust background conditions and structural injustices can be a source of vulnerability as well. Indeed, informed consent procedures do not protect against 'dangerous protocols, researchers with conflicts of interest, or dysfunctional institutions, all of which make participants vulnerable by increasing their risk of harm' (Rogers, 2013, p.67).

To address these critiques, various theorists have formulated alternatives. Florencia Luna for example, suggests the idea of vulnerability as *layers* instead of *labels* (2009), avoiding the application of the term

vulnerability to large groups at the same time. Another influential account is Martha Fineman's *universal* approach to vulnerability (2013). She contrasts a (neo)liberal conception of personhood and citizenship with a physically embodied and socially embedded, vulnerable view. Judith Butler (2016), then, remarks that reclaiming vulnerability in social justice struggles doesn't imply accepting paternalistic forms of remediation, nor settling for victimhood. Rather, she proposes that vulnerability, 'understood as a deliberate exposure to power, is part of the of the very meaning of political resistance as an embodied enactment' (p.22). This way, mobilising 'vulnerability' changes from being an avoidable term which doubles down on marginalisation, to a productive term which might help formulating ethical arguments that support the social change neurodivergent and disability movements are working towards.

Interestingly, feminist ethicists Wendy Rogers, Catriona Mackenzie and Susan Dodds (2012), and bioethicist Henk ten Have (2016) both came up with comparable frameworks of vulnerability, integrating the aforementioned critiques and alternatives. Rogers et al. define a framework consisting of two primary sources of vulnerability: 'inherent and situational vulnerability'. This latter source also implies a subcategory named 'pathogenic vulnerability'. Ten Have retains two overarching categories as well: a philosophical view of 'anthropogenic vulnerability' and a political view of 'special vulnerability'.

According to Rogers et al., inherent sources of vulnerability arise from our human embodiment, dependence on others, and neediness as human beings. When thinking about our basic needs and wants for food and water, housing, energy, mobility, social interaction and support etc., it is hard to claim that anyone of us is entirely invulnerable in these respects. To be vulnerable is a descriptor of human life. Therefore, vulnerability is not something negative per se that needs to be overcome entirely. On the contrary, this common-sense idea of being vulnerable gives rise to claims of care, accommodation and solidarity towards one another. As socially embedded and embodied beings, inherent vulnerability reminds us that meeting our needs and wants can be challenged at any time in life. Ten Have adds here that vulnerability caused by our relational nature is 'anthropogenic' in the sense that this is what makes us human.

Ten Have posits that, as human beings, we cannot claim some invulnerable position from which we can reflect on the vulnerable other. In a more applied sense, as clinicians or ethicists, one cannot reflect on vulnerable disabled or autistic people without recognizing one's own vulnerability. On this view, there is no simple 'us' and 'them', no simple invulnerable and vulnerable groups. We are all inextricably part of a web of dependencies. This web can give rise to practices of care and mutual aid, solidarity and cooperation. Nevertheless, at the same time, these dependency relations may also involve domination, oppression and exploitation. This feature links the universal understanding of vulnerability to the second one, i.e. situational or political vulnerability.

We might indeed all be vulnerable, but for some, the risk to have essential needs go unmet is exacerbated due to asymmetries in dependency relationships. 'Personal social, political, economic, or environmental situations of individuals or groups' play an important role here (Rogers et al., 2012, p. 24). The positions we occupy in this web of dependencies make it more or less likely to benefit from advantageous relationships or to be harmed by maleficent ones, as touched upon above. One example is that all autistic children and their families are dependent on a formal diagnosis to gain access to specific clinical services. Yet, girls, children of colour, and those raised in low-income families are less likely to receive this diagnosis in a timely manner (Hosozawa et al., 2020). The negative association between mothers working full time and their possibility to engage in early intervention programs for their autistic child is another telling example how not all parents are situated equally in this web of dependencies (Bradshaw et al., 2020). Overall, this second understanding of vulnerability as



situational, or political as ten Have puts it, can thus help to translate relevant concepts of structural injustice, power asymmetries and intersectionality into disability bioethics.

Within this description of situational vulnerability, Rogers, Mackenzie and Dodds also highlight a particularly troubling subcategory, i.e. pathogenic vulnerability:

These may be generated by a variety of sources, including morally dysfunctional or abusive interpersonal and social relationships and socio-political oppression or injustice. Pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones. A key feature of pathogenic vulnerability is the way that it undermines autonomy or exacerbates the sense of powerlessness engendered by vulnerability in general (Rogers et al., 2012, p. 25).

