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Epigenetics and Moral Responsibilities for Health: a Philosophical Exploration

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Introduction

Introduction

Three cases

Hoboken

Hoboken, a district of the Belgian city of Antwerp, is home to a factory site of Umicore, one of the world's largest precious metal refiners. The factory plant is surrounded by a residential area that was constructed over the 20th century. Emissions of lead, cadmium, and arsenic have been contributing to widespread health problems in children for decades (Pano 2021). Despite efforts that have greatly reduced both the emissions and their impact, lead levels in the blood of the children living in the neighborhood continue to exceed the standards posited by public health agencies. Parents worry about the health of their children and often feel guilty about living in the vicinity of the polluting factory. In a documentary, Esther, a mother of two children with very high lead values in their blood, expresses her worries as follows: "I want my child to be able to be who he is. And that if he is good at something, it should be possible to stay that way. And if he is not as good at something, that should not become worse. I do not want external factors, such as a factory I have no influence on, to interfere… Stay away from my child, is what I think" (Pano 2021, my translation). As the Flemish report agency *Pano* succinctly puts it, parents seem to be given a choice between 'kuisen of verhuizen' – cleaning or moving.

Mexico-City

Since 1993, the ELEMENT (Early Life Exposure in Mexico to Environmental Toxicants) project has investigated the impact of environmental toxins on mother-child pairs in various neighborhoods of Mexico City. Environmental health researchers work together with public health officials to investigate the impact of those toxins on multiple generations of inhabitants of Mexico City, one of the most polluted cities on earth. Elizabeth Roberts is an ethnographer of science, medicine and technology who collaborates with this project. Three environmental substances feature prominently in her work: lead-glazed plates, soda, and a dam filled with waste. Her fellow researchers found that eating off traditional lead-glazed plates, which are said to make the food taste sweeter, was the surest predictor of high lead levels in mothers and children (E. F. Roberts 2019; Téllez-

Rojo et al. 2002). The exposure to lead is both gendered, because women are the ones cooking with them and inheriting them from their (grand)mothers, and cultural, because the plates connect their users to a rural past (E. F. Roberts 2019). Additionally, the high consumption of sweets and sugary soda is said to be an important factor in the high obesity and diabetes rates in poorer neighbourhoods such as this one. Soda is almost as cheap as bottled water and more reliably available than tap water (E. F. Roberts 2017). Because it performs important social roles, campaigns exhorting individuals (primarily mothers) to stop providing soda to their children have little effect. Inhabitants know that soda and sweets *can* make you sick, but "in Moctezuma sharing soda, liquid-food, filled with sugar, is love" (Roberts 2015, p. 248). Finally, there is a penetrating smell in the neighbourhood, caused by "a narrow stream of dam runoff, filled with *aguas negras* (untreated sewage) and garbage" (Roberts 2015, 592). In rainy seasons the dam often overflows, leaving the walls of the cement houses with salmonella, E. coli, and fecal enterococcus (Roberts 2017, 593).

Farah and Alex

Farah is a postdoc researcher at a prestigious university. She loves her job and considers being an academic an important part of her identity. At the same time, various elements of her job are causing her quite some stress. When Farah gets pregnant, she makes a conscious decision to continue working her stressful job, even though she is aware of the potential influence of the accumulated she experiences might impact her offspring. Ten years later, her child Alex receives a diagnosis of ADHD after experiencing some difficulties in home and school settings. Although he sometimes continues to struggle with some aspects of his ADHD, throughout his teenage years Alex starts to consider ADHD as an integral part of his identity that he would not want to change.

Suppose Alex learns about studies that imply an association between stress during pregnancy and ADHD in offspring. Maybe when he is in college, he talks with his mother to learn more about the decisions she made before and during her pregnancy. What might his reaction be? He might have conversations with his mother to learn more about the decisions she made, and the circumstances that perhaps constrained them. Such conversations might lead to new insights for both Alex and Farah.

What do these three cases have in common? Firstly, they link environmental influences to health outcomes. Whether it is exposure to toxic substances such as lead or sewage, intake of sugary foods, or the psychosocial impact of stress, all of these cases show that our bodies are sensitive to our environments. The cases of Mexico City and Farah and Alex also point toward the intergenerational inheritance of the effects of those exposures. How can the link between environment and health be explained biologically? In all three cases, *epigenetics* seems to be a part of the puzzle. Epigenetics is the biological study of heritable regulations of DNA expression that do not entail changes in the DNA itself. Epigenetic mechanisms influence how and when our genes are expressed, and they are often triggered by environmental influences inside or outside of the body. Those mechanisms can play a role in the development of conditions such as ADHD (Bock et al. 2017), obesity (Rosen et al. 2018; Slomko, Heo, and Einstein 2012) and lead-induced neurological issues (Téllez-Rojo et al. 2002; Senut et al. 2012).

A second aspect shared by all cases is that they may invite us to ask ethical questions. What, if anything, should be done about the situation in Hoboken or the one in Mexico City? Who, if anyone, is to blame for negative health outcomes in inhabitants of those places? Which duties do (future) parents such as Esther or Farah have towards their offspring concerning their health? What does it mean, or what should it mean, to say that we want children to be healthy? How does that relate to wanting to protect them from the harmful effects of pollution? What is the role of scientists, policy-makers, and public health institutions? Do social injustices exacerbate health disparities, and if so, what does that imply for our moral evaluation of them? All of those questions are, in one way or another, related to an overarching question of responsibility: who is responsible for what with regard to whom?

The combination of the two elements ‘epigenetics’ and ‘responsibility’ forms the core of this thesis. All chapters that will follow are written with this overarching question in mind: ‘who is responsible for the epigenetic health of current and future generations?’.

Epigenetics, interdisciplinarity, and the role of the philosopher

I will discuss each of the above-mentioned cases in more detail in subsequent chapters. For now, I want to dwell on the role of the moral philosopher in debates about epigenetic responsibility. The reader may wonder what a philosophical thesis could have to say about a technical subdiscipline of molecular biology such as epigenetics. One might pose an epistemic objection, arguing that a philosopher with limited biological knowledge cannot sufficiently grasp the relevant aspects of epigenetics sufficiently to make normative claims. Or one may wonder whether it is valuable or worthwhile that a philosopher thinks about issues of epigenetic responsibility, thereby posing some kind of role-related objection. Perhaps a philosopher is overstepping her disciplinary boundaries by venturing into a domain she is not trained in. In short, *can* and *should* a philosopher contribute to normative debates about epigenetics?

I worry the least about the first objection. Of course, a basic understanding of the field is necessary (and I hope to provide such an understanding in the next chapter). But it seems to me that non-epigeneticists do not need to understand every epigenetic mechanism in detail to be well-placed participants in normative discourse about the field. The inverse, of course, also holds: epigeneticists should be allowed to make moral claims about their findings without first needing to become experts in moral or political philosophy. Ideally, however, epigeneticists and moral philosophers partake in informed conversations with each other.

Furthermore, the epistemic objection rests on the false assumption that science and politics can ever be considered fully separate domains. As Maurizio Meloni illustrates in great detail in his book *Political Biology*, scientific statements and politics have always been closely related. For him, political biology tracks “the ambiguous and contingent space where science is mobilized on behalf of politics and helps us understand the variable coloring of political options and worldviews via scientific vocabulary” (Meloni 2016, 17). When describing the political and societal uptake of epigenetics, Meloni draws parallels with how scholars historically mobilized biological ideas of soft heredity – the idea that environmental signals can cause changes in biology that are transferable to succeeding generations. One the one hand, right-wing intellectuals emphasized the degenerative effects of bad environments, arguing that “alcohol, sexual diseases, and the moral and physical squalor of the slums all could poison heredity” (Meloni, 210). More left-leaning scholars, on the other hand, championed eugenic projects of using various techniques to mold heredity in desirable ways. Although present intentions are usually much more benevolent, epigenetics does seem to have reactivated this ‘parallel politicization’ to some extent ibid., (212). In line with the first tendency, some commentators focus on historical and psychological traumas and the biological damage they cause (Lawson-Boyd 2022). In contrast, other researchers may choose to emphasize the reversibility of epigenetic marks for a variety of reasons. Whereas some take a hopeful approach and see this reversibility as evidence of our biology no longer being a “blind destiny” (Warin, Kowal, and Meloni 2020, 89), others emphasize reversibility claims to bolster the “neoliberal advice to take care of one’s own epigenome” (Meloni, 212). I will give examples of the latter later in this introduction, when I explain that the focus of this thesis lies on countering such narratives.

The second worry regarding the proper role of the philosopher calls for a defense of ‘epigenetic interdisciplinarity’ in general. In chapter 3, I argue that we can characterize epigenetic injustice as a kind of historical-structural injustice. Without already explaining this argument here, I note that such an injustice affects all of us, albeit in very different ways and to different extents. Some agents are primarily complicit in current health disparities, others are particularly vulnerable to factors causing health problems, and many are both. We might thus call the problem of responsibility for epigenetic health a ‘wicked problem’ – a problem of social policy for which the search for scientific bases to solve it is bound to fail (Rittel and Webber 1973).

The fact that knowledge concerning epigenetic mechanisms can shed light on structural, global, and multigenerational issues seems to warrant interdisciplinary engagement with it. Ethical claims related to the distribution of responsibility for epigenetic health should not only be made and studied by epigeneticists. Scholars from a broad variety of disciplines have already engaged fruitfully in such research during the past few decades. Those disciplines include philosophy of science, bioethics, moral philosophy, political and social theory, and science and technology studies (STS). In this thesis, I also engage with many of these fields, as well as some that are more novel in this context. For example, I rely on insights from 1) critical disability theory in multiple chapters, 2) anarchist political theory in chapter 4 and 3) philosophy of education in chapter 7.

In which ways can philosophers contribute to epigenetic interdisciplinary debates? Which tools does the philosopher have in store, and which methodologies can she use? Here, I discuss a few tools that are typical of philosophy. I do not intend to argue that these are all unique to philosophy, nor do I wish to deny that there exist many other ways of doing philosophy that might be of great value in this context. I merely posit them as a few elements of the philosophical toolkit that play a particularly important role in my thesis.

Questioning self-evident claims

I follow André Cloots in his characterization of philosophy as a radically-critical reflection (Cloots 2012, 31-35). Philosophy is a discipline that does not have content of its own as a starting point, but rather reflects on what is already present or given. It does so in a critical way (κρίνειν – ‘judge’) that can be perceived as dissenting: philosophy is never satisfied with obvious or self-evident truths and continues to ask questions. The radicality of the philosophical project lies in its relentless search for the root (*radix*) of issues.

In the context of applied moral philosophy, this characterization entails ‘taking a step back’ to pause for reflection in fast-paced applied normative debates. Because of her radically-critical commitment, the philosopher may not always be praised for this. The philosopher’s role as the sometimes bothersome ‘Socratic gadfly’ may cause apprehension in scientists and politicians at the thought of collaborating with her (Hens 2022). Even when the philosopher means well, her calls for reflection and her ‘itchy’ questions (as Kristien Hens aptly calls them) may be interpreted as attempts to obstruct or prevent progress in important societal debates. The field of epigenetics, specifically, is incredibly prolific and has made significant progress toward understanding and improving human health in the past few decades. Arguably, such a promising field should not be too hung up on philosophical qualms.

But philosophical reflection about the value-laden nature of its core concepts, its assumptions, and its uptake by broader society, can strengthen the field in the long run. Moral philosophical approaches can show how even ‘hard scientists’ such as epigeneticists work with normative assumptions that may sometimes be implicit. Making those more explicit allows not only the philosopher, but all parties involved, to consciously reflect on them. Philosophers do not work in a vacuum. Rather, they should start from the moral judgements and sensitivities of scientists, parents, and policy-makers and try to enrich existing debates with refreshing or critical insights.

Conceptual analysis

Conceptual analysis is perhaps the most well-known tool in the toolkit of an analytic philosopher. Understood in a narrow sense, it entails making explicit the underlying principles of a concept by defining it in terms of its logically necessary and/or sufficient conditions (Cuypers and Martin 2013). But because many words in ordinary language are used in a rather vague and loose sense, an exhaustive overview of such conditions is often impossible. What we can do instead, is try to make explicit defining characteristics of concepts (Hirst and Peters 2012). We can ask ourselves when a concept applies, and when it does not. For example, which health effects count as instances of epigenetic harm? A nuanced analysis of key concepts such as ‘epigenetic harm’, ‘epigenetic (in)justice’, and ‘responsibility for health’ can benefit the mutual understanding of those participating in debates about epigenetic responsibility, thereby improving communication.

We may also consider how we can distinguish concepts that are closely related to each other. In this thesis, I take the approach of introducing distinctions within the concept of responsibility. Analyzing such a concept with many layers and dimensions can help towards making more accurate normative statements about epigenetics. The claim ‘parents are responsible for the health of their children’ is overly broad and vague, which invites misunderstandings and debates without focus. In contrast, consider the claim ‘based on a backward-looking justification, namely having contributed to creating a polluted environment, corporation X has a forward-looking-oriented responsibility towards the children living in its vicinity to ensure that the health effects they may experience as a result of this pollution limit their quality of life as little as possible’. This claim is much more specific. To adequately assess whether you agree with this responsibility claim, its elements of course require more explanation. But the claim is a better starting point for a focused discussion.

Conceptual analysis has been criticized as being status-quo-preserving. When picking out conditions or characteristics of a concept, philosophers rely on people’s existing assumptions about the use of the concept. However, a philosopher’s view of the ‘common sense’ understanding of something, of how most people delineate a concept, often remains limited at best. In the worst case, a philosopher’s ‘armchair assumptions’ are plain wrong and come from a privileged position. Ideas of an able-bodied philosopher on what does or does not constitute a ‘life worth living’ often belong to this category.

Although I think a more descriptive approach to concepts can still have some value, it is important to supplement this with what is called an *ameliorative* approach. Such an approach "defines concepts partly by reference to normative goals that challenge the status quo" (Ciurria, 2019, 4). This approach starts with the question of why we have a specific concept in place. Then, it constructs a definition that is sensitive to the current situation and at the same time aims to strive toward an ameliorative goal (Ciurria 2019; Ciurria 2022; Haslanger 2006).

Describing ‘procreative autonomy’ in the context of epigenetics, for example, would then entail both recognizing the power dynamics that influence how various people think about this concept and striving towards epigenetic justice in characterizing what having such autonomy would entail.

Experimental philosophy

Another way to mitigate the risk of philosophy reflecting privileged biases is to integrate experimental research into it. Philosophers often avail themselves of thought experiments to spell out their own intuitions and draw out those of their readers. These intuitions are then typically used to ground the arguments they develop or to inform the direction of their philosophical investigations. Experimental philosophy can test those intuitions.

Experimental philosophy is a very broad field of research that aims to shed light on questions and theoretical frameworks traditionally associated with philosophy, with the use of experimental methods traditionally associated with psychology and cognitive science (Knobe and Nichols 2017). As Kwame Anthony Appiah explains, much of this work can be understood as an empirical approach to the project of conceptual analysis: “If conceptual analysis is the analysis of ‘our’ concepts, then shouldn’t one see how ‘we’ – or representative samples of us – actually mobilize concepts in our talk?” (Appiah 2008, 17). Chapter 6 of this thesis reports on a study in experimental ethics that reflects on some intuitions and concepts in Derek Parfit’s ethical work. Experimental ethics can be understood as “an interface of *all* methods applicable in the study of moral reasoning and action”, including vignette studies, choice and behavioral experiments, surveys of moral attitudes, and field and archive studies (Luetge, Rusch, and Uhl 2014, 3).

Experimental approaches can be a valuable addition to the philosopher’s toolbox for a variety of reasons. For example, I believe that my own experimental philosophy study is *epistemically* and *morally* valuable. If we want to be sure the knowledge Parfit’s theories offer us is useful, I believe we need to know more about the intuitions and assumptions that underpin it. It also has moral value, because the voices, opinions, and intuitions of various groups Parfit and others talk about, particularly women and disabled people, are still underrepresented in philosophy.

Intersectional feminism

This thesis combines the use of the tools mentioned above with a normative commitment to intersectional feminist theory. Elizabeth Wilson argues convincingly that feminists should rethink their resistance to biological data (Wilson 2015). Biological knowledge of our bodies can be useful for feminist theory, and engagement with it is necessary because there is no clear-cut distinction between the biological and the cultural realm. The epigenetic entanglements between our bodies and our physical, social, or cultural environments call for a feminist engagement with them. Meloni, for example, warns us that the unwarranted focus on maternal effects in debates on epigenetics might mean that “a sexist society has hijacked scientific research for its own goals, sidelining alternative approaches that might foster greater equality” (Meloni 2016, 17).

Mich Ciurria has been the first philosopher to develop a comprehensive philosophical model of intersectional feminism and its characteristics in her book *An Intersectional Feminist Theory of Moral Responsibility* (2019). When introducing intersectional theory, she provides a summary from Collins and Bilge:

> Intersectionality is a way of understanding and analyzing the complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other. (Collins and Bilge 2016, 1-2)

Intersectional feminists thus ask us to be aware of how power dynamics manifest themselves in every area of our lives. As Ciurria puts it, they emphasize that “no space is a truly even playing field” (Ciurria 2019, 37).

One characteristic tool of intersectional feminist theory is ameliorative analysis, of which I already briefly discussed how it plays a role in my thesis. Another hallmark of intersectional feminist theorizing that I adopt in various chapters is a **nonideal approach**. In contrast to ideal theory, such an approach does not assume just background conditions such as flawlessly functioning economic and political institutions or universal human rights. It also tries to avoid idealization or abstractions that misrepresent or exclude all aspects in which our moral and political reality are currently not ideal (O’Neill 1987; Haslanger 2020; Michelle Ciurria 2019; Mills 2005).

A famous example of an ideal theory approach is *A Theory of Justice* by John Rawls, who introduced the distinction between ideal and nonideal theory himself (Rawls 2020; Simmons 2010). Rawls arrives at his principles of justice by imaging which principles people would come up with if they had to choose them from behind a ‘veil of ignorance’. This means that they would not know anything about their position or characteristics in the society they are designing those principles for. In contrast, the positionality of individuals and the defects in existing societal structures are always a focal point of nonideal theory. Charles Mills adds that to work towards an improved situation, we do not only need to recognize the actual nonideal one. We should also be careful not to assume an ideal state of affairs in our theorizing because such theories would not be applicable to our actual situation. That would mean that the theories would not be able to contribute to changing existing injustices, and thus would allow the nonideal situation to persist (Mills 2005).

Another influential critic of the ideal approach is Amartya Sen. In *The Idea of Justice* he argues that we always need to start from injustice in our theorizing about a just society (Sen 2008). As David Schmidtz puts it in a review of Sen, “justice is less a property than an absence of properties that make for injustice” (Schmidtz 2011, 774). If we understand justice in such a way, our approach can differ significantly from an ideal one. The realization that justice is an ongoing work in progress rather than a well-defined ideal may lead us to attach less import to the search for answers that are imaginary, complete, converging or final (Schmidtz 2011; Sen 2008).

Nonideal theory has already been applied fruitfully applied to debates in bioethics, as exemplified by the foundational ideas of Onora O’Neill (2002) and a recent edited volume on the approach aptly subtitled ‘living and dying in a nonideal world’ (Victor and Guidry-Grimes 2021). As Daniel Beck succinctly puts it, ideal theory does not suffice in bioethics, because “the ambition towards consistency and explanatory completeness is inappropriate for a practical field like bioethics where one cannot ignore the moral relevance of context” (Beck 2021, 43). One of the ways in which a nonideal approach can be applied to epigenetics is to sufficiently take into consideration the role of social determinants of health and disease in the triggering of adverse epigenetic effects in parents and offspring.

Social determinants of health are conditions in the social and physical environments of people that influence health outcomes throughout their life course (Mancilla et al. 2020; Notterman and Mitchell 2015). Those conditions are not distributed equally, and they are hard to change for any individual parent or couple.

Acknowledging how social justice and epigenetic health are intertwined thus leads to an important red thread throughout this thesis. In short, I wish to provide philosophical arguments for moving away from overly individualized accounts of responsibility for health. In chapter 7, I specifically discuss the relationship between epigenetic knowledge, individual agency, and the individual responsibility of (future) parents. The mere fact that epigenetic knowledge of associations on a societal level exists, does not imply that everyone is able to act on this knowledge or even get access to it. In chapter 3, I explore what it means to say that there exists a collective responsibility for health instead.

Another way in which I try to keep my theoretical reflections relevant to our complex, nonideal reality is to look at cases such as those I started the introduction with. Discussing those cases may help to show how specific conceptual choices impact our normative appraisal of situations such as those in Hoboken and Mexico City as well as the questions we can ask ourselves when confronted with them. My motivation to engage in experimental philosophy (chapter 6) can also be explained by the commitment to this feminist approach. Vignette studies can investigate whether the ways in which often privileged philosophers use certain idealized concepts are actually shared by a more diverse public.

Responsibility

When thinking through issues of fairness and justice with regards to public health, the concept of responsibility has often proven to be an indispensable tool. In fact, it seems safe to say that issues related to responsibility are the most-discussed ones in the context of the ethics of epigenetics. Before this thesis delves into debates about various kinds of responsibility in epigenetics, a few more general marks about the concept are in order. Responsibility is a concept of which everyone has an intuitive understanding. As legal philosopher H.L.A. Hart famously showed, 'responsibility' is ubiquitous in our everyday language because we employ a multitude of notions of responsibility that cover a very diverse range of meanings. Consider the following short story in which the concept features in many different ways:

> As captain of the ship, X was responsible for the safety of his passengers and crew. But on his last voyage he got drunk every night and was responsible for the loss of the ship with all aboard. [...T]he doctors considered that he was responsible for his actions. Throughout the voyage he behaved quite irresponsibly, and various incidents in his career showed that he was not a responsible person. He always maintained that the exceptional winter storms were responsible for the loss of the ship, but in the legal proceedings brought against him he was found criminally responsible for his negligent conduct, and in separate civil proceedings he was held legally responsible for the loss of life and property. He is still alive and he is morally responsible for the deaths of many women and children. (Hart 2008, 211)

In this project, I pick out ‘moral responsibility’ from the vast pool of responsibility concepts. Moral responsibility is distinct from purely causal responsibility (which might also be ascribed to natural phenomena) in the sense that it can only be ascribed to or taken up by a moral agent satisfying certain conditions. Whereas storms can be causally responsible for something, we typically reserve moral responsibility for animate beings. As Cristian Neuhäuser explain, we might also distinguish various kinds of responsibility based on the *normative standard* against which we use them. Neuhäuser distinguishes a moral, legal, and political standard. Legal responsibility, for example, usually entails legal consequences, whereas moral responsibility tends to be less coercive. An agent can be responsible on the ground of multiple standards at once: it makes sense, for example, to say that a doctor is both morally and legally responsible for a patient (Neuhäuser 2014). I am aware that it is sometimes very hard to draw the line between those various kinds of responsibility in practice. For example, the relation between law and morality is fundamentally contested one. However, apart from a brief discussion of a political standard of responsibility, this thesis engages primarily with debates about *moral* responsibility in the context of epigenetics.