As discussed before, certain aspects of the early intervention study by Whitehouse and colleagues (2021) could be understood in this framework as inducing pathogenic vulnerability. The intervention intends to ameliorate autistic lives but doubles down on the harmful presentation of autism as a set of deficits and on the asymmetrical power relation between autism professionals and autistic communities.

Overall, this reconceptualization of vulnerability provides some valuable insights. On this view, vulnerability is not purely a negative condition, but it refers to a universal aspect of being human in relation to others and to the physical environment. Vulnerability is no longer just an indicator of a lack of autonomous decision-making, yet it becomes a critical tool to analyse background conditions and power asymmetries as specific (groups of) people experience them. Also, the ethical obligations stemming from this revised view of vulnerability differ. Negative obligations such as protection or exclusion of vulnerable groups make space for the avoidance of paternalism, as the pathogenic understanding of vulnerability posits. Beyond avoiding harm, this new view also gives rise to positive obligations of fostering autonomy and justice, which I'll discuss directly in the context of disability in the following section.

#### 4. Crippling vulnerability for a disability bioethics

At first sight, proposing a disability bioethics centred on vulnerability may seem somewhat alienating to disabled people. In Western bioethics, healthcare and public discourse, vulnerability is, indeed, dominantly interpreted as a weakness or an autonomy deficit. In this form, vulnerability-discourses are often mobilised to justify unsolicited interventions on marginalised groups, including disabled people. Or, as we have seen in our case as well, people in power may present themselves as vulnerable in order to turn down bottom-up resistance. This way, traditional interpretations of vulnerability precisely represent the unjust power dynamics of ableism that disability and neurodiversity scholars and activists aim to dismantle (Spaan & Schippers, 2020).

However, the feminist reinterpretation of vulnerability challenges this concept's hegemonic understanding. What is more, it turns things upside down. Instead of using vulnerability in its traditional, problematic sense, disabled and neurodivergent communities can reclaim it to do the exact opposite. It can trouble the demarcation between the vulnerable and the invulnerable, stress structural injustices over individual deficits and justify solidaristic, empowering interventions over paternalistic ones. Building on this reinterpretation, the formerly problematic term vulnerability gets turned into a productive one. Or, to use a different lexicon: vulnerability can be 'crippled' in the sense that the traditional interpretation of vulnerability is read against the grain, given a twist and put to work in favour of disabled people's interests. This reclamation of 'vulnerability' parallels the way the term 'crip' has been reappropriated by ill and disabled folks from being a derogatory term ('cripple'),

to a critical tool and ironic self-reference breaking up ordinary binaries between undesirable, disabled bodies and desirable, able ones (Kafer, 2013; Vanaken & Van Goidsenhoven, 2021).

### Disability and universal vulnerability

Universal aspects of vulnerability shed new light on the needs of disabled and neurodivergent people and how to respond to those. Needs for accessible healthcare, education, decent work, mobility, housing, leisure, social support etc., are shared needs, although their manifestation may vary given the diversity of body-minds we inhabit.

Regarding our case for example, every parent needs support in raising their young child, seeks information about their developing child, and asks for help when they feel insecure. Young children, in turn, need sensitive and responsive caretakers who stimulate their development. The need to develop social and communicative skills through engagement with others is not categorically different in autistic children, even though it may be expressed differently.

In this respect, inhabiting a 'normal' body-mind gives a certain comfort because many parts of society are organised to accommodate those 'normal' needs structurally. This way, the omnipresence of dependency relations is largely obscured for able-bodied people, and they might experience a kind of independence. For disabled and neurodivergent people however, these same dependencies are often much more visible and explicit (Lid, 2015; Scully, 2013). Inspired by the universal take on vulnerability, 'ableism' can be described then as the set of practices which structurally privilege the needs of able body-minds over those of disabled and neurodivergent ones. In this sense, recognising universal aspects of vulnerability underpins reasonably well the first claim of the neurodiversity movement as discussed above, i.e. to acknowledge that humanity entails a natural and non-hierarchical diversity of minds.