The concept of moral responsibility needs to be distinguished from related concepts such as *moral obligations* and *moral duties*. Some authors use at least two of these concepts interchangeably, either implicitly or explicitly (e.g. Archard 2010). More often, subtle differences between the concepts seem to be assumed but not made explicit. When something is actually said about the difference in works of applied ethics (rather than metaethics, where the distinction is actually a topic of debate, see for example Brandt 1964; Darwall 2009), the distinction is usually not very clear or ‘hard’. Both Iris Young and Marion Smiley argue, for example, that while ‘responsibility’ is no less obligatory than ‘obligation’, the language of responsibility leaves for room for an agent’s own judgment of how to bring about a certain desired state of affairs, whereas ‘obligation’ focuses more on a particular act (Young 2011; Smiley 2022). Still others choose to redefine one of the concepts to make the difference between them more pronounced (e.g. Isaacs 2014, who equates ‘obligation’ with what I would call ‘forward-looking responsibility’). In this thesis I stick to the concept of responsibility as much as possible. This helps me to maintain a clear connection to the bodies of literature I will be engaging with, since they usually focus on the concept of responsibility, rather than duty or obligation. Unfortunately, a consequence of the existing confusion is that what I refer to with ‘responsibility’ will be what some others might call ‘obligation’ or even ‘duty’. I commit myself to a continuous awareness of this ambiguity and wish to avoid it whenever possible.

This thesis often relies on a few distinctions between kinds of responsibility. It does not only discuss backward-looking or retrospective notions of responsibility, which are traditionally associated with liability to praise or blame. Instead, it also investigates whether forward-looking or prospective responsibilities are relevant for the ethics of epigenetics. Such forward-looking responsibilities are generally used to point out that agents have a role to play in bringing about a certain desirable state of affairs, or in remediating existing problems (Smiley 2022; Miller 2007).

Another distinction central to this thesis is that between individual and collective subjects of responsibility. The subject of responsibility can be an individual agent, a group of individuals, or a collective agent. Although debates about the requirements for and limitations to individual responsibility ascriptions are central to the philosophy of action, the individual agent is often seen as the ‘basic bearer of responsibility’ (Narveson 2002). Collective responsibility is often confused with shared responsibility. The latter is a distributable responsibility that falls on multiple individual agents without them necessarily having any connections or means of communication between them. The notion of collective responsibility, in contrast, “locates the source of moral responsibility in the collective actions taken by these groups understood as collectives" (Smiley 2022). Although collective responsibility is not an uncontroversial notion, as we will see in chapter 3, it is employed extensively (and I believe rightly so) in applied philosophy and in literature on the ethics of epigenetics.

As was mentioned before, this thesis investigates how we can conceptualize collective responsibility for health instead of strengthening the prevailing discourse of individualized responsibility. Criticizing accounts of responsibility for health that place a great burden of responsibility on individual shoulders is hardly novel. This thesis features many examples of other philosophers and ELSI scholars who did so in the context of epigenetics. They point out tendencies towards the individualization of responsibility for health in the work of epigeneticists and the uptake of their findings in public discourse, for example through media coverage and public health policy. For now, I just wish to illustrate that we are not arguing against a strawman here by sharing two telling quotes. In a general paper about clinical epigenetics, the authors state: “Arguably, the most important contribution is that epigenetic research has provided a molecularly based incentive for individuals and populations to invest in healthy nutrition and lifestyle behaviors to improve health outcomes for individuals presently and for future generations” (Grayson et al., 2014, 4). In the introduction of a textbook on human epigenetics, we read: "It is well known that there is a high level of individual responsibility for staying healthy, but a detailed understanding of epigenetics provides a molecular explanation for this life philosophy" (Carlberg and Molnár 2019, vi). It is the belief that epigenetic knowledge should be employed to bolster narratives of individual responsibility for health, embodied by such statements, that this thesis seeks to reflect upon in a radically-critical way.

Structure of this thesis

When we are thinking about responsibility relations, there are typically at least three elements at play. We have in mind, or are looking for, a certain agent (who is responsible?), an object of responsibility (what are they responsible for?), and often also an indirect object (towards whom are they responsible?). This thesis is structured around the elements of this combined question 'Who is responsible for what toward whom?' in the context of epigenetics.

Chapter 1 of this thesis introduces the reader to the field of epigenetics. It explains some epigenetic mechanisms, some subfields in epigenetics, and epigenetic inheritance, and it gives examples of diseases that are being studied by epigeneticists as well as promising research on epigenetic drugs. It also displays the debate on ‘epigenetic exceptionalism’ that revolves around the question of how scientifically or ethically novel the challenges posed by epigenetics actually are.

Then, the thesis turns toward the question of the **object of epigenetic responsibility**. What is it that we want to hold agents responsible for in the context of epigenetics? **Chapter 2** starts from the observation that most, if not all, of the ways in which the object of epigenetic responsibility is characterized in existing literature rely on an understanding of 'epigenetic harm'. The chapter proposes that we need to strive toward a multidimensional understanding of epigenetic harm that goes beyond a simplistic focus on causation. Instead, I apply insights from disability studies and feminist philosophy to draw attention to two other dimensions of epigenetic harm: lived experience and relationality.

The following section of the thesis comprises two chapters that discuss the **subject of (epigenetic) responsibility**. A subject of responsibility can be an individual agent, a group of individuals, or a collective agent. **Chapter 3** starts with a literature review of discussions that concern the relation between individual and collective epigenetic responsibility that are ongoing in ELSI literature on epigenetics. Then, it zooms in on what the concept of forward-looking collective responsibility (or FLCR) can contribute to a nuanced account of responsibility in the context of epigenetics. I argue that FLCR is well-suited to be integrated into an ethical account of epigenetic responsibility that also leaves for backward-looking concerns in targeting epigenetic injustice, which I characterize as an instance of historical-structural injustice.

Chapter 4 aims to deepen our thinking about the concept of collective responsibility by looking at a debate on the topic in social anarchism. This chapter does not deal with epigenetics; instead, it uses some conceptual tools developed in contemporary philosophical scholarship to analyze the Platformist debate. This is a historical social anarchist debate about the desirability of a principle of collective responsibility in radically non-hierarchical organizations. It analyses this debate as ultimately revolving around the question of how much unity is compatible with a non-coercive way of organizing and tries to look for compromises. This chapter is an example of my two-fold belief that 1) theories and distinctions developed in analytic philosophy are capable of elucidating discussions in (anarchist) political theory and 2) social and political philosophy can draw inspiration from the rather unfamiliar political theory of social anarchism, as well as from other grassroots organisations and activists groups struggling with the same issues.

Finally, the third section of this thesis deals with the question of **toward whom** agents might have epigenetic responsibilities. It specifically considers how transgenerational epigenetic inheritance might imply that we have responsibilities toward future generations. When individuals and collectives such as parents, policymakers, and governmental agencies – take decisions based on knowledge knowledge of the epigenetic connections between exposures and health outcomes, those decisions do not only impact those agents themselves or even the members of currently existing generations. Those decisions also seem to influence people who do not yet exist. However, various philosophers have pointed out that when the people that are impacted by our choices do not yet exist, this may seriously complicate our moral reasoning about those choices. The tension between those complications and our intuitions is generally referred to as the Non-identity problem. **Chapter 5** is devoted to the discussion of this problem in the context of epigenetics. With this chapter, I hope to show that we should not let this problem stop us from being concerned with the well-being of future generations. I suggest that existing theoretical approaches focusing on the role and intentions of the agent may help us circumvent the problem to some extent. Moreover, I show that experimental research on the Non-identity problem is far from conclusive.

In **Chapter 6,** I report on the findings of my experimental vignette study on lay people’s judgments about vignettes involving the Non-identity problem. I investigate whether a diverse sample of non-philosophers shares the No-Difference View: the view that there is no *moral* difference between choices that affect who comes into existence and choices that merely affect already existing people. I found that the non-philosophers in our sample do not hold more moral import to identity-affecting, pre-conception choices than to those made by a woman who is already pregnant. The second part of the chapter critically engages with the use of disability in thought experiments related to the Non-identity problem. It finds that aspects of the stories which Parfit seems to deem morally irrelevant are actually considered to be relevant by other people. As mentioned before, the chapter also discusses what the epistemic and moral value of those and other results might be.

Finally, **Chapter 7** zooms in on a specific group of agents: (prospective) parents. I argue that we need to direct more of our attention toward imagining the potential positive effects of epigenetic knowledge for parents and their children. Thus, I propose a novel way in which we could employ epigenetic knowledge positively based on ideas from philosophy of education. The central claim of this chapter is that epigenetic knowledge can contribute to constructing the narrative identity of children and families. The integration of epigenetic knowledge in a shared narrative identity may benefit mutual understanding and self-knowledge. This way, epigenetic knowledge can be used in a framework that goes beyond deterministic etiologies to embrace the complexities and interrelatedness of all factors influencing the health of future generations.

I have added a short **appendix** to this thesis to give the reader an idea of other academic work (in English) I have been doing in the past few years. It contains the abstract of a paper provisionally entitled ‘Gender and Race differences in Moral Judgments of Implicit Bias: an Empirical Study’ that I am currently working on with Kris Goffin. I also added the abstract of my paper ‘Paternalism, Authority and Compulsory Schooling in Social Anarchist Educational Thought’, published in the *Journal of Philosophy of Education* in 2020. Finally, I included a short piece with my reflections on the letter exchange ‘On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with my Son’ (Kittay and Kittay 2000). This piece was published in the section ‘What are you reading?’ of *DiGeSt – Journal of Diversity and Gender Studies*.

Notes on the creation of the chapters

Some of the chapters in this thesis were written specifically for this dissertation and have not (yet) been submitted for publication. This is the case for Chapter 1, Chapter 5, and Chapter 7.

Chapter 4 is intended for publication, but is currently not under review anywhere.

Some other chapters are based on articles or book chapters that are currently in various stages of the publication process. The article on which Chapter 2 is based will be included in a prospective topical collection of *History and Philosophy of the Life Sciences* entitled ‘Postgenomic Determinisms: Environmental Narratives after the Century of the Gene’.

Chapter 3 is based on a chapter in the edited volume *Epigenetics and Responsibility* I am editing together with Daniela Cutas and Anna Smajdor, which will be published with Policy Press in autumn 2023. It also contains some elements of contributions I made to the introduction of the same volume.

A slightly different version of Chapter 6 is included in the collection *Advances in Environmental Philosophy of Medicine*. This publication is edited by Kristien Hens and Andreas De Block and will be available in October 2023.

I updated and edited each chapter with the overall structure of this thesis in mind. However, some overlap and some tensions between chapters may still be possible because I did not want to fundamentally alter the foundational structure or line of argumentation of chapters. This means that, although a linear reading of this thesis is recommended, it should be possible to read the chapters in a more non-linear way too. Remaining tensions or different ways of explaining ideas between chapters can perhaps also give some insight into my thinking process and my development as a researcher. Thus, the chronological order of the chapters is as follows (from first written to most recently written): Chapter 4, Chapter 6, Chapter 2, Chapter 3, Chapter 5, Chapter 7, Chapter 1.

All work for this thesis has been done within the project NeuroEpigenEthics, led by Kristien Hens. The NeuroEpigenEthics team aims to investigate how dynamic concepts of human biology influence the ascription of responsibility, specifically in the context of neurodevelopmental disorders. We use a combination of theoretical and empirical methods, with a special focus on the importance of experience stories The project has received funding from the European Research Council (ERC) under the European Union’s Horizon 2020 research and innovation programme (grant agreement No 804881).

Chapter 1

Introduction to Epigenetics

Chapter 1 Introduction to Epigenetics

1. Basics of epigenetics

Discussions of ‘epigenesis’ as a theory that an organism develops gradually from undifferentiated material have a long history that far precedes modern epigenetics as a molecular science (Hens 2022; even Aristotle already used the term, albeit in a somewhat different context, see Lennox 2002). An important figure in the history of this theory was Conrad Waddington (1905-1975) who coined the term 'epigenetic landscape' to refer to then still unknown mechanisms that had to contribute to the development of an organism (Waddington 1942; Waddington 2014; Sweatt 2013). Jablonka and Lamb describe this landscape as follows:

> Waddinton depicted developmental procresses as a complex landscape of hills and branching valleys, descending from a high plateau. In this “epigenetic landscape” (as he called it), the plateau represent the initial state of the fertilized eg, and the valleys are developmental pathways leading to particular end states, such as a functioning eye, a brain, or a heart. (Jablonka and Lamb 2014, 62)

As we will see below, Waddington’s landscape has foreshadowed much of modern epigenetics, such as the idea epigenetic programming is responsible for the differentiation of stem cells into specialized cells. However, in what follows, I will talk primarily about the epigenetics of the last few decades.

The modern term 'epigenetics' has multiple related meanings. Firstly, it denotes the whole of processes in gene function that are mitotically and/or meiotically heritable and do not entail changes in DNA sequence (Carlberg and Molnár 2019). Secondly, epigenetics is used to refer to the study of those processes and mechanisms and their implications for biological functioning. In this thesis, I do not reserve the term exclusively in one of the two senses because it is usually clear from the context which one is meant. But to avoid misunderstandings, I sometimes use terms such as 'epigenetic mechanisms' when I want to refer to the first sense and phrases such as 'epigenetic research' and 'epigenetic knowledge' in the context of the second sense. In this chapter, I provide some scientific background on aspects of epigenetics relevant to my thesis and explain how I take epigenetics to relate to other concepts and research fields.

Epigeneticists do not study changes in DNA itself but rather mechanisms that influence how and when genes, which are stretches of DNA bases, are expressed in an organism (Carlberg and Molnár 2019).[1] Epigenetic mechanisms can affect the transcription and translation of genes in various ways. Two important processes are histone modification and DNA methylation.

- *Histone modification*: The histone is a kind of spool made of proteins around which the genomic DNA is wrapped to save space. The complex of the DNA and the histone proteins is called chromatin. How tightly the DNA is wrapped around the histone influences how easily the DNA can be accessed and thus copied. The more tightly packed it is, the less gene expression is possible. Tightly-packed and thus less accessible parts of the chromatin are called heterochromatin. The more readable parts are called the euchromatin - genes can only be expressed when they are located here.
- *DNA methylation*: this epigenetic mechanism entails that a methyl group gets added to a DNA molecule. This does not change the DNA itself, but it does influence whether certain parts of it can be read and transcribed. We can think of DNA methylation as a process to 'silence' genes by making them inaccessible.

By regulating gene expression, epigenetic processes influence the phenotype (observable characteristics), function, and developmental state of cell types and tissues (Carlberg and Molnár 2019, 6). Firstly, epigenetic programming is responsible for the differentiation of stem cells into specialized cells, providing them with the 'memory' of their differentiated identity. Such programming explains how all cells in an organism contain the same DNA while still performing a wide variety of functions. Each of the around 400 tissues of the human body, for example, has a different epigenome (i.e. a different set of epigenetic

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[1] The explanation in the next two paragraphs is primarily based on the introduction to epigenetics *Human Epigenetics: How Science Works* (Carlberg and Molnár 2019).

modifications), whereas normally each of us only has one genome (ibid., 8). This is the role of epigenetics that was already postulated by Waddington.

Next to the function in cell differentiation, epigenetics also has other functions throughout the lifetimes of an organism. One way in which our epigenome changes is the 'epigenetic drift' associated with aging (ibid, 78). In general, more epigenetic changes mean that the aging process has progressed further, meaning that epigenetic marks can be seen as some kind of biomarkers of aging. However, our epigenome changes mostly due to environmental exposures, which are most relevant for this thesis and ethical perspectives on epigenetics in general. Mechanisms such as DNA methylation can be triggered by environmental factors, both stemming from within the body and from the outside environment. Crudely put, this means that the material and psychosocial circumstances of our body – our diets, the quality of the air we breathe, and the stress we experience – can have an impact on epigenetic mechanisms. This is why epigenetic mechanisms are often treated as missing links between our lifestyle and environments and our physical and mental health. I give more concrete examples of such epigenetic social determinants of health and disease later in this chapter.

Perhaps a metaphor that integrates some of the aspects discussed above is helpful at this point. Epigenetics can be explained by thinking of a musician such as a piano player (Raz, Pontarotti, and Weitzman 2019).[2] The piano player interprets or decodes the musical score when he wants to play a composition. The score can be seen as the written message of the DNA. Multiple musicians might have the same DNA, just like multiple nuclei contain the same DNA. How this DNA is expressed, however, or how the piece is interpreted and performed, depends on the epigenetic mechanisms at work or on the interpretation of the piano player. Even if they have the same sheet music, two pianists may perform the piece in completely different ways. They may choose to add notations to the sheet music indicating aspects such as the speed and the dynamics they want to use in specific parts (as violinists might add 'bow notations'), or the emphasis they want to put on some sections. Such annotations are usually done with a pencil so that the pianist can still erase or re-write them. Epigenetic methylation patterns on the

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[2] Raz. et al critically discuss the use of metaphors in epigenetic science communication. From their conversations with focus groups, they conclude that both lay people and epigeneticists preferred the metaphor of the piano player over others such as 'cook and cookbook', 'map reading' and 'switching a light switch on/off' (Raz, Pontarotti, and Weitzman 2019).

DNA are also dynamic to a certain extent, which means that they can change over time. The interpretation of each musician, in turn, is dependent on environmental factors and changes. A pianist may alter his playing style of the same piece depending on whether he plays it for his family at home or in a big concert hall. Similarly, epigenetic signals can be triggered by environmental factors.

Areas of epigenetics research

To get a somewhat fuller picture of what epigenetics is and what it is not, some short clarifications and demarcations are in order. First, as we already saw, the difference between epigenetics and genetics is located in the prefix 'epi', meaning that epigenetic mechanisms are something upon, attached to, or beyond genetics. [3] Epigenetic information can be regarded as another layer beyond genomic information, that not only enriches but also challenges insights from more traditional understandings of genetics. For example, it questions the unidirectional assumption of the 'central dogma' of genetics that dictates that DNA is transcribed into RNA, which is in turn translated into proteins that determine the phenotype (Hens 2022). Epigenetics shows that the interface between the genetics and the environment of the genes is much more complex; perhaps even the idea of distinct layers that can be neatly analyzed in isolation from each other is too simple.

Even though contemporary epigenetics as a research field exists for no more than three decades, quite some different study domains have already been established. The definitions of those domains may vary, and there is often considerable overlap between them. I will now provide some examples that are relevant to this thesis, but there are many more subdisciplines to be discerned.

Environmental epigenetics research is interested in how epigenetic alterations might mediate effects caused by environmental exposures or toxins (Bollati and Baccarelli 2010; Niewöhner 2011; Jirtle and Skinner 2007). *Neuroepigenetics* is concerned with the regulation of DNA in the nervous system (Sweatt 2013).

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[3] Although I follow many author who explain the term in this way, I acknowledge that it cannot serve as a proper aetimology of the term. Stotz & Griffiths note that C.H. Waddington introduced the term as a fusion of ‘epigenesis’ and ‘genetics’ rather than one of ‘genetics’ with the prefix ‘epi’ (Stotz and Griffiths 2016).

Epigenetic epidemiology combines insights from epigenetics with those from epidemiology to improve our understanding of the mechanisms behind observations between environmental, genetic, and stochastic factors and the distribution of diseases (Jablonka 2004; Heijmans and Mill 2012). Finally, I want to mention the difference between *epigenetics* and *epigenomics*. The latter focuses on researching broad or even genome-wide profiles of epigenetic modifications and their effects (Kato and Natarajan 2019). Recent research has also been investigating how epigenomics can fruitfully engage with other 'omics' such as genomics, which studies the whole of the genetic material in an organism (i.e. the genome), and proteomics, a field dedicated to the large-scale study of proteins (Zaghlool et al. 2020; van Mierlo and Vermeulen 2021). In STS (Science and Technology Studies) and ELSI (Ethical, Legal, and Social Implications) literature on epigenetics, the terms 'epigenetics' and 'epigenomics' are sometimes used interchangeably. Although more can be said about the relation between the two, for this thesis I consider epigenetics to be the more general term, and epigenomics as a field within epigenetics research that focuses especially on the scale of the epigenome but that can nonetheless be regarded as part of the bigger epigenetic project.

Epigenetic inheritance

Can the epigenetic marks that someone accumulates due to exposures and lifestyle be transmitted to subsequent generations? This question has been intensely discussed and has led to much speculation and ethical theorizing in the past two decades. Most epigenetic programming is rewritten or reset between generations, but there is increasing evidence that this is not always the case. When considering the transmission of epigenetic marks between generations, we need to distinguish between *transgenerational* and *intergenerational* effects.

Intergenerational epigenetic inheritance refers to epigenetic marks in offspring that are the result of *direct* exposure of their germline to environmental stressors. This means that intergenerational inheritance is limited to the first generation of male offspring (i.e. children) and the first and second generations of female offspring (Cavalli and Heard 2019). The second generation of female offspring is included because environmental triggers during pregnancy can directly affect the oocytes (egg cells) that are already present in the fetus.

A famous example of intergenerational epigenetic inheritance is that of the famine during the Dutch Hunger Winter of 1944-1945. The children of mothers who experienced this famine during their pregnancy were six decades later found to have less DNA methylation of the imprinted IFG2 gene, which is associated with the risk of metabolic diseases (Heijmans et al. 2008). These and other findings contribute to empirical support for the hypothesis that early-life environmental conditions can cause epigenetic changes in humans that persist throughout their lives (Heijmans et al. 2008; Lillycrop 2011; Painter et al. 2008). The public discourse and research are often focused on maternal effects, perhaps based on "implicit assumptions about the 'causal primacy' of maternal pregnancy effects" (Sharp, Lawlor, and Richardson 2018, 20). However, epigenetics offers an opportunity to show how not only influences *in utero,* but also paternal factors and postnatal exposures in later life play a role in offspring health. Thus, in epigenetics research attention is also paid to paternal effects such as the influence of the father’s diet on spermatogenesis and offspring health (Rando 2012; Milliken-Smith and Potter 2021; Pascoal et al. 2022).

Transgenerational epigenetic inheritance is more contested. It denotes the *indirect* transmission of epigenetic information that is passed on to gametes without alteration of the DNA sequence (Carlberg and Molnár 2019). This means that we can only speak of transgenerational inheritance if the epigenetic effects of exposures of the current generation are still present in the second generation of male offspring or the third generation (i.e. great-grandchildren) of female offspring (Cavalli and Heard 2019). So far, most transgenerational epigenetic effects have been discovered in plants and non-human animals such as rats and mice. For example, researchers working with mice have found third-generation epigenetic effects of maternal diet (Dunn and Bale 2011) as well as social stress levels (Matthews and Phillips 2012), although others argue that multigenerational inheritance of methylation patterns in mice is an exception rather than the rule (Kazachenka et al. 2018). A study with C. Elegans worms by Adam Klosin and colleagues also had impressive results (Klosin et al. 2017). They genetically modified these worms to glow when exposed to a warm environment. The worms did not only start to glow more when the temperature was raised, but they also retained their intense glow when researchers lowered the temperature again. Moreover, “their progeny inherited the glow and even seven generations further down the line, glowing worms were born. If five generations of C. Elegans worms were kept warm, this characteristic was passed on to fourteen generations” (Hens 2022, 48).

Such findings in animal research are sometimes too hastily translated into conclusions about human health and disease (Juengst et al. 2014). This translation is very tempting, however, given that it is virtually impossible in research on human inheritance to exclude potential confounding elements such as changes in utero and postnatal effects (Cavalli and Heard 2019). It is hard to distinguish ‘real’ epigenetic inheritance from the offspring having the same experiences or health problems because the context is reconstructed or culturally inherited. Still, there are some studies that transgenerational epigenetic inheritance is possible, albeit limited, in humans. First, studying historical data of cohorts in Överkalix, researchers found associations between grandpaternal food supply and the mortality rate of the generations of their children and grandchildren (Kaati, Bygren, and Edvinsson 2002). Because no molecular data were available, however, no epigenetic links could be proven. Pembrey and colleagues build on those findings to find evidence of sex-specific male transgenerational inheritance in humans (Cavalli and Heard 2019; Pembrey et al. 2006. In a longitudinal study in an area around Bristol, they found transgenerational effects of smoking before puberty on the growth of future male offspring of men. Specifically, early paternal smoking (before puberty) was associated with a greater BMI in their sons. The researchers posit DNA methylation as a potential mechanism behind those links between acquired epigenetic traits of a generation and the epigenetic marks present in the next generations.

Epigenetics, DOHaD, and social determinants of health

Although knowledge about epigenetic mechanisms contributes to increased insights into the processes behind intergenerational inheritance and asks us to consider the possibility of transgenerational epigenetic inheritance, studying inheritance in general is of course nothing new. This means that epigenetics needs to relate itself to other fields of research. For example, *Developmental Origins of Health and Disease*, or DOHaD, can be defined as the study of how the early life environment can impact the risk of diseases from childhood to adulthood (Bianco-Miotto et al. 2017). DOHaD also studies the mechanisms involved here, which means that there are intricate connections between DOHaD and epigenetics (Vickers 2014). A core assumption of DOHaD is amusingly summarized by Maurizio Meloni: “We are not so much what we eat, but what our parents ate.” (Meloni 2016, 209). Thus, both fields overlap, but only partly: epigenetics does not only focus on prenatal and perinatal exposures, whereas DOHaD also studies other mechanisms than epigenetic alterations.

Many epigeneticists, especially those working in fields such as environmental epigenetics and 'social epigenomics' also see their work as a contribution to the body of knowledge about **social determinants of health**. These are conditions in the social and physical environments of people that influence health outcomes throughout their life course (Mancilla et al 2020). Such conditions might include influences of one's family, neighborhood, and one's broader social context, but also values, attitudes, knowledge, and behaviors (Notterman 2015). Mancilla and colleagues, for example, argue that epigenetics is not the only field that can shed light on social determinants of health, but one that can contribute to explanations of how socio-environmental factors influence our biology through epigenetic modifications (Manc et al). The role of the epigeneticist then lies primarily in discovering more about the mechanisms that connect environmental triggers to gene expression (Milliken-Smith and Potter 2021). A well-known example of such research is the work of McGuinness and colleagues, who investigated the relationship between socio-economic and lifestyle factors and epigenetic status in Glasgow, a city known for great socio-economic and health disparities. The data had been gathered in the context of a broader study on the psychological, social, and biological determinants of ill health (pSoBid). They found lower levels of global DNA methylation in those with a low socio-economic status as well as in participants who did manual work. Lower global DNA methylation content was in turn associated with biomarkers of cardiovascular diseases and inflammation (McGuinness et al. 2012). As Milliken-Smith & Potter note, we must be aware that the dynamic between social processes and (epi)genetic information about our health goes two ways. The authors above primarily focus on providing "an explanatory link between the social determinants of health and physiological outcomes". But conversely, "a critical appraisal of how this emerging epigenetics knowledge is debated and employed can highlight the very processes that reinforce existing gender disparities in the social determinants of health framework" (Milliken-Smith and Potter 2021, 1).

Diseases and conditions

The previous sections already contained some examples of studies on epigenetic links between environmental exposure and health. Here I will list a selection of some other associations that have been found. This relative weight given to topics in the overview is not intended to be an accurate representation of the emphases placed in current epigenetics research. Rather, it is intended to provide the reader with some background on the scope of epigenetic health and disease that may prove useful during subsequent chapters. It is worth noting that some health aspects mentioned here, such as stress and obesity, have both been posited as causal contributors to disease development and the outcome of epigenetic processes.

Stress

Exposure to stress in the womb or during early childhood has been associated with epigenetically mediated adverse health effects. For example, childhood maltreatment might trigger long-lasting epigenetic marks, contributing to PTSD in adult life (Mehta et al. 2013). Epigenetic studies have also found that stress in early life can contribute to behavior typical of attention-deficit hyperactivity disorder (ADHD) (Bock et al. 2017).

Other noteworthy results were found in studies investigating the impact of witnessing the September 11th attacks in the United States. Children of survivors of the attack who were pregnant at the time seem more vulnerable to PTSD and behavioural issues (Jablonka 2016; Yehuda et al. 2009; Sarapas et al. 2011).

Oberlander and colleagues found that the methylation status of the human NR3C1 gene in newborns is sensitive to maternal depression. They argue that these findings offer a potential epigenetic process that links the antenatal mood of the mother to how infants respond to new situations, such as an increased stress response to new visual stimuli (Oberlander et al. 2008).

Environmental pollution

As is well known, **air pollution** has numerous harmful effects on health. Emerging data indicate that air pollution exposure modulates the epigenetic mark. These changes might in turn influence inflammation risk and exacerbate the risk of developing lung diseases (Rider and Carlsten 2019).

It is well known that **lead** is a common neurotoxic pollutant that disproportionally affects the health of children. Evidence of the epigenetic basis of the effects of lead is increasing (T. Wang, Zhang, and Xu 2020; Senut et al. 2012).

Metabolic conditions

The epigenetic mechanisms behind the development of metabolic conditions are becoming well-documented. Molecular links between environmental factors and type 2 diabetes have been discovered (Rosen et al. 2018; Slomko, Heo, and Einstein 2012; Ling and Groop 2009), as well as mechanisms that regulate the expression of genes associated with diabetic kidney disease (DKD) (Kato and Natarajan 2019). Various studies have also looked into the epigenetics behind obesity, both as a contributory factor and a health outcome (Rosen et al. 2018; Slomko, Heo, and Einstein 2012; Lillycrop 2011). Since type 2 diabetes patients or often more likely to suffer from cardiovascular disease, the influence of environmental factors and the diet of ancestors on the epigenome has also been investigated (Lillycrop 2011; Kaati, Bygren, and Edvinsson 2002). Like stress, obesity has been posited not merely as a health outcome but also as a causal factor in epigenetics. Paternal prepuberty overweight has been associated with diminished lung function and asthma in adult offspring (Lønnebotn et al. 2022).

Neuroepigenetics

Neuroepigeneticists investigate how epigenetic regulation plays a crucial role in the development and functioning of our brain. Conditions for which epigenetic regulatory mechanisms have been suggested include Parkinson, Huntington, schizophrenia, epilepsy, Rett syndrome, and depression (Carlberg and Molnár 2019; Tsankova et al. 2007). Much research seems to be particularly geared towards a better etiological understanding of neurodevelopmental conditions such as Tourettes syndrome (Müller-Vahl et al. 2017), ADHD (Wang and Jiang 2022; Pineda-Cirera et al. 2019; Bock et al. 2017) and autism (S. E. Wang and Jiang 2022; Gowda and Srinivasan 2022; Eshraghi et al. 2018; Waye and Cheng 2018; Schanen 2006). However, there is still much uncertainty about the concrete causative evidence that might be implicated in the development of such conditions establishing concrete causative evidence that is implicated in the development of such conditions (Wang and Jiang 2022).

Reversibility: the promise of epigenetic drugs

Epigenetic changes seem to be more readily reversible than epigenetic ones (Hens 2022). This reversibility holds promising potential for epigenetic therapy of diseases since epigenetic marks such as methylation patterns can be seen as targets for medical interventions and treatments (Nakamura et al. 2021; Heerboth et al. 2014; Carlberg and Molnár 2019).

Many of the clinical research efforts in this domain are directed toward treatments of cancers (Falahi, Sgro, and Blancafort 2015; Lu et al. 2020). Cancer cells are often characterized by epigenetic drifts, and many tumors are associated with epigenetic reprogramming (Carlberg and Molnár 2019). While some studies investigate the possibility of such epigenetic interventions in general, others focus on specific types of cancer such as breast cancer (Falahi et al. 2014) and prostate cancer (Pacheco et al. 2021). Lu and colleagues list so-called ‘epidrugs’ in clinical trial, with targets also including melanoma, lymphoma, ovarian cancer, bladder cancer and brain tumours (Lu et al. 2020) But research on epidrugs for other conditions is also very prolific. Recent projects have aimed to target conditions such as Covid-19 (Zannella et al. 2021), hypercholesterolemia (Paez et al. 2020), neurodegenerative diseases (Janowski et al. 2021), autoimmune diseases such as chronic kidney disease (Tejedor-Santamaria et al. 2022) and depression (Tsankova et al. 2007).

2. Epigenetic exceptionalism

Is there something scientifically or ethically *unique* about epigenetics to such a degree that we should dedicate an entire thesis to its relation to responsibility questions? After all, thousands of books and papers have already been written about genetics and its ethical implications. Is epigenetic exceptionalism, a term coined by Mark Rothstein in line with Thomas Murray's 'genetic exceptionalism', warranted (Murray 1997; Rothstein 2013)? In other words, are new findings in epigenetics so "extraordinary in kind or degree" that they necessitate new analytical frameworks or novel approaches to deal with their unique character (Rothstein, 2013, 733)? Before discussing answers to this question, a distinction must be drawn between the potential revolutionary scientific character of findings in epigenetics on the one hand, and the potential unique ethical and social implications, including those with regards to responsibility, of such findings.

Scientific exceptionalism

Rothstein argues that the label of *scientific epigenetic exceptionalism* is warranted on multiple grounds. Firstly, he contends that epigenetic changes occur much more frequently than mutations in DNA sequences. Moreover, "an individual's susceptibility to epigenetic change is highly dependent on the dose of the environmental agent and the stage of development at which exposure occurs" (Rothstein, 2013, 734). Furthermore, Rothstein notes that epigenetic changes are intrinsically reversible and tissue- and species-specific. He concludes: "From a scientific standpoint, epigenetic discoveries are extraordinarily exciting because they represent a new way of understanding the processes by which various harmful exposures cause disease in humans and, in some cases, their offspring. Furthermore, epigenetics could point the way to new methods of preventing and treating numerous disorders" (ibid., 734).

Other researchers are divided about the exceptionality of epigenetics. Laura Benítez Cojulún lists some expressions by researchers that "evoke a substantial transformation" (Cojulún, 2018, 135): 'epigenetics revolution' (Meloni, 2015, 141), 'epigenetic turn' (Nicolosi and Ruivenkamp 2012), 'epigenetic shift' (Willer, 2010, 13). Others use the less favourable term 'epigenetics hype' (Deichmann 2016; Maderspacher 2010) to designate "the far-reaching, revolutionary claims of having discovered entirely new mechanisms of heredity and evolution which are supposed to replace older concepts" (Deichmann, 2016, 252). Hans-Jörg Rheinberger and Staffan Müller-Wille note that the fast rise in epigenetics research has led to a ‘deflation’ of the gene concept, although it seems “impossible to draw a line that unambiguously separates genetic from epigenetic factors in terms of their causal role” (Rheinberger and Müller-Wille 2018, 114). Juengst and colleagues seem to hold that the exceptionalist language itself is what makes epigenetics exceptional, noting that "scientific hyperbole rarely generates the level of professional and personal prescriptions for health behaviour that we are now seeing in epigenetics" (Juengst et al., 2014, 427). Based on a series of in-depth interviews, Kasia Tolwinski has shown that members of the epigenetics research community hold a variety of ideas with regard to the impact and future of their field. She notes that some epigeneticists are 'champions' of epigenetics as a promising new field. In contrast, others hold a more moderate position, and still others could be considered 'sceptics' regarding the novelty or autonomy of epigenetics as a discipline (Tolwinski 2013).

Ethical exceptionalism

The ethical and social implications of epigenetics findings depend on their scientific status. However, arguing for some kind of scientific exceptionalism does not force one to hold that ethical implications are equally exceptional. Rothstein, for example, does not think the scientifically distinctive features of epigenetics warrant ethical exceptionalism, saying, "there is nothing inherently unique about the science of epigenetics that it demands an entirely new ethical paradigm and legal regime" (Rothstein 2013, 734). Researchers interviewed by Martyn Pickersgill generally hold similar positions. They "expressed various kinds of unease about the notion that epigenetic research held straightforward implications for healthcare and society" (Pickersgill 2021, 609). Moreover, the respondents "did not generally conclude that there were immediate ethical ramifications distinct to epigenetics" (ibid., 610).

Jonathan Huang and Nicholas King agree. They do not wish to "shy away from the potential of epigenetic research" (Meloni & Testa 2014, 129). They believe it "holds promise in identifying and clarifying the different ways in which environments, broadly construed, directly interact with human biology, both within and across generations" (Huang & King 2018, 77). However, they have a few concerns that prevent them from arguing in favour of epigenetics' ethical exceptionalism. Firstly, they note that "there is already copious evidence for the impact of social, economic and environmental factors on the health of current and future generations" (ibid., 75). Additionally, they point out that epigenetic mechanisms in themselves are often not sufficient for a disadvantages outcome; "they always work in concert with extant social and economic disadvantages. As such, the injustice of a particular epigenetic variation is always perfectly circumscribed by an existing mechanism of disadvantage, which includes both a prior recognition of a disadvantaged group and an undesirable outcome" (74). With regards to responsibility theories in particular, they believe that commentators should refrain from the impossible enterprise of ascribing responsibility and remedy based on epigenetic findings alone, because such findings "never imply who should be held responsible for any particular causal mechanism (73). They conclude that, in many instances, "the role of epigenetics is to recapitulate existing claims rather than generate new ones" (78). Moreover, they warn against straightforwardly "using epigenetics to bolster existing ethical claims" (73) because of the various difficulties involved in characterizing epigenetic changes as harmful and in "separating unjust epigenetic variations from the social or environmental processes that produced them" (ibid.).

Other authors lean more towards at least a 'change in degree' (Hedlund 2012) in which certain ethical concepts or themes should be used. Luca Chiapperino holds that "epigenetics poses no new ethical issue over and above those discussed in relation to genetics" (Chiapperino, 2018, 49). However, he does believe epigenetics may have important implications for pre-existing ethical issues, arguing that "epigenetics encourages [...] 'thickening' moral exercises of privacy, responsibility, justice and equity with a complex biosocial description of situations, of persons or actions, in order to afford their significantly balanced evaluation" (ibid., 59). Findings in epigenetics urge us to "adjust and refine, in a situated manner, the problem frames and categories that inform our ethical and political questions as well as judgements" (ibid.).

Similarly, Charles Dupras and Vardit Ravitsky argue that "the normative accounts of epigenetics do require a heightened degree of bioethical attention, especially considering its potential impact on the political theory of the family and its relation to social as well as intergenerational justice" (Dupras & Ravitsky, 2016, 2). Rothstein and colleagues argue that most ethical issues related to epigenetics are similar to those already raised by genetics. However, they hold that "the role of environmental exposures in producing epigenetic effects adds new concerns" such as those about individual and societal responsibilities to prevent hazardous exposures and the multigenerational impact of such exposures (Rothstein et al., 2009, 2).

I tend to agree with authors such as Chiapperino, Hedlund, Dupras & Ravitsky that while real ‘ethical epigenetic exceptionalism’ is unwarranted, the rapid rise of the field does make certain ethical discussions and moral exercises more urgent. This means that this thesis is based on the assumption that epigenetics is not so fundamentally different from other complex bioethical or public health issues that it needs to employ different or more ethical concepts. In some chapters, however, I do identify a few characteristics of epigenetics that seem *particularly relevant* to my ethical endeavors. For example, in chapter 2 and 3 I list the following characteristics as relevant for the development of a responsibility framework: 1) the role of the environment (broadly understood) in the health of an organism at the molecular level; 2) the possibility, even if still very contested of transgenerational inheritance; 3) causal complexities and uncertainties that make it very hard to define epigenetic harm or health; and 4) the potential reversibility of epigenetic mechanisms. Those are not exceptional to epigenetics, especially not when taken individually, but all together taken together they make some approaches more salient than others.

What then, are some of the normative issues that have been said to require a closer look in light of epigenetic findings? In their literature review, Dupras, Saulnier and Joly (2019) identify nine areas of discussion at the crossroads of epigenetics, law and society: traditional nature-nurture dichotomy; embodiment or 'biologization' of the social; public health and other preventive strategies; reproduction, parenting and the family; political theory; legal proceedings; the risk of stigmatization, discrimination or eugenics; privacy protection; and knowledge translation. Additionally, authors have discussed issues such as environmental justice (e.g. Rothstein, Harrell, and Marchant 2017), the need for bioethical approaches that integrate concern for both the environment and medicine (Hens 2022) and ethical, legal and social issues of epigenetics research in the context of personalized medicine (Santaló and Berdasco 2022). Most of these normative issues are typically being discussed with the means of responsibility language. This thesis does the same: it thinks about various elements of the epigenetic responsibility relation, thereby engaging with many of the above-mentioned areas of discussion.

Chapter 2

A Multidimensional Account of Epigenetic Harm

Chapter 2 A Multidimensional Account of Epigenetic Harm

This chapter is likely to be included in a topical collection of *History and Philosophy of the Life Sciences* entitled 'Postgenomic Determinisms: Environmental Narratives after the Century of the Gene'. After acceptance by the editors of the collection, it is currently under external review. I made some small changes to the text to increase the general coherence of this thesis. I left out a few introductory paragraphs on epigenetics to avoid repetition after my explanation of epigenetics in Chapter 1. I also changed the title, which is 'A Multidimensional Account of Epigenetic Harm' in this thesis but will be 'Normative Implications of Postgenomic Deterministic Narratives: The Case Study of Epigenetic Harm' in the topical collection. I added references to other chapters to draw connections between this chapter and the overall structure of the thesis.

Introduction

Who is responsible for epigenetic harm? This question has been central to most normative debates relying on findings in epigenetics in the past two decades. This chapter, however, is a plea to take a step back. Before a meaningful discussion about responsibility ascriptions and distributions can take place, we need to obtain a clearer view of what we want agents to be responsible *for*. What is epigenetic harm? This question is central to this chapter; so is the overarching claim that its answer will inevitably be at once complex and incomplete.

Section 1 begins with an overview of some of the ways in which the object of epigenetic responsibility has already been conceptualized in ELSI literature (dealing with Ethical, Legal, and Social Implications) of epigenetics. I note how they are all somehow related to conceptions of epigenetic harm: something negative that happens to people in which epigenetic mechanisms play a role or rather something that might happen and needs to be avoided. I then characterize epigenetic harm as a bridging concept between relatively neutral findings on epigenetics on the one side, and potential ethical and societal implications of those findings, primarily in terms of responsibility ascriptions and distributions, on the other. Its role as a bridging concept makes epigenetic harm a particularly important object of investigation because it is an intermediate, interpretative step between epigenetic findings and any normative conclusions about them.

In section 2, I propose that a sufficiently nuanced account of epigenetic harm should include at least three dimensions. First, I discuss the dimension of *causation,* which has been most prominent in the existing literature. A wrong understanding of this dimension that does not take into account issues of unpredictability and indeterminacy surrounding epigenetics might lead researchers to support an excessively simplistic epigenetic determinism - "the belief that epigenetic mechanisms determine the expression of human traits and behaviors" (Waggoner and Uller, 2015, 179). I argue that a multidimensional analysis of epigenetic harm is less vulnerable to this threat and more reflective of the various kinds of harm that may be experienced by the subjects of epigenetic alterations. I apply insights from disability studies and feminist philosophy to draw attention to two dimensions of epigenetic harm that have been largely neglected in literature on the normative implications of epigenetics, namely *lived experience* and *relationality.* In Section 3, I explore what a shift towards a multidimensional approach to epigenetic harm might mean for epigenetic research and the theory and practice of responsibility ascriptions. Here, I also emphasize that wariness of determinist narratives is recommended if one wants to leave room for a fair responsibility distribution.

1. Epigenetics and normative debates

The consensus about the need to adjust and refine some of our ethical and political thought prompted by findings in epigenetics is based on a collective identification of some relevant characteristics of epigenetic mechanisms. Many ELSI scholars refer to multiple of the following four aspects:
Environmental influence: epigenetic mechanisms regulate the expression of the DNA, and by definitions they do so when triggered by environmental signals (either within in or outside of the organism). As Chiapperino (2018) puts it, epigenetics includes studies that emphasize the role of the epigenome as a 'biological interface' that "links one's milieu and life conditions with one's basic biological functioning" (50).
Transgenerational impact: changes in epigenetic patterns acquired during the life of an organism may, at least in part, be transferred to the next generation (Carlberg and Molnár 2019, 75). The evidence for transgenerational inheritance of acquired epigenetic traits is much more contested for humans than it is for other species, but it is expected to increase (Rothstein, Harrell, and Marchant 2017).

Thus, the implications of certain environmental exposures, behaviours and lifestyles could reach beyond an individual's own life or even beyond that of their children.
Causal complexities and uncertainties that make it very hard to define epigenetic harm or health.
Reversibility: epigenetic mechanisms may be reversed, which means that there is potential to reverse or mitigate their phenotypical effects as well.