Besides differences in whose needs are met, there are also discrepancies in how this catering of universal needs is justified. Meeting disability claims for accessibility and reasonable accommodations are now often perceived as a form of charity or as burdensome, costly efforts to meet so-called 'special needs'. Under the universal view of vulnerability, these claims can be rephrased as a call for taking up shared responsibility in the spirit of solidarity. Solidarity, indeed, is often defined as a sense of unity within a group based on the community of interests and objectives. Focusing on universal aspects of vulnerability may extend this sense of unity beyond the able/disabled, typical/neurodivergent, 'high/low', us/them binaries (Heikkilä, Katsui, & Mustaniemi-Laakso, 2020). Solidarity is thus not based on a pre-existing identity category, nor does it entail forcing others to act in according to one's self-interest. Here, the ethical ground for solidarity is the realisation that meeting our needs is fundamentally an interdependent affair that entails vulnerability of unmet needs for all of us (Magnani, 2020).

### Disability and situational vulnerability

Focusing on universal aspects of vulnerability helps to break some of the dis/abled boundaries. Nevertheless, the second, i.e. situational or political source of vulnerability is equally vital in a crippled account of vulnerability. We might all have needs to be met, but we are not all disabled, we are not all a bit autistic, as is regularly claimed. Nor do we all live in societies that define (in)dependence alike. Such claims would indeed 'conflate all experiences of physical, mental, or sensory limitation without regard to structural inequality or patterns of exclusion and discrimination,' as crip theorist Alison Kafer points out. 'Deconstructing the binary between disabled and able-bodied/able-minded requires more attention to how different bodies/minds are treated differently, not less' (2013, p. 14).

Indeed, autistic children and their families often find themselves in positions of increased vulnerability compared to non-autistic families, even if autism isn't considered as a vulnerability per se. Children with autism do experience more mental, behavioural and physical health problems, drop out of day-care and school more frequently and become victims of bullying more often. At the same time, parents of young autistic children experience a lack of recognition and support, increased stress levels and deliver above average care labour in the private sphere. Moreover, autistic children and their families are also at risk of being wronged as subjects of healthcare interventions. Despite good intentions, professionals still largely decide on the objectives, methods and discourse of such programs, including early interventions. As mentioned, this can be described as inducing pathogenic vulnerability. Finally, autistic self-advocates can also put themselves deliberately in a vulnerable position by speaking out publicly against harmful practices and risking a backlash from conservative powers-that-be, as shown before.

Situational and pathogenic understandings of vulnerability imply thus ethical obligations to address these particular wrongs without causing additional ones. Or, as described before, it requires to 'avoid harm without harming' and 'tackling injustice without reproducing injustice'. This does not mean clinical care for disabled and neurodivergent people is always problematic, but it does turn clinical practices into political spaces where status quo gets contested. Concretely, when designing early autism interventions, professionals should be aware not to double down on the issues autistic people highlighted as harmful or unjust. Instead, early interventions should tackle prioritised difficulties of autistic children and their families in ways that redress pathological understandings of autism and rebalance unjust power relations between professionals and receivers of care. This obligation might be summarised well as an obligation to *empower* people who experience situational vulnerability.

I understand empowerment here in line with its original, more radical conception in Paulo Freire's liberatory pedagogy where it refers to 'producing social change through mutual deliberation and critical thinking about the shared situationality [i.e. the sociopolitical conditions] of individuals' (Chiapperino & Tengland, 2015, p.211). More specifically, in a healthcare context, I see empowerment both as an outcome and a process. Empowerment as an outcome refers to having (more) control over the determinants of one's quality of life. As a process, empowerment implies creating professional relations where both individual healthcare users and the disabled and neurodivergent communities take (more) control over the change process, determining both the goals of this process and the means to use (ibid). This way, demanding to be empowered based on an acknowledgement of heightened vulnerability doesn't imply being passive, but rather becoming an active agent in the change process.

Although implicit, this obligation of empowerment seems to be at the heart of two recent efforts to outlining neurodiversity-informed early autism interventions. According to Leabitter et al. (2021) and Schuck et al. (2021), a first, key change would be to engage systematically in meaningful partnerships with autistic people and communities when developing, testing and implementing such interventions. Instead of aiming to reduce autism symptomatology for example, autistics-endorsed priorities such as overcoming anxiety, improving quality of life and fostering autism acceptance by others, should guide outcome-setting and measurements of success of early interventions. Departing from therapist-led, more rigid interventions, researchers should continue working on child-led and parent-mediated programs taking place in naturalistic settings. Starting developmental interventions from autistic strengths and fostering healthy, autistic ways of reaching relevant functional outcomes can be ways of embracing developmental diversity without taking a non-interference position. Also, rather than focusing on the individual child, more attention should go to changing its environment, both in private as in public spheres. Such improvements in person-environment fit could be obtained through

neurodiversity-informed psychoeducation on autism for key people in the child's world, including experiences from autistic people themselves.