As was mentioned in the previous chapter, most of these normative issues are typically discussed with the means of responsibility language. Although legal responsibility is not overlooked, ELSI papers on epigenetics tend to focus on the moral responsibility of agents for their role in avoiding or causing some kind of epigenetic harm. However, I argue later on in this chapter that it is exactly this responsibility object of epigenetic harm that is relatively underdeveloped in the existing literature. Before the key argument of this chapter is laid out, I present a very short overview of the state of the art on epigenetic responsibility.

In the context of epigenetics, matters concerning the appropriate *subjects* of responsibility have received ample attention. Viewpoints in this debate can be most easily distinguished by their answers to the question of to which extent it is appropriate to hold individual people personally responsible for epigenetic harm caused to them and/or their offspring. Most commentators wish to move away from a still rather popular discourse of heightened individual responsibility prompted by findings in epigenetics (e.g. Hedlund 2012; Pentecost and Meloni 2018). They often do so by arguing for the inclusion of *collective* agents such as governments, public health organizations, and a variety of corporations in responsibility distributions. In recent years, however, various authors have warned against a one-sided focus on collective responsibility as a kind of panacea for the ethics of epigenetics, because the concept is not free from conceptual and normative complications (Chiapperino 2020; Dupras and Ravitsky 2016). Those debates about the subjects of epigenetic responsibility will be discussed in much more detail in chapter 3.

For now, note that epigenetic deterministic narratives may be employed by both ‘individualists’ and ‘collectivists’. An individualist epigenetic determinist might stress the impact of lifestyle choices and behaviour, as well as the changes an agent can make to their environment, for example by moving. A collectivist epigenetic determinist might focus more on the impact of environmental exposures and the changes societies can make to change individual behaviour, for example through nudging (Thaler and Sunstein 2009). As will be argued below, however, epigenetic determinism also risks giving rise to a sense of defeatism, because it does not do justice to the complex involvements of various factors and agents in the affliction of epigenetic harm.

The *indirect object* of epigenetic responsibility, denoting *towards whom* the person(s) or the agents discussed before are responsible, has also been taken into account in normative debates. Because of the potential transgenerational inheritance of epigenetic changes, it should come as no surprise that most attention has been paid to the responsibility that current generations may have towards future ones (e.g. Hens 2017a; Del Savio, Loi, and Stupka 2015). On an individual level, this has led to debates on issues such as the responsibility future parents might have towards children they have not yet conceived – or indeed, they may not even have considered having children yet. Such discussions also touch upon the famous philosophical non-identity problem, in which harm also plays an important role (Chiapperino, 2018). It should be noted that the subject and the indirect object can overlap: the person held responsible and the person they are said to bear responsibility towards can be one and the same. Indeed, popular discourse often holds individual people responsible for their own epigenetic health: crudely put, people should just eat healthier and smoke less.

Issues surrounding the indirect object of epigenetic responsibility are discussed in chapters 5, 6, and 7 of this thesis. But what is it we are responsible *for* in the context of epigenetics? In contrast to the subject and the indirect object, the *direct object* (henceforth simply 'object') of epigenetic responsibility has barely been the focus of systematic discussion. This is not to say that scholars working on normative implications of epigenetics do not mention any object of responsibility. Indeed, authors have identified a variety of possible objects of responsibility in their accounts. These objects can be broadly distinguished in two ways.[4]

Firstly, the object can be part of a responsibility that has either a forward- or backward-looking (or: prospective or retrospective) *temporal orientation*. For instance, stewardship of one's epigenome or that of future offspring can mean that one has a prospective duty to protect it, or, once it is too late to do so, a

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[4] The authors cited mention those objects in their work. They do not necessarily endorse them as sound objects of epigenetic harm; often, they do not make any normative claims about them at all.

retrospective responsibility for damaging one's epigenome or that of a child (Chiapperino 2020). Other backward-looking objects include increased epigenetic risks or dispositions (Chiapperino 2018); epigenetic alterations (Hens 2017b); detrimental effects as causal consequences of a bad lifestyle or environmental exposures (Santaló and Berdasco 2022); an aberrant epigenome (ibid.) or aberrant epigenetic effects (Chiapperino 2018); and generally having played a role in the causation of epigenetic harm (Dupras and Ravitsky 2016). Some forward-looking objects of epigenetic responsibility that are often mentioned are: mitigating disadvantageous epigenetic effects (Santaló and Berdasco 2022; Dupras, Saulnier, and Joly 2019; Loi, Del Savio, and Stupka 2013); improving one's epigenome (Chiapperino 2018); avoiding transmission of epigenetic predispositions to disease (ibid.); improving children's future (mental) health (Dupras, Saulnier, and Joly 2019); preventing epigenetic risks (ibid.); and epigenetic health (Dupras and Ravitsky 2016).

Secondly, objects of epigenetic responsibility can have different *scales*. While the protection or damaging of one's own epigenome takes place on an individual level, ELSI authors have also identified *societal* or macro-scale objects of epigenetic responsibility. These include protecting the most vulnerable citizens from hazardous exposures that could adversely affect their offspring (Rothstein, Harrell, and Marchant, 2017); epigenetic risk distributions and communication (Juengst et al., 2014); environmental justice (Dupras, Saulnier, and Joly, 2019; Chiapperino, 2018); intergenerational equity (ibid.); health justice (Loi et at, 2013); and developing and providing cures, which is the aim of clinical epigenetics (Dupras and Ravitsky, 2016). The scale of the object often corresponds with that of the subject (i.e. an individual or a collective agent), but this does not need to be the case. For example, a collective subject can coherently be said to bear responsibility for harm that has occurred on an individual level.

Epigenetic harm

Not all objects of epigenetic responsibility are compatible with each other. Especially in the process of translating them into public health policy, tensions may arise. For instance, Dupras and Ravitsky (2016, p. 4) ask: "Should we focus on the best environment for the healthy programming and maintenance of epigenetic health or rather promote programming the epigenome so that it best matches the living environment or lifestyle of the individual?" However, it should be noticed that all of these objects (perhaps with the exception of improving one's epigenome, although improvement also implies transitioning to something more desirable and potentially less harmful than before) are related to each other in virtue of their relation to epigenetic harm, understood as the negative consequences of epigenetic alterations on people. Epigenetic health can then be defined as a state in which epigenetic harm is absent. Other forward-looking approaches to responsibility do not avoid talking about epigenetic harm either. Rather, their objects concern the mitigation, distribution, reversal, or prevention of epigenetic harm. In short, even though theorists working on the normative implications of epigenetic findings may consider various objects of epigenetic responsibility, all of them are to some extent underpinned by a notion of epigenetic harm.

The conception of harm that is being employed in those works is rarely the subject of reflection or extensive discussion, leave alone an analysis of how various conceptions of epigenetic harm are related to each other. Nonetheless, the choice of an object of epigenetic responsibility may be closely linked to, or even inform or be informed by, an author's views on a fair or just responsibility distribution. For example, an author focusing on discussing cures for conditions that may be partially caused by epigenetic mechanisms may well be a proponent of a medical model of disability (cf. section 2). The normative literature on epigenetics would benefit from making the conceptual discussion of 'epigenetic harm' more explicit, which I intend to do here. This is primarily so because of the essential role the concept fulfills in discussions of normative implications of epigenetics. Indeed, epigenetic harm derives its importance from its status of a *bridging concept* between, on the one hand, relatively neutral findings on epigenetics on the one side, and potential ethical and societal implications of those findings, primarily in terms of responsibility ascriptions and distributions, on the other. I do not want to imply that findings in epigenetics can ever be free from values (cf. also the Introduction of this thesis). The formulation of hypotheses, the choice of research methods, the way that perceived phenomena are (not) conceptualized, ...: none of these aspects exist in a moral, social, or political value. However, much of the broader uptake of those findings, and their more ‘intensified’ political meaning and use, seems to hinge on one’s conception of what does and does not count as epigenetic harm.

As various authors have carefully emphasized, no ethical implications, with regard to responsibility or otherwise, follow automatically from epigenetic findings (Stapleton, Schröder-Bäck, and Townend 2013). Moreover, those findings are never truly objective or neutral themselves. Huang and King, for instance, note that "identification of epigenetic mechanisms that are influenced by environmental exposures (social, biological, chemical or otherwise) never imply who should be held responsible for any particular causal mechanism nor what the appropriate remedy might be" (Huang and King 2018, 743). They conclude that biomedical knowledge is neither necessary nor sufficient to inform moral claims. An interpretation in which certain values are attached to those findings is necessary before any normative conclusion can be reached. I argue that 'epigenetic harm' is such an intermediate step. As mentioned before, the researcher's choice of a conception of epigenetic harm – the object of responsibility they think is worth discussing – is a crucial step in their arguments for specific claims about epigenetic responsibility, particularly about claims as to the appropriate responsible subjects. The central role of epigenetic harm in any normative (ethical, legal, social, or political) account of epigenetics warrants a richer discussion of it.

2. Dimensions of epigenetics harm

In this section, I will argue that, in order to obtain a sufficiently nuanced and realistic account of epigenetic harm, we should move towards a *multidimensional understanding of epigenetic harm.* The first dimension, that of causality, has received a considerable amount of attention, but it has become increasingly clear that it runs into some difficulties. Because of that, and aided by insights from disability and feminist theory, I argue that this dimension should be supplemented by at least two other dimensions that have been largely neglected (noteworthy exceptions being Saulnier, 2020 and Saulnier et al., 2022): that of lived experience and that of relationality.

Causal dimension

How does information about the causal connections between epigenetic changes and certain phenotypical outcomes influence thinking about epigenetic harm? In this section, I draw on insights from existing literature on epigenetics to reiterate the point that the causal dimension of epigenetic harm is a very complicated one.

Firstly, normative accounts based on findings in epigenetics should not be based on excessively simplistic beliefs about the *predictability* of the occurrence of epigenetic mechanisms. Epigenetic mechanisms can be triggered or influenced by a combination of factors, not only in the environment external to an organism but also in its internal (cellular) environment, sometimes due to genetic differences (Cavalli and Heard, 2019). Thus, Luca Chiapperino argues that discovering which elements of a person's lifestyle, environment, and genetic makeup contribute to certain epigenetic marks is a complex puzzle that is extremely difficult to solve (Chiapperino 2018; 2020).

Indeed, one may wonder whether it will ever be possible to solve this puzzle. Perhaps the vast complexity of interplays between all elements leaves us no choice but to accept that a certain degree of unpredictability remains unavoidable even in a technologically and scientifically more advanced era. Maybe we should heed the call of philosopher Alfred North Whitehead, discussed in the context of epigenetics by Kristien Hens: "As Whitehead says: *beware of certitude*. Reality, in all its concreteness, is only partially knowable" (Hens 2022, 83). Perhaps predictions based on epigenetic knowledge are somewhat similar to weather predictions. Epigenetic findings underline the idea that an organism such as a human being is a complex, open system, much like the weather. This dynamic interaction between the body and its environment limits our potential to make predictions considerably.

Similar problems arise when epigenetic harm is understood as the materialization of some kind of epigenetic *risk*. The concept of risk typically has at least two components: 1) a bad outcome with some magnitude and 2) a certain probability of that outcome materializing. As Ulrich Beck puts it, “in definitions of risk the sciences’ monopoly on rationality is broken” (Beck 1992, 29). This means that statements about risk are always partly value judgments that can moreover have an impact on our moral theories (Hansson, 2013). When we talk about the probability of something neutral or even positive occurring, we usually talk about chances, rather than risks: calling something a risk implies that the potential outcome is negatively valued. This is why, for example, autistic advocates object to ‘risk of autism’ language in research on the etiology of the condition (or indeed, argue that such research receives too much attention tout court). But even when we agree that epigenetic risk is the right term in other instances, ethical questions about risk impostion and the distribution of risks show that other values than merely that attached to the potential outcome are at play (Hermansson and Hansson 2007; Hayenhjelm and Wolff 2012; Ferretti 2016).

Finally, the *'mismatch model'* of epigenetic disease development further complicates issues. According to this model, "an adverse phenotype does not depend merely on the presence or absence of a specific epigenetic variant, but rather on the mismatch between the previously programmed variant and the individual's lifestyle or living conditions" (Dupras and Ravitsky 2016, 3; see also

Stapleton, Schröder-Bäck, and Townend, 2013). This means that the same lifestyle behaviours or environmental exposures may lead to different outcomes, depending on an individual's environment. Such findings have implications for attempts at defining epigenetic normality and epigenetic harm. As Dupras and Ravitsky conclude, "it is often unclear whether epigenetic differences - potentially perceived as epigenetic abnormalities - should be treated as impairments or rather functional adaptations conferring advantages in specific environments" (Dupras and Ravitsky 2016, ibid.). In short, it is very difficult to define a healthy or a reference epigenome (Santaló and Berdasco 2022; Dupras, Saulnier, and Joly 2019). Thus, "we should be careful not to conflate the atypical epigenome with the detrimental" (Dupras and Ravitsky 2016, 4).

Those warnings do not mean that epigenetic knowledge is not useful or actionable at all. If we return to the weather analogy, we can see similarities with climate change studies. Although the short-term and local weather is not very predictable, it is possible to discover tendencies and predict general changes to the long-term climate. Similarly, epigenetic epidemiology can discover tendencies in populations, as well as detect significant statistical associations (Santaló and Berdasco 2022). Moreover, even though the precise level at which specific factors contribute to an outcome may be very hard to determine, it may often nonetheless be clear *that* those factors contribute.

The difficulties mentioned above make causality-based aspects alone not very suitable candidates to serve as the exclusive dimension of the concept of epigenetic harm that fulfills such an important bridging function. In line with Kristien Hens and Leni Van Goidsenhoven, I will now explore the potential of epigenetics to introduce an approach that is "not deterministic, but dynamic" and that moves the discussion "from the search for causes and culprits to experiences and understanding" (Hens and Van Goidsenhoven 2017).

Lived experiences

As mentioned before, 'epigenetic harm' is always a normatively laden term that designates a state of affairs that is deemed by the user of it to be of negative value, (ceteris paribus) undesirable, or to make a person affected by it worse off than they were before it affected them. In this paragraph, I argue that more emphasis should be put on the *lived experience* of the subject affected by epigenetic alterations when we try to delineate what counts as epigenetic harm and when we distinguish between harmful and neutral epigenetic variation. For this, I rely on insights from disability studies and critical disability theory.

Disability theory has rarely been applied to normative issues surrounding epigenetics. In her thesis, which constitutes a very noteworthy exception to this general lacune, Katie Saulnier (2020) explains why insights from disability studies are urgently needed to interrogate some assumptions in ELSI literature on epigenetics. She notes that "epigenetics as an emerging field is already showing a tendency to feed into harmful narratives around the value of certain bodies over others" (13). For instance, epigenetics research often seems to take a focus on identifying and discussing epigenetic 'deficits' or 'defects' for granted. If employed without caution, such terms may (perhaps unintentionally) have harmful effects.

Problems of pathologization have already been thematized extensively in the field of disability studies. Many scholars in this field share a critical stance towards a medical model of disability. This still prevalent model "frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms" (Kafer 2013, 5). Those adopting critical disability theory as a methodology, for example, aim to “analyze disability as a cultural, historical, relative, social, and political phenomenon” (M. Hall 2019). That does not mean that the medical perspective is always shunned. Alison Kafer, for example, argues for a political/relational model of disability that is critical of individualist or medical understandings of disability, but does not completely want to reject medical intervention (Kafer 2013). Gert-Jan Vanaken is motivated by similar concern, noting that “the oft-cited ‘models of disability’ leave little room to criticise clinical research and practice constructively” (Vanaken 2022, 26).

In the context of epigenetics, adherence to a medical model is visible in the search for cures and therapies for certain conditions, in light of the promise of the reversibility of epigenetic mechanisms. Disability theorists point out that it is harmful to assume an implicit connection between bodily differences – epigenetic or otherwise – and deficits. They often hold variations of the Mere-Difference View, arguing that disability is not *by itself* something that makes disabled people worse off (Barnes 2014). Illness, too, cannot simply always be understood as a harmful or undesirable state without qualifications. For example, in nursing ethics the concept of health-within-illness has been developed to describe how illness or acquired disabilities can lead to new insight about oneself and one’s relatedness with the environment (Moch 1998; Zagorac and Stamenković Tadić 2022).

Such ethically driven criticism of simplistic descriptions of harm and illness connects well to the more analytic concerns about identifying a healthy reference genome by ELSI scholars of epigenetics mentioned before. But if not all instances of epigenetic variation count as epigenetic harm, how can we determine which ones are? The key to answering this question lies in paying attention to the lived experiences of people with conditions to which epigenetic mechanisms contributed. As Hens and Van Goidsenhoven claim, the dynamic, nuanced view of human biology suggested by epigenetics leaves room for valuing "lived experiences as integral part of research endeavors" (Hens and Van Goidsenhoven 2017). We need to listen to people's descriptions of their quality of life, how they experience their interaction with their environment, and the obstacles they encounter. Saulnier believes that epigenetics could "push us to consider the value of bodies *as experienced*" (Saulnier 2020, 46) when interrogating tendencies towards determinism in epigenetics, because the body can only be experienced in its physical and social context.

Such attention to lived experience would not only broaden our understanding of epigenetic harm, but it might also mean that it is not justified to conceive of some conditions that are currently understood as instances of - among other kinds of harm - epigenetic harm as such anymore. A good example of this is autism, a condition of which the evidence of epigenetics playing a role in its development is steadily increasing (Eshraghi et al. 2018; Gowda and Srinivasan 2022; Wang and Jiang 2022; Schanen 2006). As Kristien Hens explains, ascribing responsibility to future parents to take steps to avoid triggering epigenetic mechanisms that might contribute to autism presupposes wrongfully that autism is self-evidently a condition to be prevented (Hens 2017a).[5] The neurodiversity movement combats this assumption and proposes instead that cognitive differences such as autism are "part of a necessary and positive spectrum of human experiences" (Saulnier, 2020, 43). Stories and reports from autistic people are an important source of knowledge about the "potential joys found in autistic traits" (ibid., 75). The neurodiversity movement came into existence to share and think through the lived experiences of autistic people (Kapp 2020). It is important to note that neurodiversity theorists do not wish to diminish the harms or challenges that may

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[5] For instance, in their introduction to a paper on the epigenetic epidemiology of autism, Wang and Jiang (2022) speak of an 'alarming increase' of autism over the past decades.

nonetheless accompany neurodivergence.[6] Such harms may include stigmatization or epistemic injustice, as I will discuss in the next subsection.

Although moving from a one-dimensional model of harm towards one that takes the concerns of disability theory seriously is important, a challenging tension arises from it. This is the tension between identifying harmful (environmental) influences on the one hand and not wanting to attach negative value to the bodies affected by those influences on the other. This problem is not only apparent in epigenetics research but has already been thematized by other scholars concerned with both disability justice and environmental justice. Eli Clare, Alison Kafer, and Thomas Bretz all recognize the difficulty of striving toward environmental justice without reproducing ableist presuppositions.[7] I juxtapose their formulations of the tension with each other to make it as tangible as possible.

In his book *Brilliant Imperfection*, Eli Clare captures what is at stake, asking: “How do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds [...] while not equating disability with injustice?” (Clare, 2017, p. 56). He wants to avoid using disability as a ‘cautionary tale’ that should urge people to take fewer risks and care more for their environment. Such a strategy that is sometimes used by environmental justice movements reduces the experiences of disabled people and people with chronic illnesses to proof of injustice. Clare argues that this ignores the ‘brilliant imperfection’ of their lives.

Alison Kafer formulates a similar challenge in *Feminist, Queer, Crip (*2013). She notes that disabilities often feature in environmental justice literature as “stories of error and aberration” (Kafer, 2013, 157). She asks: "How can we continue the absolutely necessary task of challenging toxic pollution and its effects without perpetuating cultural assumptions about the unmitigated tragedy of disability? How can we attend to 'serious health problems' while also deconstructing the stigma attached to those problems or even historicizing the very construction of such conditions as problems?" (ibid., 159). In short, what she desires are analyses

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[6] For an introduction to the key concepts and arguments of neurodiversity theory, see Chapman 2019. The discussion of the Mere-Difference View by Elisabeth Barnes (2014) may also help to understand this point.

[7] I owe this formulation of the tension to Gert-Jan Vanaken.

critical of the exploitation of environments and the living beings part of it, “without demonizing the illnesses and disabilities, and especially the ill and disabled bodies, that result from such exploitation” (158).

Thomas Bretz writes about this topic primarily from the perspective of environmental ethics, approaching the problem from the perspective of responsibility practices in a paper devoted to the issue. He contends that being disabled “should not be routinely listed as a prima facie harm in environmental (justice) literature” (Bretz 2020, 175) because it is in itself a neutral condition. But he wonders: "if disability is neutral with regard to well-being, doesn't this reduce our ability to politically, morally or legally challenge the creation of toxic environments by government, corporate or private actors and to demand their removal?" (ibid., 177).

How can we address this tension? Saulnier is convinced that disability theory can help us to deal with the fact that the environment can have a significant impact, for example through epigenetic mechanisms, on a body, without drawing any conclusions about the moral value that should be assigned to that body (Saulnier 2020, 47). Bretz argues that it is possible "a) to demand an investigation into the state of an environment, b) to object to toxic environmental conditions and c) to hold polluting parties accountable without assuming any overall difference in value or desirability between disabled and non-disabled lives" (Bretz 2020, 169). According to him, we can be concerned about change, such as bodily changes or a change in the prevalence of a disease in a population, without attaching negative value to the nature of this change. I am not fully convinced that this distinction is sufficiently powerful to dissolve the tension. Neither do I think that his suggestion to evaluate environmental conditions based on what they do to central life processes (177) is airtight, because even changes to those life processes and the illnesses caused by this may not always be a bad simpliciter. Most convincing is his call to move away from a normative classification of living bodies and instead focus on an environment's ability "to sustain human and non-life" and allow it to flourish (Bretz 2020, 178) in its environment.

This project of focusing on flourishing can only succeed by heeding the call for more room for lived experiences in epigenetics research. I agree with Kafer that by listening to the experiences of people living with certain disabilities, illnesses or conditions, "disability scholars and activists can work to ensure that descriptions of the possible impairments linked to toxic exposures do not replicate ableist language and assumptions" (Kafer 2013, 159). In general, people with first-hand experience of the impact of environmental factors and lifestyle behaviours on their bodies are best placed to judge whether or not they have been harmed.[8] Admittedly, asking people for their lived experiences will always result in a wide variety of stories that may sometimes conflict with each other. This means that such lived experiences need to be interpreted with other factors in mind if one wants to base normative statements on them.[9]

Truly solving the tension will perhaps prove to be impossible. Instead, we may need to learn to live with the 'inconsistency' pointed out by it (Hens 2022) or to 'stay with the trouble' (Haraway 2016). ELSI researchers of epigenetics should allow themselves to cautiously think through the tension and employ the insights that flow from it to go beyond any simplistic narrative of epigenetic harm.

Love my child, hate Umicore

The tension is very apparent in the case of the Belgian district Hoboken, with which I started the introduction to this thesis. Hoboken is home to a factory site of Umicore, one of the world's largest precious metal refiners that made an operating profit of 971 million euros in 2021 (Vansteeland 2022). The factory plant is surrounded by a residential area that was constructed over the 20th century. Emissions of lead, cadmium, and arsenic have been contributing to widespread health problems in children for decades (Pano 2021). Despite efforts that have greatly reduced both the emissions and their impact, lead levels in the blood of the children living in the neighborhood continue to exceed the standards posited by public health agencies. Epigenetic mechanisms may contribute to lead-induced health effects in children, such as behavioural issues and problems with developing gross motor skills (Senut et al. 2012; T. Wang, Zhang, and Xu 2020).

Parents worry about the health of their children and often feel guilty about living in the vicinity of the polluting factory, as becomes clear in a news documentary on the situation (all quotes below are my own translations for Dutch of quotes from Pano 2021). For example, the couple David and Tiffany express self-blame for not understanding the gravity of the pollution early enough. David says: “We knew that the factory had an emission, but that is the same as living next to the

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[8] That is, if they have the epistemic tools to do so. In the next subsection, I address concerns about hermeneutic injustice.

[9] I thank Lisanne Meinen for this reminder.

highway, there is also emission there. That is why I convinced myself back then: alright, we are going to live next to that factory now.” Tiffany explains that she has had to terminate a pregnancy because the fetus had hydrocephalus (‘water on the brain’). Lead exposure might have contributed to this, but there is no certainty. When the interviewer asks the couple how they feel about this, Tiffany immediately answers: “Guilty. Because, well, we did decide to come live here, I did become pregnant… and yes, in hindsight you do have to live with not knowing whether that was the cause or not.”

But a striking illustration of the tension discussed above is that parents are choosing their words very carefully and slowly when describing how they feel about the effects of lead on their children. Nancy, the mother of Hanna, blames both Umicore and herself because she thinks “Hanna would have been a different child if we hadn’t lived there”. She does not say that Hanna would have been better off or healthier, but simply that she would have been a *different* child. And remember Esther, a mother of two children with very high lead values in their blood, who expresses her worries as follows: "I want my child to be able to be who he is. And that if he is good at something, it should be possible to stay that way. And if he is not as good at something, that should not become worse. I do not want external factors, such as a factory I have no influence on, to interfere… Stay away from my child, is what I think”. Esther does not so much want to say that there is something wrong with the characteristics or abilities of her child, but she does want to express that there is something wrong with how those came about. ‘Love my body, hate the military’ here becomes ‘Love my child, hate Umicore’. Her words also show a striking resemblance in sentiment to those of Alison Kafer in her introduction to *Feminist, Queer, Crip*: “As much joy as I find in communities of disabled people, and as much as I value my experiences as a disabled person, I am not interested in becoming more disabled than I already am” (Kafer 2013, 4).

To minimize the amount of lead that gets into children, parents are urged in flyers of public health organizations to clean their homes as often and as thoroughly as possible. Nancy explains how she feels about this: “For a long time already we have been feeling that they were pointing fingers at us, saying ‘it lies with you as parents’. Then at a certain point, they even wanted to see Hanna because she might have too much sand under her nails or because we perhaps hadn’t been honest about her not sucking her thumb or not having a pacifier.” Parents are also advised to let their children play outside in the neighborhood as much as possible, and they receive memberships to a zoo in another part of Antwerp. Esther feels conflicted about her responsibilities: “The burden is always put on us, we are always the ones who have to solve it [...] and at the same time, it's complicated. You do want to know what you can do to lower [the lead levels in your children's blood] but at the same time you think that that is the world upside down somewhat."

Umicore does take action to cut back its pollution and invests between 20 and 25 million euros a year to mitigate its effects. Their CEO states: "The primary goal is to ensure no children are living in that neighborhood anymore." The company is buying houses close to the factory and advising people to move elsewhere. The houses will be demolished to make way for a green buffer zone. Additionally, Umicore provides parents living in its vicinity with a limited budget to spend on the care their children need. Parents and children regularly protest against the situation and the proposed solutions which they feel are unfair and inadequate. But how can they resist the injustices they experience without presenting their children as mere victims? In November 2022, my colleague Gert-Jan Vanaken and I taught an MA seminar at the University of Antwerp on the tension between disability justice and environmental justice, and this case in particular. We asked students to come up with slogans that people might want to use when they regularly take to the streets. While trying to be mindful not to replicate ableist language, they came up with the following slogans: 'Umicore aan zet: meer zorgbudget!' ('It's Umicore's turn: more healthcare budget'), 'Onze zorg? Jullie zorg!' ('Our care? You should care!'), 'Jullie vervuiling weegt loodzwaar' ('Your pollution weighs on us like lead'), 'Ons huis: geen thuis' ('Our house: not a home') and 'Wij gaan niet verhuizen, de CEO mag komen kuisen' (We're not going to move, the CEO should come and clean).

Relationality

This third dimension deals with concerns related to imposition, relationality, and involvement, and their relation to epigenetic harm. Those who care about the normative implications of epigenetic knowledge should not only consider the direct bodily impact of epigenetic mechanisms, but also the *indirect* kinds of harm that may emanate from it or be otherwise related to it. The following indirect harms pertain to the relation between the subject of epigenetic harm and others.

Stigmatization

Katie Saulnier and colleagues argue convincingly how stigmatization could be a harmful result of epigenetic research focused on already vulnerable or minority groups:

> Because epigenetics enables us to examine the social and environmental contributors to health and disease at a molecular level, populations that have experienced large scale trauma or early-life adversity are being examined to provide evidence of the patterns already noted by researchers in other medical and social science fields. In providing a new layer of evidence for existing observations of health precarity and reduced health outcomes for populations that face discrimination, stigmatization, and trauma, researchers risk reifying stereotypes and placing contestable normative values on cultural behaviours or cognitive differences. (Saulnier et al. 2022, 69)

In particular, epigenetic research has the potential to increasingly pathologize specific socio-cultural practices, or to place disproportionate personal responsibility for health on vulnerable groups. Saulnier and colleagues end their paper with a helpful list of recommendations for researchers, ranging from the involvement of vulnerable groups in study development to caution regarding extrapolation from animal models and careful communication of results that stress study limitations (ibid., 75).

Process-related harms

When discussing the tension between disability justice and environmental justice, Bretz argues that we should not only consider outcome-related wrongs but also process-related ones, in terms of "the exclusion of communities and individuals from the decision-making process that determines the distribution and location of harmful facilities and structures" (Bretz 2020, 178). In accordance with this call, I contend that *process-related harms* may be inflicted if epigenetics research is not conducted carefully. The disability justice slogan 'nothing about us, without us' should remind us of the importance of the involvement of research subjects and communities in all stages of the research. When people are insufficiently involved in research design, data collection, and the drawing of practical and political implications from findings, they are being harmed. And such involvement requires careful consideration of the language used by researchers. As Valerie-Ann Johnson points out in the context of environmental justice: “Constant reference to environmental causes of disability renders those who are disabled passive recipients of harm and implies their inability to be full participants in environmental justice work” (Johnson 2017, 83).

Process-related harm does not only occur in research practices and activism. The concept may also help us to make sense of what is wrong with environmental pollution, for example, without wanting to classify the epigenome of impacted individuals as aberrant or an outcome-related harm. Changing the environment in such a way that a person's epigenome undergoes significant changes can harm this person if the changes are imposed upon them without their consent.[10] Bretz calls this a kind of "ontogenetic trespass, such that we impose certain temporally unfolding forms of embodiment on others without the possibility of consent" (Bretz 2020, 179).

Epistemic injustice

The concept of epistemic justice has gained significant philosophical interest in the past two decades thanks to the work of Miranda Fricker. She argues that epistemic injustice, a kind of injustice with regard to knowledge, can include impairments in at least two ways: testimonial credibility and the availability of hermeneutical resources (Saulnier 2020; Fricker, 2007). Both kinds of injustice may be related to epigenetic research. Testimonial injustice could arise when the testimonials of subjects of epigenetic studies about their environments and experiences are insufficiently taken into account.

Hermeneutical injustice is a kind of injustice related to how people interpret their life. Kidd and Carel speak of pathocentric epistemic injustice in particular. Such injustice includes hermeneutical difficulties associated with the experience of illness and healthcare access. One of the foundations of such injustice, they argue, is the reliance on a one-sided biomedical model that overlooks experiences of illness (Kidd and Carel 2019). Such injustice may also occur in epigenetic research. For instance, Saulnier argues that this is particularly risky in autism research: "In contributing to inaccurate stories about autism, epigenetics research that does not do the work to unpack the social and cultural context in which it is taking place actively contributes to harm in autistic individuals’ ability to know and name their own lived experiences" (Saulnier 2020, 73).

At the same time, communication of epigenetic knowledge might also help to alleviate hermeneutical injustice with regard to personal health. Information about the ways in which environmental factors and lifestyles might have played a

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[10] For a mundane example, consider the Muddy Mountainbiker. Although she may not mind or in fact even enjoy cycling in a muddy forest, it makes perfect sense for her to say that she has been wronged by the driver of a car narrowly driving past her when she is on the road, thereby causing her to be covered in mud.

role in the health of one's predecessors or oneself might even have an empowering effect (Chiapperino and Testa 2016; cf. chapter 7 in this thesis for a critical discussion of empowerment). However, in the context of autism, what is also needed to decrease existing testimonial injustice is not only the cultivation of autistic self-understanding but also that of neurotypical epistemic humility with regard to autistic experiences and different conceptions of living a good life (Chapman and Carel 2022).

3. Implications

In this section, I discuss some implications of moving from a one-dimensional towards a multidimensional account of epigenetic harm for responsibility ascriptions and epigenetic research. I first discuss the connection between a multidimensional model and epigenetic determinism. Then, I list some suggestions for both epigenetics research itself and research into the normative implications of its findings.

Epigenetic determinism

The potential for epigenetics to add an epigenetic determinism to the still existing genetic determinism has been recognized by various authors (Santaló and Berdasco 2022; Dupras, Saulnier, and Joly 2019; Huang and King 2018; Waggoner and Uller 2015; Juengst et al. 2014; Lock 2013). Waggonner and Uller highlight three features of (discourses on) epigenetics research that show a deterministic tendency: "the notion of genetic control of epigenetic regulation, the metaphor of fetal and developmental 'programming', and the discussion of transgenerational epigenetic inheritance" (2015, 182). Most authors consider such an epigenetic determinist narrative as a risk that researchers need to be warned about. They argue that epigenetic mechanisms should never be understood as exclusive determinants of characteristics or behaviours (Santaló and Berdasco 2022). Epigenetic determinism "threatens a more robust understanding of the role of both genetics and human agency" (Huang and King 2018, 72). When it comes to responsibility ascriptions, deterministic interpretations of epigenetic findings might lead to a limited uptake of responsibility due to a sense of defeatism or a laissez-faire attitude.

In general, a multidimensional understanding is less vulnerable to epigenetic determinism than conceptions of harm that lean too heavily on claims about causality and predictability. This means that it may avoid the sense of defeatism that can arise as a result of deterministic narratives, leaving more room for nuanced and just distributions of responsibility to both individual and collective agents. In particular, taking into account insights from disability studies may help to nuance (epi)genetic determinist claims. Melinda Hall, for example, argues in a paper on negative genetic selection that a disability critique can be employed to deflate belief in genetic determinism (Hall 2013).

Epigenetic research

A broader understanding of epigenetic harm might also lead epigenetics researchers to question their methods. The call for the inclusion of lived experience in descriptions of epigenetic harm could be translated into an uptake of *qualitative research* in epigenetics. Such research, primarily in the form of interview studies, has already been conducted by ELSI scholars and philosophers of science working with epigenetic scientists (e.g. Tolwinski 2013). However, epigeneticists themselves may find it valuable to supplement their biological molecular focus with qualitative research practices such as interviews, focus groups, and ethnographic fieldwork. Interdisciplinary work could investigate how certain epigenetically mediated diseases or conditions are experienced by people, and which implications they think epigenetic explanations of conditions should have for responsibility questions such as the attribution of blame (for a quantitative study exploring similar issues, see Bervoets, Kampen, and Hens 2022).

Additionally, a multidimensional understanding of epigenetic harm implies that the attitude of researchers and medical practitioners alike is one of *epistemic humility* when working with populations affected by environmental exposure or certain lifestyle aspect through epigenetic mechanisms. This would entail that researchers combine a nuanced appraisal of knowledge on epigenetic causality with an openness towards knowledge and narratives that may only be accessible to them through conversation with research subjects or patients (Ho 2011). As Megan Warin and Anne Hammarström suggest, biological data can be used side to side with, instead of privileged above, the everyday experiences of study populations (Warin and Hammarström 2018). Paying close attention to the experiences of people living in polluted communities, for example, can help resesearchers to notice “the first clues of environmental threat” sooner (Verchick 2004).

Such research is already happening. For example, Elisabeth Roberts works together with life scientists such as epigeneticists in the ELEMENT project (see Introduction and chapter 3). Another research project, in which University of Antwerp researchers are involved, examines the roles of dairy nutrition in Kichwa mothers in Ecuador and the influences on their infants. The project does not study the oral saliva epigenome, but also investigates the social-cultural environments, food availability, and cultural meanings of food (Maldonado Lino et al. 2022).

Responsibility distribution

As mentioned before, a fair degree of consensus already seems to have been reached about the inadequacy of a responsibility discourse that only talks about individual or personal responsibility for (avoiding) epigenetic harm. Saulnier (2020) emphasizes that such an individualistic responsibility narrative may indirectly cause harm such as discrimination. However, the alternative of a one-sided focus on collective responsibility is not a solution. Chiapperino (2020) uses the terminology of moral luck (Nagel, 1979) to argue that both individual and collective subjects are much more limited by factors outside of their control than most accounts of responsibility for epigenetic harm often seem to assume (cf. chapter 3 for a more detailed explanation of his account). The problems with causality claims described above are often used to talk about collective instead of individual responsibility for health, but as Chiapperino shows, collective responsibility is not a panacea, because it is not exempted from the problems troubling personal responsibility accounts (cf. chapter 3).

Instead, in the next chapter I propose that an account of harm that includes concerns about lived experience and relationality strengthens the case of *forward-looking* epigenetic responsibility that is taken up by individual and collective actors. I believe that epigenetic responsibility should primarily be understood as a kind of political responsibility of individuals, institutions, and corporations alike to secure moral and political progress in an egalitarian sense (Smiley, 2017). As authors such as Huang & King note, it may be very difficult or even impossible to distinguish some kind of 'purely' epigenetic harm from social harms that also have epigenetic consequences:

> Epigenetic mechanisms do not in themselves necessarily produce disadvantage; they always work in concert with extant social and economic disadvantages. As such, the injustice of a particular epigenetic variations is always perfectly circumscribed by an existing mechanism of disadvantage, which includes both a prior recognition of a disadvantaged group and an undesirable outcome. (Huang and King 2018, 74)

Even those who do not want to go so far as to say that epigenetics is in this regard a kind of epiphenomenon (Tolwinski 2013) cannot deny the overlap between concerns about epigenetic health and concerns for the impact that environmental factors and individual behaviours have on public health in general. Because epigenetic harm is so intricately bound up with other kinds of harm and inequality, striving to avoid epigenetic harm implies striving towards increased social and economic equality as well as disability justice.

4. Conclusion

Although discussions of epigenetic responsibility and its objects have not been absent from recent ELSI literature on epigenetics, an investigation devoted to the concept of epigenetic harm was still lacking. In this chapter, then, I have aimed to contribute to an interdisciplinary debate on the nature and instances of epigenetic harm. Motivated by intersectional feminist philosophers such as Mich Ciurria and Sally Haslanger, I argued for a broader ameliorative understanding of epigenetic harm that can be used to argue for more socially just and equitable environments that allow human beings to flourish (Haslanger 2006; Ciurria 2019).

Behind the term 'epigenetic harm' hide a myriad of biological and ethical complexities. I discussed that not only concerns about causality should play a part in conceptions of epigenetic harm. Instead, I argued that more attention should be paid to two other dimensions. The lived experiences of research subjects suspected to be impacted by epigenetic harm should be an important source of knowledge about the actual impact of certain epigenetic changes. Although at first sight there may be some friction between concerns for disability justice and environmental justice, this tension might not be very problematic or even prove to be productive. Additionally, researchers should be cognizant of harms emanating from the relational nature of human beings, such as those having to do with stigmatization, discrimination, and imposition of environmental exposures. I argued for those dimensions out of a moral concern inspired by insights from disability studies and feminist philosophy. A sufficiently nuanced understanding of epigenetic harm may make discourses on the normative implications of epigenetics less vulnerable to be interpreted in simplistic determinist terms. Although I discussed just three dimensions of epigenetic harm, I chose to denote my approach as 'multidimensional' on purpose. I wish to leave room for other researchers to explore additional dimensions that can contribute to a richer understanding of epigenetic harm.

Chapter 3

Epigenetics and Forward-Looking Collective Responsibility

Chapter 3 Epigenetics and Forward-Looking Collective Responsibility

This chapter was accepted for publication in the edited volume *Epigenetics and Responsibility* I am editing together with Daniela Cutas and Anna Smajdor, which will be published with Policy Press in autumn 2023. The full reference is: Moormann, Emma. 2023. "Epigenetics and Forward-Looking Collective Responsibility." In *Epigenetics and Responsibility*, edited by Anna Smajdor, Daniela Cutas, and Emma Moormann. Bristol University Press.
I made some very small changes to the text to increase the general coherence of this thesis. I also added references to other chapters to draw connections between this chapter and the overall structure of the thesis.

Introduction

This chapter is concerned with the ethics of epigenetics from an egalitarian perspective. Our societies are currently deeply unequal in the ways in which resources, opportunities, and exposures to harmful phenomena are distributed. Disparities and injustices are also present in the occurrence and distribution of epigenetically mediated harm. One does not have to be an epigenetic exceptionalist (cf. Huang & King 2018; Rothstein 2013) to contend that findings in epigenetics are another addition to the vast heap of empirical evidence that social inequalities have an impact on individuals and their offspring both physically and mentally.

When thinking through issues of justice concerning public health in general and epigenetics in particular, the concept of responsibility has often proven to be an indispensable tool. The present chapter aims to add to the literature on epigenetics and responsibility by zooming in on a specific group of responsibilities: forward-looking collective responsibilities (henceforth abbreviated as FLCRs). I will explore what the concept of FLCR can contribute to a balanced account of responsibility in the context of epigenetics.

The first section of this chapter gives the reader some background about the use of collective responsibility in philosophy. Section 2 provides an overview of existing debates about collective and specifically forward-looking responsibility in the literature on the ethics of epigenetics. In section 3, I develop my own set of recommendations for using FLCR in this context. To an important degree, those recommendations are the result of applying insights from more general philosophical accounts in political philosophy and analytic responsibility theory to the specific challenges that have been derived from epigenetic knowledge. I will argue for the following claims: a) We need to steer clear of epigenetic eliminativism; b) FLCR is particularly well-suited for an ethical account that strives towards epigenetic justice. Conversely, epigenetic injustice can fruitfully be understood as an instance of historical-structural injustice; c) Intersectional feminist thinking, and particularly disability justice, provides good methodologies to approach the topic of epigenetic justice; d) FLCR ascriptions can be based on a variety of sources and concerns. FLCR is only useful when integrated into an account of epigenetic responsibility that also leaves room for backward-looking concerns. Section 4 brings those recommendations to life by discussing a few examples of epigenetics in action in Mexico City.

Two notes on terminology are in order. Firstly, unless otherwise stated, when I talk about responsibility, I have in mind *moral* responsibility rather than e.g. a legal or causal kind, although all these concepts can sometimes be intricately connected when it comes to complex structural problems such as epigenetic (in)justice. Secondly, although not all scholars referred to in this chapter use the term 'forward-looking (collective) responsibility', their accounts are nonetheless within the purview of this exploration because they meet two requirements: 1) they are in some sense *forward-looking,* i.e. primarily concerned with future states of affairs and 2) they allow for ascribing responsibility to a *collective agent.*

1. Collective responsibility

Individual and shared responsibility are, as we saw in this thesis' Introduction, relatively uncontested concepts. With collective responsibility, matters are more complex. According to proponents of the idea, the collectivity of the subject lies in some qualities of the actions and capacities of the agent that make it apt to ascribe responsibility to this collective agent rather than to the individual agents that constitute it (Smiley 2022; Tuomela 2013). But many debates have been had about *collective* responsibility (CR). Methodological individualists (such as Lewis 1948; Sverdlik 1987) do not believe that collective agency can be the kind of agency required for ascriptions of moral responsibility. Normative individualists argue that even if such agency exists, it would be wrong, impractical, or unfair to ascribe responsibility to collectives rather than to their members.[11]

This thesis in general and this chapter in particular do start from the assumption that collective responsibility is an ethically fruitful concept in the context of epigenetics. Epigenetics shows us how organisms are affected by their physical and psychosocial environment on a molecular level, suggesting a dynamic conception of human biology. A discussion of moral responsibility for epigenetic health would thus not only have to take individual, but also collective actions into account. The concept of collective responsibility seems necessary to adequately think about the ethical complexities of epigenetics health because it recognizes that human beings are not atomistic agents, but instead social and relational beings.[12] The fact that employing the idea of collective responsibility is not self-evident, however, urges me to make a few remarks on debates surrounding it before I continue to discuss its application to epigenetics.

Since I focus on forward-looking collective responsibility in this chapter, I need to worry somewhat less about the metaphysical debates on the requirements for collective agency and intentionality. As Smiley notes, the metaphysical foundations of this notion are less controversial than those of its backward-looking counterpart, since "forward-looking collective responsibility is not designed to capture an agent's will. Instead, it is designed to distribute moral labor" (Smiley 2022).

However, I do leave room for backward-looking considerations, because holding collective agents responsible for harm can help us to do important things in the world: "we can raise consciousness among groups about what they are doing. We can get them to stop harming others. We can reinforce social norms that prevent such harm from occurring in the future. And we can make clear to the world that those being harmed are worth taking seriously" (Smiley 2022). Additionally, we can use practices of blame and praise to point out and ameliorate situations of social and political oppression (Michelle Ciurria 2019). This means that I need to

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[11] In the next chapter, I discuss normative individualism in an anarchist context.