Undoubtedly, striking the right balances will remain an ongoing challenge for all parties involved. For example, fostering communicative skills in order to promote children's autonomy could be in line with autistics-endorsed outcomes. At the same time, overly intensive socio-communicative exercising may cause overburden for children, just like camouflaging does for adolescents and adults. Evidently, the crippled account of vulnerability is no silver bullet, but it does propose an ethical framework to have these complicated discussions.

Overall, I do see Leadbitter & Schuck's suggestions as applications of the obligation to empowerment, both as outcome and process. What the crippled account of vulnerability adds here, is an ethical groundwork for these suggested reforms in early autism interventions in particular, and for the emancipatory goals of the neurodiversity movement in general. Clearly, a neurodiversity-informed approach to early autism interventions, does not require the elimination of clinical interference. I rather propose that clinical practices become spaces of constructive, political contestation where social change happens as neurodiversity and disability movements advocate for.

## Conclusion

In summary, this paper outlined the contours of a disability approach to bioethics. Beyond pointing to ableist biases in mainstream bioethics, I analysed which issues in disability studies need to be overcome to contribute to such a disability bioethics. Then, building on previous work of feminist scholars, I proposed a crippled account of vulnerability as a valuable ethical tool for the case of early autism interventions in particular, and for this emerging disability bioethics in general. This proposition holds two key strengths. First, it provides an ethical underpinning for claims of neurodiversity and disability movements in a way that might appeal to clinical practitioners and researchers as well. Second, this crippled account of vulnerability offers alternatives for ableist narratives on clinical care. It supports a move away from treating, curing or preventing disability, from narratives of 'costly accommodations' and 'special needs', and from idealising independency and individual autonomy. Instead, it introduces ethical narratives of interdependency, a shared responsibility to care and solidarity to meet each other's needs. Also, the crippled account of vulnerability highlights empowerment in its radical sense as means and ends of care for disabled and neurodivergent people.

Looking ahead, I believe more scholarly work is needed to clarify how vulnerability relates to different aspects of ethical theory, in the context of disability. The relationship between vulnerability and other ethical concepts such as justice and responsibility could be strengthened. Also, vulnerability's position regarding more systematic ethical frameworks, such as principlism, the capabilities approach and care ethics could be clarified. Lastly, the relation between disability bioethics and other bioethical approaches 'from-the-margins' such as feminist, queer and critical race bioethics could be formulated more explicitly.

Evidently, now it will be up to disability and neurodiversity communities, and to autism professionals to decide whether or not this crippled account of vulnerability sufficiently appeals to benefit their work. As Judith Butler remarks however, it might not be 'sufficient politics to embrace vulnerability [as ethical argument] as if that might inaugurate a new order of moral values', without continuing to resist ableist practices (2016, p. 25). In any case, I hope it did become clear that embracing and mobilising vulnerability can support such resistance very much.

## Author bio

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## End notes

<sup>1</sup> I'll mainly use identity-first language ('e.g. autistic person), in line with preferences of English-speaking autistic communities. Sporadically, I'll employ person-first language (e.g. children with autism) to underscore diversity of opinions on this topic, for ex. in Dutch speaking regions (Bottema-Beutel et al., 2021; Riley & Wevers, 2020).

<sup>2</sup> There is no such thing as *the* ultimate neurodiversity paradigm or theory. As in all academic fields and social movements, a variety of views floats around. One such point of contention is whether neurodivergency is mainly to be seen as an *identity* category one can either adhere to or not, or if neurodiversity paradigm(s) should rather be seen as a critical *perspective* instead, as a way of 'looking and talking back to power – of 'queering' the cognitive normative gaze' (Rosqvist, Stenning, & Chown, 2020, p. 228). In this latter sense, there is indeed a clear parallel with concepts of 'queer' and 'crip', in the sense that these do represent fluid, non-essentialist identity categories whose common denominators are the critical positions towards power manifested in gender, sexuality and bodily norms (Vanaken & Van Goidsenhoven, 2021).

<sup>3</sup> Recently, queer disabled people of colour have started to organise around *disability justice* principles, departing from the individual-focused, single-issue *disability rights* groups. These disability justice principles highlight interdependency, cross-disability solidarity and intersectional struggle (Berne, Morales, & Langstaff, 2018). Also within the neurodiversity movement, solidarity across neurotypes and across levels of needed support have become a key topic (Rosqvist, Chown, et al., 2020). This paper's scope doesn't allow to point out more similarities, although the proposed 'crippled account of vulnerability' probably fits well with these ideas.