[12] As becomes evident in the fascinating edited volume *Landscapes of Collectivity in the Life Sciences*, many life scientists have been working on overcoming a preference towards methodological individualism in biology by looking at collectivity and collective agency instead (Gissis, Lamm, and Shavit 2017).

position myself in relation to the existing debates. I summarize some positions in the debate, before noting that I take a pragmatic and pluralist approach.[13]

Methodological individualists doubt that groups can be understood as morally blameworthy in a way that is distinct from the aggregated blame of their individual members. They may for example argue that only individuals can take actions, or that only individuals can form intentions or have minds. In response, defenders of collective responsibility are quick to point out that blaming groups is something we often do in practice, and that this practice and our reactive attitudes towards collectives are hard to analyze from the viewpoint of methodological individualism (e.g. Cooper 1968; Tollefsen 2003). They discard the idea that our practices and language use might be misguided. Peter French, for example, refers to oft-used predicates that we cannot explain in an individualist way, such as ‘disbanded’, ‘lost the football game’, ‘elected a president’, and ‘passed an amendment’ (French 1998, 37; through Smiley 2022). Larry May emphasizes the relationality of many of our actions, arguing that social contexts allow individuals to act in ways that would not be possible if they acted alone (May 2010).

Those who believe that collective responsibility is a legitimate concept in moral philosophy offer various requirements for collectives to be appropriate holders of such responsibility. Some emphasize the importance of having good decision-making procedures in place (e.g. French 1984). Others argue that groups at the very least need to be sensitive to reasons and can be motivated to act on them (Silver 2022). An influential account is the ‘group agency’ approach developed by List and Pettit (2011). They argue that collectives need to have ‘joint intentions’ to count as proper moral agents. Mich Ciurria, before formulating critical remarks, summarizes those as follows:

> To share a joint intention is to intend to act on a shared goal, to know that other members of the group intend to act on the same goal, and to know that other members share the same common awareness of each other’s intention to act on that goal.” (Ciurria 2019, 65)

Such group agency approaches allow for relatively limited options for ascribing collective responsibility. As Ciurria points out, we might not only have moral but

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[13] The following 3 paragraphs are based on an excellent overview of debates on collective responsibility by Marion Smiley (2022).

also epistemic reasons to want to broaden our scope of collective responsibility because we are as a culture “quite inept” at identifying group agents (ibid., 68).[14]

Others are more permissive concerning the amount of structure needed in a collective, and hold for example that shared interests and needs or some kind of group solidarity are enough for collectives to count as moral agents (Feinberg 1968). Various authors have pointed out how such a sense of community solidarity might even warrant ascriptions of moral responsibility to groups whose present members were not yet alive when the actions under scrutiny took place (Abdel-Nour 2003; McKeown 2021 on reparations for slavery). Although not many would say that even less-structured groups of people such as mobs or social groups could be assigned moral responsibility, this view is also defended by some. Virginia Held argues that bystanders of a crime are collectively responsible if they fail to organize themselves to effectively intervene (Held 1970). Larry May holds that collectives can also be legitimate targets of moral responsibility ascriptions if they have shared attitudes that might produce harm and that require acceptance by many individuals in a community to be effective (May 2010; Smiley 2022). He gives examples such as racism and sexism and has used this approach together with Robert Strikwerda to argue for collective responsibility of men for rape culture (May and Strikwerda 1994). I find such a ‘structural’ model of collective responsibility more useful than stricter group agency approaches. That means I follow Ciurria, who notes that such a model shows how structural injustices are not “individual transgressions perpetrated against individual victims, but they also aren’t blameless effects of faceless, non-agentic systems and processes, over which we have no control. Instead, collective transgressions are committed by social groups that are structured by socialization, affinity, and privilege.” (Michelle Ciurria 2019, 67) I say more about the role of structural injustice in my approach to epigenetic responsibility in section 3.

In light of debates with methodological individualists, I take a pragmatist and pluralist approach. The pragmatism entails that I agree with those authors who emphasize the beneficial roles that collective responsibility practices already play in our moral lives. Even most recent individualists “are generally willing to

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[14] The example she gives is that of perpetrators of mass shooters. We have a tendency to group racialize mass shooters as domestic terrorists acting from some shared ideological commitments, whereas we tend to downplay the extent in which the majority of mass shooters, white men, have joint intentions or shared commitments.

acknowledge the sensibility of collective responsibility in a limited number of cases" (Smiley 2022). This approach has similarities with that of Martin Sand (2018), who contends that the way we talk about collective responsibility in ordinary life should be understood as a kind of 'pragmatic foreshortening'. We resort to ascribing responsibility to an organization or a group as a whole in cases in which "we lack insight into the complexity of the decisional situation" (Sand 2018, 209). However, while Sand focuses on corporate responsibility, I wish to include more loosely-structured collectives in my approach as well. I thus also take a pluralist stance when it comes to the requirements collectives need to meet to count as proper moral agents. It seems to be that collectives can be fuller or more limited candidates for responsibility ascriptions based on their attributes. Collectives with clear decision-making procedures, role divisions, and internal communication can be held to high standards of responsibility. But I do not want to let more loose groups (such as the social groups targeted by May & Strikwerda and Ciurria) off the hook either: shared contribution to or benefit from existing injustices constitutes enough reason to ascribe some degree of responsibility to such groups.

Finally, there are the worries of normative individualists, who worry that practices of collective responsibility might go against values of individual fairness and individual freedom. Smiley summarizes the worries as follows: "What would happen, critics ask, if we were to replace individual responsibility with collective responsibility? Would we be letting individuals off the hook? Would we be eroding the practice of personal responsibility in general?" (Smiley 2022). In general, I am very sympathetic to the worry of normative individualists. Even a theory that investigates the potential of collective responsibility should do so with the ultimate aim of clarifying how individuals might benefit from such practices. For example, in chapter 7 I argue that the collective responsibilities of the state and healthcare organizations should be geared towards enabling individuals, especially the most vulnerable or oppressed ones, to freely and autonomously take action. In a similar vein, in chapter 4 I look at the tradition of social anarchism in which it is assumed that individual freedom and social equality presuppose each other.

2. Responsibility and the ethics of epigenetics

This chapter assumes that ethical epigenetic exceptionalism (cf. chapter 1) is unwarranted. The ethics of epigenetics is not so fundamentally different from other complex bioethical or public health issues that it needs to employ different or more responsibility concepts. Moreover, some of the characteristics of epigenetics warrant the search for responsibility concepts that are being used in normative work on global issues such as climate change and structural racism. Although they are not exceptional to epigenetics, especially not when taken individually, at least four characteristics of epigenetics are *particularly relevant* for the development of a *responsibility framework*. Those are: 1) the role of the environment (broadly understood) in the health of an organism at the molecular level; 2) the possibility, even if still very contested (cf. the introduction to this thesis), of transgenerational inheritance; 3) causal complexities and uncertainties that make it very hard to define epigenetic harm or health; and 4) the potential reversibility of epigenetic mechanisms.

Individual and collective responsibility

There has been a lively debate about which kind of responsibility concepts to use when discussing the ethically salient characteristics of epigenetics. An emphasis on individual epigenetic responsibility is often criticized because it is believed to be unfair in light of the complex and limited connection between individual choices and changes to the epigenome. For example, epidemiologists Bastiaan Heijmans and Jonathan Mill bring up a variety of biological, technical, and methodological issues that plague those in their discipline trying to determine the effects of individual behaviour and living conditions on the epigenome (Heijmans and Mill 2012; Mill and Heijmans 2013).

Political scientist Maria Hedlund asserts that epigenetics may provide new insights into the complex causality relations between various factors involved in the health of individuals. Particularly structural conditions may be beyond the capacity of individual agents to influence. She argues: "Considering the complex causal relations contributing to actual possibilities to make free and voluntary choice, it would be a rather demanding task to behave in an epigenetically responsible way" (180). Hedlund argues that "epigenetic responsibility primarily should be a political and not an individual responsibility" (Hedlund 2012, 172). Thus, Hedlund contends that there are at least three important reasons to ascribe epigenetic responsibility primarily to the state: 1) complex causality relations, 2) structural conditions constraining individual choice, and 3) solidarity.

Charles Dupras and Vardit Raditsky share the concern that "some scholars, the public, and the media are at risk of too hastily and simplistically assigning most epigenetic responsibilities to individuals" (Dupras and Ravitsky 2016, 6). However, they are equally wary of simplistic prospective and state-focused solutions, instead proposing a 'diversity of types' of epigenetic responsibility that takes into account the nuances regarding epigenetic normality and epigenetic plasticity. Firstly, they argue that defining the normal epigenome is "scientifically and ethically challenging for many reasons" (ibid., 3). For example, according to the mismatch model of epigenetic disease development, "an adverse phenotype does not depend merely on the presence or absence of a specific epigenetic variant, but rather on the mismatch between the previously programmed variant and the individual’s lifestyle or living conditions" (3). The full impact of epigenetic alterations can only be assessed contextually, by taking someone's environment and lifestyle into account. This is problematic for responsibility discourse because arguably some notion of a 'reference' genome "is required prior to determining personal and collective goals regarding epigenetic health" (1). Instead, they propose a 'diversity of types' of epigenetic responsibility that can deal with the nuances regarding the definition of a 'normal' or healthy reference epigenome in a specific context (*epigenetic normality*) and the dynamic nature of epigenetic modifications (*epigenetic plasticity).*

Luca Chiapperino summarizes that the critical treatment of claims of individual responsibility has "resulted in a consensual emphasis put on collective epigenetic responsibilities as an ethically and politically sound uptake of epigenetic evidence" (Chiapperino 2020, 2). Many critics have pointed out that "appeals to individual responsibilities to protect one’s epigenome overestimate individual capacities of bearing such backward- and forwardlooking types of responsibilities" (ibid., 12). Chiapperino himself provides another version of this critique based on the influence of moral luck on individual agency. Moral luck designates "the import that factors beyond one’s control have on the justification and cogency of normative claims such as responsibilities" (2). He goes a step further, however, by showing that much of the critiques of individual responsibility in the context of epigenetics also apply to collectives. He argues that it may be unwarranted to exempt collectives "from a consideration of how intrinsic limitations and deficiencies, trying and unwanted circumstances, as well as imperfectly predictable results, temper their blameworthiness for failing to act responsibly to protect our epigenomes and health" (ibid., 12). For instance, it may be hard to determine the contributory liability or backward-looking responsibility of individual members of a collective. Furthermore, it is often far from clear to what extent past and present members of a collective have contributed to its actions leading to certain epigenetic effects. This concern is not unique to epigenetics. It has also been made, for example, to criticize calls for ‘corrective justice’ in dealing with climate change (Posner and Sunstein 2007).

Given those problems with causal responsibility, can we salvage any kind of collective responsibility? In a forthcoming article, Chiapperino and Sand try to ‘shield’ some residual collective epigenetic responsibility from concerns about luck and uncertainty, because they are convinced that collective responsibility plays an important role in both ordinary language and social debates about an “effective societal uptake of epigenetic knowledge” (Chiapperino and Sand forthcoming). They rely on insights from John Greco to argue that the ‘moral worth’ of a collective need not always just be the result of its moral record (Greco 1995). We can judge the moral blameworthiness of collectives even if we are uncertain about the extent to which they have contributed to an outcome.

On what basis, then, can we do so? Chiapperino and Sand suggest taking an ‘aretaic’ perspective that evaluates whether an agent fulfills their proper function in the moral community and society (Cheng-Guajardo 2019). As Chiapperino and Sand note, such a perspective “highlights that blame is attributable to agents when they adopt an end or commit to a conception of value, which in the end they fail to realize”. This relies on the idea that collective agents have a certain character, goals, and orientation. In the context of epigenetics, the state, corporations, and public health agencies can be held responsible for contributing to e.g. promoting resilience or limiting the impact of unequal social structures on the health of disadvantaged groups.

Although this is an appealing approach, I think it needs a bit more elaboration to make it more powerful. A crucial matter in need of disambiguation seems to be how the ‘proper functioning’ is determined. Do we want 1) the collective agents in question to live up to their own pre-existing values and commitments? Or do we 2) want the goals and values of the commitments to properly serve societal well-being?

If we prefer the first option, we use the current values and characters of collective agents as a standard for assessing their moral worth. But this approach is insufficiently powerful to deal with collectives that do not take into account the (epigenetic) health effects on broader society that their activities have. While this approach might be helpful in specific cases in which we can clearly point at a discrepancy between a collective’s stated values and its actions. However, it also risks reifying of roles and values of collectives that might actually need to be revised or improved upon. Some self-formulated standards may be formulated so vaguely that they leave too much room for interpretation, and some may simply go against the values of the communities they affect.

The second option allows more room for change, as it is based on ideas of what the proper functioning of such collectives *should* be in light of epigenetic evidence. However, who should evaluate this? The collectives and their individual members themselves (which brings us back to the first point), or rather outsiders such as moral philosophers, social scientists, or the general public? In some public collectives, those two groups arguably overlap, but when this is not the case, we need to think about how to weigh different interests and perspectives. It seems inevitable that we ultimately need to ground ideas on what does and does not count as the proper functioning of a collective on normative claims about how knowledge of epigenetic mechanisms should be employed. Perhaps my approach in section 3 of this chapter can be seen as an attempt to formulate such claims about forward-looking collective responsibility in particular.

Forward-looking collective responsibility

As Marion Smiley explains, what is specific about *forward-looking* responsibilities is that they are "ascribed for the purpose of ensuring the success of a particular moral project rather than for the purpose of gauging the moral agency of a particular group" (Smiley 2014, 6). Such an approach does not focus on the question of who has caused a current state of affairs. Rather, it aims to find suitable individual or collective agents who can take up the responsibility for bringing about a desirable state of affairs.[15]

The concept of forward-looking collective responsibility has quickly gained ground as a tool to discuss new complex global as well as generation-superseding problems, such as racism and climate change. The health impact of epigenetic mechanisms is an equally complex phenomenon. It comes as no surprise, then, that the aptness of the concept has been discussed by a few authors interested in the ethics of epigenetics. The first substantive account of FLCR in an epigenetics context is that of Maria Hedlund. She argues that epigenetic responsibility should

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[15] However, as Martin Sand helpfully pointed out to me, not all accounts of FLCR include direct implications for what desirable state should be brought about. See, for example, the work of Virginia Held (2006).

primarily be collective instead of individual (Hedlund 2012). Hedlund then draws on the social connection model of responsibility proposed by Iris Marion Young (cf. section 3) to argue for *prospective* political responsibility shouldered primarily by state institutions. Whereas backward-looking models strive to isolate a responsible agent, such a forward-looking one "will tend to disregard the structural factors that shape the norms of appropriate behaviour and that an integrated forward-looking responsibility model brings into question" (ibid., 179). According to Hedlund, "the moral dimension of solidarity justifies why agents with capacity or in a position to act should be responsible in a forward-looking way" (178). If we care about equality, and if we value solidarity with the worse off, we should pay more attention to forward-looking collective epigenetic responsibilities.

Dupras and Ravitsky (2016) are critical of FLCR approaches. They are not only skeptical of the focus on collective instead of individual agents, as shown above, but also of any exclusively forward-looking account. Such an account would be ineffective if put into practice, because "attributing mere prospective responsibility without the possibility of holding actors responsible for past negligence (through health policies or laws) may result in a very limited upholding of the suggested prospective responsibility" (Dupras & Ravitsky 2016, 3). Put simply; if there are no consequences for not doing what is prospectively required, neither individual agents nor institutions might be very motivated to act on their responsibility by making efforts that may well be costly for them in some way (Neuhäuser 2014).

Chiapperino (2020) also discusses forward-looking collective responsibilities. He argues that criticism that can be levelled against the use of collective responsibility in general also applies to the use of specific forward-looking kinds, be it in a somewhat different form. Firstly, he criticizes accounts that equate "remedial collective responsibility to the capacity […] of taking informed action about a given situation" (Chiapperino 2020, 10). Secondly, he reminds us that "appeals to forward-looking collective responsibilities do not automatically support the idea that action should tackle the structural configurations of society producing epigenetic hazards" (ibid.). Perhaps other solutions or approaches, such as personalized medical interventions on an individual level, might be more apt. Third, he argues that collective agents are exposed to "contingencies and circumstances of agency or the stochastic and highly contextual dependency of epigenetic predispositions to disease" (ibid.) no less than individuals are. The outcome of the actions of collective agents may be influenced by factors outside of policy control, just like that of individual actions may be influenced by structural factors.

3. Suggestions towards a framework

Against (epigenetic) eliminativism

If responsibility concepts in the context of epigenetics are so fraught with problems, would developing recommendations for a framework of epigenetic responsibility not be futile? The criticisms such as those in the discussions summarized above, directed towards both individual and collective responsibility may tempt those thinking through the ethical implications of epigenetics to become 'epigenetic eliminativists' about responsibility. Eliminativism is the philosophical view that "we should eliminate our belief in responsibility and our corresponding responsibility practices (blame, praise)" (Ciurria 2019, 233). One prominent defender of eliminativism is Bruce Waller (Waller 2011).

This chapter does not endorse epigenetic eliminativism. I agree with Mich Ciurria that we cannot do without our responsibility practices. The best we can do in the face of existing flaws in responsibility models is to correct them in a reasonable way. Inspired by her commitment to intersectional feminism (cf. section 3.3), Ciurria argues for a radical transformation of the responsibility system instead of its eradication in the face of the problems with our current responsibility practices. She situates her position as follows: "Whereas eliminativism seeks to address the problem of excessively punitive blame, intersectional feminism instead identifies the core problem as a matter of asymmetrical power relations" (Ciurria 2019, 227). Importantly, in such asymmetrical circumstances, responsibility practices can contribute to the emancipation of those people or groups that are holding others responsible for something.

Even Luca Chiapperino, who expresses pointed criticism of a wide variety of epigenetic responsibilities in his 2020 paper and his contribution to a forthcoming edited volume, does not seem to want to opt for an epigenetic eliminativism of responsibility. He argues that "dominant atomistic framings" (Chiapperino 2020, 13) in which either individual or collective agents are central fail to do justice to the entangled reality of our lives, bodies, and environments. But instead of moving away from responsibility ascriptions altogether, he emphasizes "the need of delineating pragmatic, conventional or role collective responsibilities, based on distributive theories of agency, on accessory justifications of autonomy, solidarity, vulnerability, and human flourishing, or other norms of our moral and political life" (ibid.) that could guide actors in taking up their responsibility.

We still need to work with responsibility concepts, imperfect as they may be. I suspect that leaving some room for responsibility ascriptions and distributions may be more effective than, for example, arguing for increased unspecified solidarity with regard to public health. Albeit a noble endeavour, perhaps not many agents would be inclined to take action based on such a call for solidarity. This could lead to a kind of action void that undermines the agent's motivation to act. Moreover, an emphasis on individual responsibility for health still prevails in public debates as well as many scholarly discussions. I cherish the hope that sufficient attention to collective responsibility in the context of epigenetics helps to provide some counterweight to this focus on individual responsibility.

Epigenetic justice

If we accept that responsibility concepts have their place in analysing the ethics of epigenetics, can FLCR also play a role? If so, what could we hold agents responsible *for*? Since the nature of FLCR is primarily prospective or forward-looking, its object needs to be some future desirable state of affairs. Because of its collective nature, its object need not be identified on an individual scale. Instead, it can be an object on a societal level. I propose that a suitable object of epigenetic FLCR is *targeting epigenetic injustice* and *striving towards epigenetic justice*.

Note that this claim is compatible with other claims regarding epigenetic responsibility objects. Firstly, it is compatible with the idea that a framework for epigenetic responsibility should also encompass backward-looking concerns. Secondly, it does not deny the validity of pursuing other responsibility objects. Other kinds of epigenetic responsibility objects may in fact be better served by other responsibility concepts. For example, striving towards epigenetic justice can go alongside the search for cures for epigenetically mediated diseases. The responsibility claims about such cures may very well be situated on a more individual level, such as that of personalized medical interventions. Other objects of epigenetic responsibility that can exist alongside (or be sometimes in tension with) a collective focus on epigenetic justice include responsibilities to prevent adverse epigenetic alterations, to avoid epigenetic harm, or to protect one's own epigenome or that of one's offspring.

Epigenetic *injustice* can be characterized as a kind of historical-structural injustice. The political philosopher Iris Marion Young defines a situation of *structural injustice* as one in which "some people's options are unfairly constrained and they are threatened with deprivation, while others derive significant benefits" (Young 2011, 52). Those situations are often the result of many individuals and institutions pursuing their own goals and interests, "for the most part within the limits of accepted rules and norms" (ibid.). Although epigenetic changes take place at the molecular level of individual organisms, their environmental causes and the distribution of their occurrence between populations are structural issues. Being responsible in relation to such structural injustice is primarily forward-looking and collective in nature. Each of us has a political responsibility to "transform the structural processes to make their outcomes less unjust" (ibid., 96) that can only be discharged through collective action.

Epigenetic injustices are not only structural, but also historical. They are instances of what Alasia Nuti terms *historical-structural injustices*: "unjust social-structural processes enabling asymmetries between differently positioned persons, which started in the past and are reproduced in a different fashion, even if the original form of injustice may appear to have ended" (Nuti 2019, 44). Epigenetic injustice can be characterized as a biosocial kind of historical-structural injustice. Skewed distributions of ill health as a result of (often among other factors) triggered epigenetic mechanisms can have historical roots. For example, epigenetics research has been employed to study the biological basis of intergenerational trauma of Indigenous Australians as a result of colonialism (Warin, Kowal, and Meloni 2020). Epigenetic knowledge about the intricate connections between biography and biology can help us to understand how persistent current health disparities can be. Moreover, Nuti's term 'banal radicality' applies very well to the reproduction of epigenetic injustice. The ways injustice is reproduced in the present are often subtle, difficult to point out, and sometimes even unconscious, but those small, often unintended reproductions together "provide the condition of possibility for radical injustices to occur" (Nuti, 44). This idea can help us to understand how many actions by people and institutions, interactions with other agents, and short- or long-term exposures to things like pollutants and toxins, affect people’s health mediated by/through epigenetics. Fortunately, the potential reversibility of epigenetic mechanisms can provide the promise of actionability to those striving toward epigenetic justice.

Intersectional feminism

Epigenetic justice is not yet a substantive goal for ascribing and taking up epigenetic responsibility. Conceptions of justice may differ considerably. This section outlines what taking an *intersectional feminist* normative perspective might entail in the context of epigenetics.

Although feminist theory has its roots in the critiquing and challenging of oppressive or limiting gender roles, misogyny, and sexism, it has long been analysing the intersections of the power dynamics involved in gender with other forms of subordination (Allen 2022). Consequently, feminist theory is closely linked to areas such as class analysis, critical race theory, queer theory, and (critical) disability theory.

Mich Ciurria identifies five central aims of an intersectional feminist theory that can be used in approaching the topic of moral responsibility (Michelle Ciurria 2019). Such an approach should be aimed at (1) foregrounding and diagnosing the intersection of injustice, oppression, and adversity and (2) actively combating them. To do so, researchers can use (3) an ameliorative method that "defines concepts partly by reference to normative goals that challenge the status quo" (Ciurria 2019, 4).[16] Ciurria also (4) urges us to take up Charles Mills' call to strive towards a non-ideal theory (Mills 2005), which has the advantage that it "avoids abstractions that misrepresent reality" (Ciurria 2019, 5) unlike ideal theory that assumes just background conditions. Finally, she characterizes an intersectional feminist approach as one being committed to (5) a relational method. When it comes to complex responsibility issues, we should develop relational explanations that combine "situational and agential, collective and individual levels of analysis in a holistic fashion, giving rise to an understanding of individual responsibility as a function of the individual's role in situations and collectives" (ibid., 229).

In the context of epigenetics, we can ask which groups are suffering the most epigenetic harm, and why. How should the benefits of epigenetic treatments be distributed? It is likely that, without intervention, privileged groups are most likely to benefit from epigenetics research – they might be able to make use of

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[16] This notion is inspired by Sally Haslanger (see e.g. Haslanger 2006).

knowledge about the reversibility of some mechanisms by getting the right nutrition and supplements, living in the right environment and, increasingly, seeking the right treatments. Underprivileged groups, on the other hand, tend to be impacted disproportionally by the environmental triggers that cause adverse health effects through epigenetic mechanisms. For example, epigenetic mechanisms are being implicated in the link between low socioeconomic status and poor health status, also known as the 'Glasgow effect' (Katz 2018; McGuinness et al. 2012; Vears and D'Abramo 2018). Also, environmentally induced adverse health effects mediated by epigenetic mechanisms affect people of colour disproportionally (Jasienska 2009; Kuzawa and Sweet 2009; Mansfield and Guthman 2015; K. M. Saulnier and Dupras 2017; Sullivan 2013). Findings in epigenetics and the influence of ancestral trauma have also already been used by activists demanding reparations for slavery (Grossi 2020; Warin, Kowal, and Meloni 2020). Gender stereotypes can also be perpetuated in epigenetics research, for example in neuroepigenetics (Lawson-Boyd and Meloni 2021) and research on maternal influences on offspring (see chapter 7 for an overview). In the original paper on which this paper is based, I included a few paragraphs to demonstrate the relevance of intersectional theory for epigenetic responsibility by zooming in on the intersections between epigenetic justice and *disability justice*. In this thesis, however, I leave those remarks out because the connection has already been extensively discussed in the previous chapter. In section 4 of this chapter, I will rely on some of those points in the discussion of a case that features some examples of epigenetic responsibility.

Dimensions and sources of (FL)CR

Intersectional feminism is thus one potential *normative lens* through which one can study the applicability of FLCR for epigenetic justice. Such a lens may help to adjudicate "the salience of various practical and normative considerations" (Smiley 2014, 11) in a particular case. This section discusses some relevant practical and normative considerations for the ascription of collective responsibility toward epigenetic justice.

Orientation & justification

Firstly, a helpful distinction that allows for a more nuanced employment of the concept of FLCR is the one made by Linda Radzik between two dimensions of responsibility: orientation and justification (Radzik 2014).

The *orientation* of responsibility focuses on the "moral attention and concern of the people enforcing or satisfying the responsibility" (ibid., 32), or the character of the responses agents make to a certain state of affairs. It is not enough to rely on established moral rules in a forward-looking orientation; one "can only fulfil one's responsibility through a more open-ended engagement with the possibilities the future might hold" (36).

The *justification* dimension of responsibility denotes "the kind of reason or justification that the victim and the community have for responding [to, for example, an action or behaviour] the way we do" (33). Backward-justified responsibility claims can be supported by desert-based or justice-based claims and focus less on the positive consequences of ascribing or taking up certain responsibilities. Forward-looking justifications, in contrast, are those that appeal to consequences or pragmatic considerations (34).

In this way, Radzik helps us understand that although forward- and backward-looking dimensions are entangled, that does not mean that they are not analytically distinguishable. Consider two examples of statements about FLCR concerning the Umicore corporation (discussed in the previous chapter) that releases excessive amounts of lead particles into the air as a side-effect of its activities, thereby triggering epigenetic mechanisms leading to a higher prevalence of neurological disorders in those living close to the factory.

(1) Umicore should take up its responsibility to avoid epigenetically induced adverse health effects in future generations.

(2) The local government is responsible for paying compensations to those people who are growing up or have grown up in the vicinity of Umicore, because the government's insufficiently stringent permit procedure enabled them to continue polluting.

Holding an agent responsible for avoiding future harms, as in the first example, is forward-looking in both dimensions. But the source of an agent's responsibility can also be more backward-looking in nature, such as the complicity of the government in the second example. The object of epigenetic justice gives FLCR a forward-looking orientation. However, the justification of its ascription can be based on both forward- and backward-looking concerns. Moreover, one responsibility ascription can have multiple sources. I will now discuss some of those.

Sources of normative responsibility

Gunnar Björnsson and Bengt Brülde have developed an account of structures and sources of normative responsibilities, which they define as requirements to care about what one is responsible for (Björnsson and Brülde 2017). Such responsibilities "are themselves primarily prospective, and are often grounded in what can be done rather than in what has been done" (ibid., 14). They can also be attributed to collective agents, making them useful for our FLCR-focused account. The authors provide a list of six distinct potential sources of normative responsibility. Each of them can be relevant to consider when ascribing FLCR in the context of epigenetics.

1) *Capacity and cost*. Responsibility may be ascribed to agents because we believe them to be particularly well-placed to take on a task or solve a problem. Dupras and Ravitsky, for example, talk about 'windows of opportunity' in the context of epigenetics, arguing that efficient preventive or curative interventions require that "moral epigenetic responsibilities should be recognized as necessarily context-dependent and relying on who has a capacity to act" (Dupras & Ravitsky 2016, 5). At the same time, we learn from Chiapperino (2020) that at least in the context of epigenetic FLCR, a narrow focus on this source is insufficient, because the capacity of collectives to bring us closer to epigenetic justice should not be overestimated.

2) *Retrospective and causal responsibility*. Other things being equal, a greater causal backward-looking responsibility (through causal connections) is positively correlated with the degree of forward-looking responsibility. This might even be the case if the agent was merely involved in creating a *risk* of harm. As Marion Smiley remarks, we need to acknowledge that there will almost always be multiple candidates for causal status with respect to harm (Smiley 2014). Determining the exact amounts of causal contribution is often nearly impossible, especially in complex cases such as racism, poverty, or indeed epigenetic harm.

3) *Benefiting*. Benefiting from someone's help may create a responsibility on your side to return the favour. But benefiting can also take the form of complicity when agents benefit from harm, injustice, or danger to others. Just like we may want to "hold corporations responsible for the profits they derived from slavery" (Young

2011, 175), we can ascribe FLCR to organizations on the grounds of having benefited from environmental pollution.[17]

4) *Promises, contracts, and agreements*. If an agent has voluntarily agreed to do something, they are in principle responsible for doing it.

5) *Laws and norms*. Epigenetic justice can and should be translated from moral into legal responsibility ascriptions if necessary. Paying attention to this source can meet the worry of Dupras and Ravitsky that attributing mere forward-looking moral responsibility might result in a very limited upholding of it.

6) *Roles and special relationships*. We may have special responsibilities by virtue of our social or professional roles, e.g. our roles as parents or our membership of a specific community (see also Cutas forthcoming). This can be compared to H.L.A.'s Hart's 'role responsibility' (Hart 2008) or David Miller's emphasis on community membership as a potential way to identify remedial responsibility to come to the aid of those who may need help (Miller 2007, 82).

This list has heuristic value; it helps those working on the ethics of epigenetics or other complex global challenges to look for a broad variety of agents and reasons to ascribe (FLC)R to them. FLCR, I contend, is most useful when embedded in an integrated approach to epigenetic responsibility that does not rule out the legitimacy of more backward-looking concerns such as (2) or (4).

4. Epigenetics in Mexico City

The research of Elizabeth Roberts in Mexico City, which I encountered through Warin & Hammarström (2018) illustrates how some of the points made in this chapter can be applied to a concrete case. Roberts is an ethnographer of science, medicine, and technology who collaborates with the ELEMENT project, in which environmental health researchers together with public health officials investigate Early Life Exposure in Mexico to Environmental Toxicants. Since 1993, they have collected numerous samples for molecular analysis (epigenetic and otherwise), primarily from working-class mother and child pairs (Roberts 2015a). In one of the

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[17] This general statement does not deny that defining the degree of complicity of an agent is sometimes (nearly) impossible (Posner and Sunstein 2007, 1597).

most polluted cities on earth, they are looking into the impact of environmental toxins on multiple generations. Roberts herself employs her method of 'bioethnography' in one of Mexico City's most polluted working-class neighbourhoods, which she sometimes calls 'Montezuma' or 'Colonia Periférico'.

Three environmental substances feature prominently in her work: lead-glazed plates, soda, and a dam filled with waste. Her fellow researchers found that eating off traditional lead-glazed plates, that are said to make the food taste sweeter, was the surest predictor of high lead levels in mothers and children (Roberts 2019; Téllez-Rojo et al. 2002). The link between lead exposure and epigenetic alterations is well-established (see e.g. Wang, Zhang, and Xu 2020; Senut et al. 2012). The exposure to lead is both gendered, because women are the ones cooking with them and inheriting them from their (grand)mothers, and cultural, because the plates connect their users to a rural past (Roberts 2019). Additionally, the high consumption of sweets and sugary soda is said to be an important factor in the high obesity and diabetes rates in poorer neighbourhoods such as this one (see e.g. Rosen et al. 2018 for associations between epigenomic changes and obesity and (pre)diabetes). Soda is almost as cheap as bottled water and more reliably available than tap water (Roberts 2017). It performs important social roles, because "in Moctezuma sharing soda, liquid-food, filled with sugar, is love" (Roberts 2015, 248). Finally, there is a penetrating smell in the neighbourhood, caused by "a narrow stream of dam runoff, filled with *aguas negras* (untreated sewage) and garbage" (Roberts 2015, 592). In rainy seasons the dam often overflows, leaving the walls of the cement houses with salmonella, E. coli, and fecal enterococcus (Roberts 2017, 593). Whether the dam also causes respiratory diseases is hard to say, according to Roberts, because respiratory problems are commonplace in the whole polluted city.

We can regard the ill health of the inhabitants of Colonia Periférico as partly epigenetic, historical-structural injustice. It is not illegal that soda is so cheap. Although tap water is not very reliably available, past injustice of lacking access to safe tap water have disappeared. Nonetheless, past injustices continue to leave their marks since bottled water and soda companies still profit from feeding the belief that tap water is unsafe (Roberts 2017). An intersectional lens is necessary to understand how those problems are connected with many other axes of inequality and oppression. Women's socially ascribed roles as housekeepers and cooks make them more vulnerable to the effects of lead consumption. It is also hard to imagine that the terrible pollution in the neighbourhood would still be accepted in a society without such rampant socio-economic inequalities.

Intergenerational justice seems relevant too; the fact that epigenetic mechanisms are involved might well mean that, even if the current environmental hazards are successfully minimized, future generations would still bear the biological marks of current exposures.

What can we say about forward-looking collective responsibility in this context? In cases such as this, collective responsibility ascriptions are to be preferred over an eliminativist approach in order to forefront the injustices that shape the situation in Mexico City. Such a focus on collectives is necessary to combat the individualist, blaming and stigmatizing responsibility discourse used by government campaigns "exhorting you as an individual, female, *ama de casa* (housewife) to stop heedlessly providing soda and junk food to your child" (Roberts 2015, 247). Roberts notes poignantly: "[O]f course, there is no discussion of revisiting, reversing or dissolving NAFTA, which has made corporate sugar, in all its forms, so cheap and plentiful while also destroying small-scale Mexican agriculture" (Roberts 2015, 247).

Expecting parents to take up forward-looking role responsibilities towards their children's health can still be part of an approach based on intersectional feminist concerns. However, we should be very clear about such structural restraints of individual behaviour and choice. Not urging collectives to take up responsibilities would thus not only be unfair, but probably also ineffective.

A more effective approach urges corporate agents and governments to take up responsibilities on a variety of grounds. First of all, this call to action can be based on their involvement in bringing about or maintaining current injustices (cf. points 2 and 3 of Björnsson and Brülde). Government agencies may also be held responsible for improving the state of the dam water, because it is their role to be concerned with public health – officials promised to do so when taking office (cf. points 4 and 6). Academics and healthcare providers also have their roles to play. For example, epigenetics researchers such as those in the ELEMENT project are using their knowledge and skills to call attention to health disparities.

Additionally, other agents such as anthropologists use their methodological skills to work *together* with research participants to tackle difficult problems. Members of the ELEMENT project convinced some women to switch to metal pots by working together with potters (Roberts 2015b, 247). They seem to achieve most success when they do not themselves aim to devise simple solutions for straightforward problems, but instead listen to the lived experience of research participants to understand their struggles and how to resolve them. Roberts provides valuable perspectives on the lead-glazed plates issue that may be easily overlooked:

> Participants tell me that the pots were less damaging when the world was less damaged. Their grandparents and great-grandparents made and ate off the pots into their 90s, and were whip smart and not neuro-affected until the end. Now they are forced to reconfigure their relationships to the pots and to each other in light of the fact that there is more contamination all around. They also must grapple with the fact that the pots now have more lead because, with less available firewood, the kilns burn at lower temperatures to melt the lead away. (Roberts 2019)

Participant testimonies may help to explain why people are not very willing to be convinced by individualizing campaigns. What outsiders see as health hazards or 'bad simpliciter' is much more ambivalent to them. Soda and lead-glazed plates *can* make you sick, but that is often not immediate or certain. What is certain, is that both are a part of the neighbourhood inhabitants’ ways of showing affection for each other. Soda and sweets make you fat, but "thinness is not necessarily to be strived for where food is love and fat is a sure sign of existence" (Roberts 2015b). Even the toxic smell of the sewage has its benefits; it protects Colonia Periférico against police violence (Roberts 2017). Disability theory and non-ideal theory can help to understand their complex relation to environmental hazards as both harmful and protective.

5. Concluding remarks

Striving towards epigenetic justice in Colonia Periférico does not involve quick fixes. In fact, ascribing such responsibilities and findings ways to hold agents accountable will never be a straightforward effort in the face of a complex web of epigenetic mechanisms and environmental factors. In this chapter, I aimed to contribute to debates on the potential role of forward-looking collective responsibility in the context of epigenetics. I showed how the concept can be useful, if connected to a clear aim and backed up by some kind of normative commitment. Then, ascriptions of FLCR can be justified on both forward-looking grounds appealing to consequences and more backward-looking claims.

Finally, distributing FLCR also means looking at one's own role or place in structures and collectives that are either related to existing health disparities in some way or can help to improve them. We do not need to be public health experts or CEOs of polluting corporations to do so. As I pointed out, epigenetic justice is intricately connected to much better known disparities and inequalities. Working towards women's rights, eradicating poverty, or increasing disability justice, is important in itself, but it may also bring us closer to a more equitable epigenetic future. This may strike some as overly demanding, but as Young puts it, "in a world with significant and multiple structural injustices, people's responsibility in relation to those injustices can and should appear to be too much to deal with" (Young 2011, 123). Indeed, epigenetic injustices are so pervasive and structural that no individual or collective can address all of them, but this should not prevent us to take action.

Chapter 4

Anarchism and Collective Responsibility: An Analysis of ‘The Platformist Debate'

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Introduction

Collective responsibility has been a controversial concept in both philosophy and social science. Discussions of the desirability and possibility of this kind of responsibility are frequently held in the aftermath of terrible atrocities involving many perpetrators, that leave us wondering: 'How could this have been avoided?' For example, H.D. Lewis (1948) was motivated by the question whether or not it would be legitimate to hold German civilians collectively responsible for Nazi crimes, and in French’ edited volume *Individual and Collective Responsibility: Massacre at My Lai*, authors try to make sense of the gruesome 1968 massacre in Vietnam (French 1972). In 1926 a group of exiled Russian anarchists in France asked the very same question about the brutal crushing of their movement by the Bolshevik party. Their pamphlet 'Organizational Platform of the General Union of Anarchists' leaves the reader no doubt as to the cause of the anarchist defeat. Their movement suffered from disorganisation; to remedy this, they propose the foundation of a single, well-structured Anarchist Union. The authors argue that their proposed organisation should adopt a principle of collective responsibility, meaning that "each of its members is answerable for the revolutionary and political activity of the union as a whole" (Dielo Truda 1926).

In this chapter, I take the anarchist debate produced by this passage as a case study of the applicability of contemporary work on collective responsibility to political theory. After a historical introduction to social anarchist theory and the platformist debate in Section 1, I proceed as follows. Using theoretical tools on responsibility from social theory and philosophy, in Section 2 I analyse the viewpoints expressed by the Dielo Truda group and other so-called 'platformists' on the one hand and those of opposed anarchist writers, especially Errico Malatesta, on the other. I describe the platformist principle of collective responsibility in terms of the model of responsibility as a four-place model proposed by Neuhäuser (2014). From this, I conclude that Malatesta's opposition to the concept of collective responsibility in the Platform text would make him a normative individualist in contemporary debates on the issue.

Normative individualism is not the only possible position for anarchists to take, however. Contrary to some anarchist thinkers, in Section 3 I argue that anarchist principles such as individual freedom and non-coercion do not automatically warrant a categorical rejection of collective responsibility. I propose two concepts that might help us to approach collective responsibility from an anarchist perspective. First, I explain how Neuhaüser's model can help us understand collective responsibility in the platform as having a political normative standard. Secondly, I zoom in on the benefits of approaching the issue in terms of forward-looking collective responsibility. In the final part of the chapter, section 4, I will give a few examples of how anarchist and other radical grassroots organisations employ the concept of collective responsibility in their thinking and practices, to support my understanding of this as an aspirational kind of forward-looking collective responsibility.

1. The text and its context

Before I can discuss the details of the anarchist discussion of collective responsibility, a description of its context is in place. This section opens with a definition of anarchism and some of its key principles, followed by a sketch of the historical context in which the Dielo Truda (literally: 'Workers’ Cause’) group wrote their programme. After this, we are in a position to summarise the passages of the written exchange that are most relevant to the discussion of collective responsibility.

Social Anarchism

‘Anarchism’ is best understood as an umbrella term for anti-hierarchical political theories that reject, among other hierarchical concepts, the concept of the state (Suissa 2010). Anarchism shares its key values of freedom, equality and fraternity with other political theories that bloomed in the 19th century, but it interprets them very differently, leading to major disagreements. As Judith Suissa describes, anarchists have always rejected the Marxist idea of a socialist state or a proletarian rule. They also do not believe that a liberal democratic state is the best way to reach a society in which their values can flourish (Suissa 2010).

One way to distinguish various anarchist viewpoints is to make a distinction between individual and social anarchism. Individual and social anarchists take different approaches in dealing with the potential tension between the principles of freedom and equality. Individualist anarchists tend to gravitate more towards advocating individual freedom, while social anarchists focus more on the social context that enables individual flourishing. The social anarchist rejection of hierarchy on the one hand and the acceptance of some form of rational authority on the other both stem from a specific conception of human nature as being essentially twofold. Anarchists like Pjotr Kropotkin (1842-1921) believe that the cultural and social environment of a person determine whether her egoistic or altruistic side will take the upper hand (Suissa 2010, 28).[18] Of course, this is not to say that social anarchists do not value individual freedom: instead, they argue that individual freedom and social equality presuppose each other. It is fair to say that social anarchists have been most numerous and vocal throughout the history of anarchist thought. In this chapter, I focus on social anarchism, because both the Platformists and most of their critics can be grouped under this label.

The stance against all hierarchies and structures of oppression, not the unconditional rejection of the state, functions as the core of anarchism from which most other values can be derived. The hostility towards the state and capitalism are only "incidental byproducts of this primary rejection of hierarchy" (Mueller 2012, 15). Furthermore, it is safe to say that all anarchists are critical of authority whenever they encounter it. It is a misconception, however, that all anarchists oppose all authority. Especially some social anarchists recognise that social life can sometimes benefit from a rational form of authority. With 'rational' anarchists here mean that someone who has expertise in a particular domain is a legitimate authority in that domain (Suissa 2010). Additionally, they acknowledge that "individuals or organisations may have a right to command others, but such a right must always be temporary, and always justifiable in terms of the needs of the community in question" (ibid., 59). Someone is justified to be an authority in certain situations, but not to have authority based on an institutionalised, artificial power relation, the latter being what the term hierarchy designates. This rather nuanced view on authority leaves room for various anarchist theories of

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[18] These issues are discussed in more detail in Moormann (2020).

organisation. In fact, concepts like 'self-organisation' are central to many contemporary anarchist theories.

Historical context of the Platform text

The publication of the Platform text in 1926 was both a continuation of a longstanding anarchist debate on organisation and a direct response to the anarchist defeat in the Russian Revolution. The issue of organisation was already heavily discussed in the anarchist movement before the Platform text appeared. It can be seen as a major theme in anarchist thought. From the start of the movement, anarchists have sought to emphasise that although anarchism wishes to abolish the state and other hierarchies deemed harmful, anarchism should not be equated with chaos. The French anarchist Proudhon already proclaimed that 'anarchy is order' (Proudhon 1876). Voline (1882-1945) writes: "Of course, say the anarchists, society must be organised. However, the new organisation must be established freely, socially, and, above all, from below" (quoted in Guerin 1970, 43).

Organisation and cooperation were absolutely vital if anarchists wanted to stand a chance against capitalism and oppressors such as bosses, the state and the police. Almost all anarchists would probably agree that some degree of unity is needed and subscribe to the need of organising understood as "continuing and coordinating our efforts effectively" (NEFAC Toronto 2002). Debates typically revolve around the question of how much unity is compatible with a non-coercive way of organising. Anarchists have struggled to find and practice forms of organisation that live up to their anti-hierarchical and non-authoritarian ideals. The issue of 'anarchy and organisation' was for example heavily debated at the 1907 International Anarchist Congress.

The more direct reason for the platformist discussion was the 1917 Russian Revolution. The Russian anarchists involved in the editorial group Dielo Truda were deeply disillusioned by their experiences in this revolution and the subsequent Bolshevik dictatorship. As Alan MacSimioin puts it in his preface to the 1989 translation of the Platform:

> They had taken part in the overthrow of the old ruling class, had been part of the blossoming of workers' and peasants' self- management, had shared the widespread optimism about a new world of socialism and freedom […] and had

> seen its bloody replacement by State Capitalism and the Bolshevik Party dictatorship. (MacSimion in NEFAC Toronto 2002)

Nestor Makhno, for example, had led an anarchist 'black' army in Ukraine in the period from 1917 until 1921 that successfully fought both the tsarist 'whites' and later the Bolshevik 'reds', before finally being defeated by a military campaign of the Bolsheviks against him. The Platformists argued that the failure of the anti-authoritarian resistance against the increasingly oppressive Bolsheviks was primarily due to their own lack of proper organisation: "This disease of disorganisation has invaded the organism of the anarchist movement like yellow fever and has plagued it for decades." (Dielo Truda 1926).

The pamphlet, entitled 'Organizational Platform of the General Union of Anarchists' was published in 1926. The 'group of Russian anarchists abroad', including Nestor Makhno, Pjotr Arsinov, Ida Mett and others, set up an international meeting in Hay-les-Roses, near Paris, in 1927 to discuss the text. Unfortunately, their meeting was violently broken up by the police before any decisions could be taken. But the pamphlet itself did not miss its mark: it sparked and continues to spark animated discussions between anarchists of all stripes. In this chapter, I will thus focus on the Platformist document and some direct criticisms of it.

Since none of the original texts on the Platform were written in English, a note on translations is in order. I primarily rely on the translations into English by Nestor McNab, bundled together in a pamphlet by NEFAC (2002). McNab explains his approach: "Previous English translations of the Platform have suffered from the fact that they were translated, not directly from the Russian, but via French. [...] We set about preparing a new translation directly from Russian. However, in order to save time, this new translation is based on the existing translations, but we have made a detailed comparison with the Russian original in order to bring it as close as possible to the original" (7). I relied on these translations for all historical texts mentioned in this chapter, except for 'Organization and Party' by Maria Isidine (also known as Mary Goldsmith) (Isidine 1928). The translator of this text is unknown to me.

Structure and key points

In the Introduction of the 'Platform', its authors set out the goal of the text. It should "serve as the first step towards gathering anarchist forces into a single active, revolutionary anarchist collective capable of struggle: the General Union of Anarchists.” In the General Section, they put forward their interpretation of some key anarchist ideas under headers such as ‘class struggle, its role and its value’, ‘the necessity of violent social revolution’ and ‘the negation of state and authority’.

More important for our purpose is that this part contains the first passage on responsibility. Although “the masses in social upheavals are prompted deep down by anarchist tendencies and slogans”, these are not coordinated in any way. The masses need to establish a specific collective, dedicated to retaining an anarchist orientation and anarchist objectives in the revolution. That collective, the general Anarchist Union, “will bear great theoretical and practical responsibilities.”

The subsequent Constructive Section is of little relevance to this chapter. It is the final, Organizational Section that is the focus of our inquiry. This section comprises a list of the four key principles of anarchist organisation: unity of theory, unity of tactics or the collective method of action, collective responsibility, and federalism. The principle of collective responsibility is introduced as a response to individualism. The authors write:

> The practice of operating on one’s individual responsibility must be strictly condemned and rejected within the ranks of the anarchist movement. The areas of revolutionary, social and political life are profoundly collective in nature. Revolutionary public activity in those areas cannot be based upon the individual responsibility of single militants.

The Anarchist Union “takes a decisive stand against the tactic of unaccountable individualism and introduces the principle of collective responsibility into its ranks”. The principle, hereafter referred to as PCR, states:

> **Principle of Collective Responsibility -** the union as a whole is answerable for the revolutionary and political activity of each member of the union; likewise, each of its members is answerable for the revolutionary and political activity of the union as a whole.

Criticism and responses

Soon after its publication, the Platform received criticism from prominent anarchists such as Errico Malatesta, Voline, Luigi Fabbri, Max Nettlau, Maria Isidine and Emma Goldman. Some of them agreed with the organisational elements, but took issue with other elements, such as that of the primacy of the class struggle, whereas other anarchist critics focused on the issue of majority decision-making. They believe this kind of decision-making to be an undesirable result of the Platformist organisational unity.[19]

In this chapter, I will focus my attention on the criticisms and debates that are concerned with the principle of collective responsibility. Although I sometimes refer to other critics to illustrate my points, I will primarily engage with the exchange between proponents of the Platform and the prominent anarchist thinker Errico Malatesta (1853-1932). Malatesta's criticism is quite representative of other criticisms. His eloquence allows us to distil his claims and analyse his arguments with relative ease. Furthermore, far from being a result of anti-organisational beliefs, Malatesta's criticism arises from a genuine concern for the organisation of the anarchist movement. As an Italian anarchist and revolutionary syndicalist, he insisted upon the necessity of properly organising anarchism. For most of his life, he adhered to a kind of organisational dualism, arguing that both mass popular movements and specific anarchist organisations are requirements for progress or revolution (Correa 2014, 6-7).

According to Malatesta, any good anarchist theory "must know how to blend the free action of individuals with the necessity and the joy of cooperation" (Malatesta 1927). He believes the organisation proposed by the Platformists does not satisfy this demand at all. He is worried that it would only make sense to say that the union has a collective responsibility if it also has the means to "monitor the action of the individual members and order them what to do and what not to do" (Malatesta 1927), and this is, he thinks, very problematic.

He foresees problems on the side of the individuals in a collective as well and asks his readers: "can an individual accept responsibility for the actions of a collectivity before knowing what it will do and if he cannot prevent it doing what he disapproves of?" (Malatesta 1927). He agrees that "anyone who associates and cooperates with others for a common purpose must feel the need to coordinate

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[19] Maria Isidine (1873-1933, also known as Marie Goldsmith) is very adamant about this. She deems it hypocritical of her platformist comrades to think they can use the much-criticized majority principle for good and wonders how "this principle, whose absurdity and unfairness are so plain where the future society is concerned, turns beneficial and fair when it is to be applied to our own circles?" (Isidine 1928)

his actions with those of his fellow members" (Malatesta 1929). However, he believes that this individual moral responsibility is fundamentally different from the proposed collective responsibility: "Moral responsibility (and in our case we can talk of nothing but moral responsibility) is individual by its very nature" (Malatesta 1930).

Based on these and other criticisms, Malatesta deems the proposal "typically authoritarian" (1927). He even wonders "what that notion of collective responsibility can ever mean from the lips of an anarchist" (1929). Instead, he proposes that an anarchist organisation must be organised as follows:

> Full autonomy, full independence and therefore full responsibility of individuals and groups; free accord between those who believe it useful to unite in cooperating for a common aim; moral duty to see through commitments undertaken and to do nothing that would contradict the accepted programme. (Malatesta 1927)

The Platformists had expected quite some criticism, but they were nonetheless shocked by the intensity of it and the directions from which it came. They wrote some responses to Malatesta and others as a group. Makhno and Arsinov also did so in their own capacity. Arsinov replies to Malatesta's worries by giving a slightly different, more elaborate explanation of the PCR:

> **Arsinov's PCR -** The entire Union is responsible for the activity of each member, knowing that they will accomplish their political and revolutionary work in the political spirit of the Union. At the same time, each member is fully responsible for the entire Union, seeing that his activity will not be contrary to that elaborated by all its members. (Arsinov 1928)

This version differs from the original PCR in two ways. Firstly, the term 'answerability' is replaced by 'responsibility'. Secondly, and more importantly, Arsinov gives us some insight in his understanding of the kind of responsibility of both the collective and the individual. The Union relies on individuals to carry out their projects in its 'political spirit', whereas each member should at least see to it that their actions do not contradict the activity of the Union and its other members. He also explains that for a member to be fully responsible for the entire Union would mean that this member is responsible "for the political line" of the union (Arsinov 1928). Arsinov concludes that "in categorically repudiating collective responsibility, [Malatesta] renders impossible the realisation of such an organisation" (ibid.). According to him, "in a vast movement, a uniquely moral and non-organisational responsibility loses all its value" (ibid.).

Makhno is even more outspoken in his disagreement with Malatesta. For him the PCR is a fundamental principle "which guides each one of us in our way of understanding the anarchist idea" (Makhno 1928). He even claims that "it is through the inspiration of collective responsibility that the revolutionaries of all epochs and all schools have united their forces" (ibid.).

2. Analysis

As we saw before, for some anarchists collective responsibility is a principle fundamental to their theory, whereas for others, it is authoritarian and going against what anarchism stands for. How can we make sense of this opposition? We may obtain a clear view on the disagreement between platformists and their critics when we reconstruct the central question of debate as follows: 'Is the PCR compatible with social anarchism?' Platformists think the two certainly are compatible (and even go so far as to say that some kind of principle like this is necessary for social anarchism to ever achieve its aspirations). Critics such as Malatesta think they are incompatible, and reject the PCR for that reason. In this section, some analytical tools will be used to pin down the claims of both sides. First, I list a few possible sources of linguistic and conceptual confusion with regards to the concept of responsibility in general. Next, I distil two claims from the PCR as it is formulated by Arsinov; one about individual, and one about collective responsibility.

As I already noted in the introduction to this thesis, the concept of responsibility has been ascribed many meanings.

a) The ambiguous nature of responsibility language. Part of the variety of opinions on the subject within anarchism may have to do with the fact that 'responsibility language' can be quite confusing at times. The philosopher and legal scholar H.L.A. Hart famously made this point in *Punishment and Responsibility* when he managed to write a one-paragraph story in which the adjective 'responsible' features nine times, having a different meaning every time (Hart 2008, 211). The anarchist authors in the Platform debate seem to use the term in multiple ways. Especially the use of 'responsible' to designate a character trait seems rather unrelated to the main question on collective responsibility. Passages such as "it is the expression of a conscientious and responsible understanding of militant work"

(Arsinov 1928) will thus not be central to this discussion and only seem to add to the confusion.[20] Hart himself goes on to distinguish four heads of classification: role responsibility, causal responsibility, liability responsibility (which can be of a legal or moral nature) and capacity responsibility (Hart 2008, 211). I will apply his characterisation of role responsibility to our discussion in Section 4.

b) Responsibility as answerability, accountability, or attributability. Some contemporary philosophers working on responsibility have pointed out that our practices of holding agents responsible allow for various ‘faces’ of responsibility. An influential account is that of David Shoemaker, who distinguishes between three kinds of responsibility (Shoemaker 2011). Talbert summarises them as follows: “On Shoemaker’s view, attributability-responsibility assessments respond to facts about an agent’s character, accountability-responsibility responds to an agent’s degree of regard for others, and answerability-responsibility responds to an agent’s evaluative judgments” (Talbert 2019). Some authors only focus on the distinction between accountability and attributability (e.g. Watson 1996). Moreover, not everyone employs the terms used by Shoemaker in the same way as he does. They nonetheless seem to point to some relevantly different kinds of holding agents responsible. Can we use them to understand some passages in the Platformist discussion better?

Of course, we cannot assume that the anarchist authors used these terms in the way some contemporary authors understand them. Moreover, we need to be cautious for translational issues, since none of the original texts were written in English. However, being aware of these more contemporary distinctions may help us to interpret the various notions of responsibility used in the historical texts. Responsibility-as-attributability is not used in the Platform discussion, which may have to do with the fact that this kind of responsibility seems hard to transfer from individual to collective responsibility (although, as we saw in the previous chapter, it may be possible to talk about the character of a collective and ascribe ‘aretaic blame’ (Chiapperino and Sand forthcoming; Cheng-Guajardo 2019). However, responsibility-as-accountability and responsibility-as-answerability are both used. As we saw before, the platformists condemn ‘unaccountable individualism’. In the

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[20] With regards to this and the following issue, the fact that I was unable to consult the texts in their original language needs to be taken into account. I cannot rule out the possibility that the original concepts used in the Russian text are sometimes different from those resulting from the interpretation of translators.

original PCR, however, the union as a whole and each of its members are *answerable* for each other’s political activity.

c) Moral responsibility. A key issue in the debate is whether or not collective responsibility can and should be of a purely moral nature. Malatesta and Maria Isidine claim that the only legitimate kind of responsibility in an anarchist context must be a moral one. Any other kind would be coercive and thus incompatible with an anarchist valuation of individual autonomy and liberty. After reading a reply to his criticism by Makhno, Malatesta still held that “moral responsibility (and in our case we can talk of nothing but moral responsibility) is individual by its very nature” (Malatesta 1930). Maria Isidine even claims that moral responsibility is already an inevitable aspect of the anarchist movement:

> Every anarchist, whether they wish it or not, bears the moral responsibility for the actions of their comrades, even if no formal connections bind them; every act contrary to the anarchist idea, every contradictory posture, has repercussions for the movement as a body, and this extends the responsibility beyond the individual, beyond even their immediate group. (Isidine 1928)

In response, platformists claim that only moral responsibility is not enough. Arsinov (1928), for example, recognises that “the principle of responsibility is understood by comrade Malatesta in the sense of a moral responsibility of individuals and of groups.” However, as we have seen before, Arsinov believes that it is impossible to organise conferences and other practical aspects of large organisations according to a purely moral and individual principle of responsibility. When he says that such a principle “loses all its value” in the context of a vast organisation, he even seems to imply that it would be not only impossible, but also undesirable to use it as a basis for an anarchist Union.

It has become clear that the proposed PCR is supposed to be more binding than moral responsibility. At the same time, the platformists painstakingly try to convince their critics that individual members who do not take their responsibility will not be confronted with coercive consequences that anarchists would deem authoritarian. Before I can suggest a possible conceptual middle ground in Section 4, I will first zoom in on the principle of collective responsibility itself. Most, if not all, participants of the debate agree that only individual responsibility can be of a purely moral nature. In doing so, they seem to make a sharp distinction between individual and collective responsibility. But in the PCR, this distinction is not very clearly expressed at all. I propose that the PCR actually consists of two principles:

one about collective responsibility in the sense in which it is understood in scholarly literature on the subject, and one about individual responsibility.

When one wants to analyse an instance of responsibility, the questions that come to mind can usually be summarised into 'who is responsible, to whom, for what?' As Neuhäuser explains, "this means that one speaks of responsibility in sentences where there is, first, an agent of responsibility; second, an event or a condition for which (s)he is responsible; and third, an addressee to whom (s)he is responsible" (Neuhäuser 2014, 234).

The PCR entails firstly that (1) the collective is responsible towards (2) its members for (3) the actions of all of these very same members. In this sense, it is in accord with a common contemporary definition of collective responsibility that associates it with a single, unified, (moral) agent (Smiley 2022). The frequent emphasis of the platformists on the unity of tactics, ideas, and political line of the union indicates that they view the Union as one collective agent, rather than as a loose collection of individuals. Hence, it appears that they would not settle for mere *shared responsibility*, "which is associated with individual moral agents who contribute to harm [or any other outcome] as members of a group either directly through their own actions or indirectly through their membership in the group" (Smiley 2022).
Secondly, the PCR contains a prescription of individual responsibility of each member. This is clearest in Arsinov's reiteration: (1) each member of the Union is responsible (3) towards (the entire Union) for (2) "seeing that his activity will not be contrary to that elaborated by all its members" (Arsinov 1928).Partitioning the PCR in this way has paved the way for the interpretations of the principle that I will work out in the next section.

3. Conceptual compromises

Now that we have a clearer view of the positions held by platformists and various critics, we are left with the task of evaluating their debate. Is the stalemate Malatesta and the exiled Russian anarchists seem to have reached after their exchange indeed unavoidable, or are there perhaps interpretations possible that focus on the commonalities of their views and proceed towards a consensus?

In this section, I will discuss two possible 'conceptual compromises', namely a political standard of collective responsibility and forward-looking collective responsibility. But before I take on this task, it may be helpful to situate this debate within the possibilities anarchists have when dealing with the tension between organisation on the one hand and individual freedom and non-coercion on the other. How could anarchists respond to the claim of Arsinov that "in a vast movement, a uniquely moral and non-organisational responsibility loses all its value" (Arsinov 1928)? It seems to me that their answers could fall into three categories.

The first approach anarchists could take is to bite the bullet, agree with the claim, and accept that large organisations will never be achievable for principled anarchists. This is the approach taken by anti-organizationalists. This branch of anarchism is at odds with the social anarchist approach and is also not endorsed by all individualists. Neither the platformists nor Malatesta, would find this a legitimate approach since they are fully convinced of the need of (a) large anarchist organisation(s).

The second approach is to disagree with the claim, and to argue instead that moral responsibility can in fact suffice as a basis for anarchist organisation. Arsinov's claim seems to have an underlying assumption when it comes to the goal of a certain degree of unity in theory and action within a collective. The assumption is that moral responsibility is less likely to bring about this unity than other kinds of responsibility that do rest on some kind of coercion or rely on punishments if the responsibility is not taken up. Without wanting to delve into this, it needs to be remarked that one could argue this assumption is not warranted. One should not underestimate the potential force and effectiveness of social and psychological mechanisms related to moral responsibility.

A helpful analysis in this regard is that of Alan Ritter, who describes how social anarchists compare legal government to social censure. According to him, anarchists argue that "censure differs from legal government in ways which make it less coercive on the whole" (Ritter 1980, 18). For anarchists, the main power of social censure lies in its use of internalisation and reasoned arguments instead of coercion. They argue (again, according to Ritter's analysis) that since it does not suffer from the remoteness, generality, and permanence that legal government is bound to, it is better able to adjust sanctions to particular circumstances so that "they interfere less with conduct" (ibid.).

This second approach, arguing for the effectivity of moral responsibility, is in line with the one Maria Isidine and Malatesta are taking in their replies to the Platform. It would make them *anarchist normative individualists* in contemporary debates on the possibility and desirability of collective responsibility. Normative individualism should be contrasted with methodological individualism. Methodological individualists primarily think it is impossible to associate moral agency with anything else than individuals. Although normative individualists do not deny the possibility of ascribing responsibility to a collective, they believe such practices to be undesirable. They argue that ascriptions of collective responsibility violate principles we should care about, such as responsibility and fairness (Smiley 2022). Not all normative individualists are also methodological individualists. Whether or not the opponents of the Platform can be called methodological individualists is hard to say. However, it becomes clear they are normative individualists on the basis of their condemning attitude towards the proposed principle of collective responsibility. Critics such as Malatesta can be called *anarchist* normative individualists, because they appeal to anarchist values such as non-hierarchical organising, anti-authoritarianism and individual freedom to ground their criticism. They believe collective responsibility is incompatible with the principles of anarchism they care about.

3) A third approach would be to agree with Arsinov and to start looking for interpretations of the PCR that are somewhat in agreement with anarchist principles. Those wanting to take this route would need to find a conception of collective responsibility not inconsistent with anarchist values. In what follows, I will propose two possible ways to work towards such a conception.

A political standard of responsibility

In Section 2, I explained the PCR in terms of two three-place relations. However, after explaining that these three places are the basic elements of an analysis of responsibility, Neuhäuser proposed a fourth: the normative standard of responsibility. This addition is worth discussing because it allows us to approach the discussion about the desirability of non-moral kinds of responsibility in a more nuanced way. Neuhäuser explains the normative standard by giving some examples. A head of government can be responsible for a lousy job market on a political level, but will not face legal consequences for this, i.e. they are not legally responsible. A doctor can be said to be both morally and legally responsible for a patient. Thus, a fourth question that we can ask when examining responsibility relations is: “On the ground of what normative standard is there a responsibility?” (Neuhäuser 2014, 235). Neuhäuser gives at least three options for this normative standard: it can be of a moral, legal, or political kind. As we saw in the example of the doctor, agents can be responsible on the ground of multiple normative standards at once.

Now we can further analyse both subprinciples we derived from the PCR by asking 'Who is responsible to whom, for what, and on the basis of which normative standard?' The individual in the anarchist union is responsible towards the whole union for acting in accordance with the tactics and ideas of the union. This individual responsibility is certainly based on a political standard, but that does not prevent it from also being based on a moral one. Perhaps a good way to characterise it is to use Hart's role responsibility:

> Whenever a person occupies a distinctive place or office in a social organisation, to which specific duties are attached to provide for the welfare of others or to advance in some specific way the aims or purposes of the organisation, he is properly said to be responsible for the performance of these duties, or for doing what is necessary to fulfill them. (Hart 2008, 213)

In a non-hierarchical, anarchist organisation, ideally no person would occupy a place or office that is very distinctive from those occupied by others within the same organisation. However, every member of the Anarchist Union can be properly seen as having duties towards advancing the aims of the organisation by virtue of their membership. Every individual, then, has a moral and primarily political role responsibility towards the entire union.

This kind of responsibility is not really coercive, but also certainly not indicative of a laissez-faire attitude. It is perfectly compatible with a statement of Malatesta himself that "those who do not feel and do not practice that duty [to cooperate and do no harm to the common cause] should be thrown out of the association." Anarchists advocate free association (and disassociation), but that does not mean association is non-committal. If the political acts of an individual are clearly in contradiction with those of the Union, they do not live up to the responsibility they accepted by joining the Union. The political standard means that the consequences of this will be of a political, organisational nature: the Union may choose to disassociate itself from this individual.

The collective, too, is responsible towards all of its members on the ground of a political standard. Neuhäuser admits that speaking of collective normative standards may seem 'a bit odd' at first glance. However, he argues that "we could speak of collectively established normative standards, for example, in political processes" (Neuhäuser 2014, 235). This seems to be in line with the 'organisational kind' of responsibility Arsinov has in mind. The normative standards of the Union, embodied by its programme, are determined by political processes in which all individual members are expected to participate. Members who come to disagree with the programme after joining the Union have two options. They can either disassociate from it, or work towards finding consensus within the collective to change elements of the programme. The Union’s collective responsibility on the ground of a political standard can then entail, for example, a commitment to facilitate decision procedures and communication between individual members and various groups of members.

Forward-looking collective responsibility

Neuhaüser’s analysis of responsibility as a four-place relation can help us in other ways as well. He argues that “understanding responsibility as a four-place relation opens up many possibilities for a collective and forward-looking understanding” (Neuhäuser 2014, 236). In the remainder of this section, I wish to investigate forward-looking collective responsibility as a possible approach to collective responsibility that might be compatible with social anarchist values. There will be some passages that overlap with content on FLCR in the previous chapter of this thesis, but I decided to leave those in because this seems beneficial to the structure of this chapter.

Acknowledging the difference between a backward- and forward-looking dimension of responsibility may pave the way for a more nuanced approach to anarchist collective responsibility. The main difference between the two dimensions lies in the function of their ascription. Discussions of backward-looking responsibility tend to focus on the appropriateness of ascribing praise or blame (in the case of moral responsibility) or of the appropriateness of certain consequences or punishments (in the case of political and legal responsibility). In contrast, forward-looking responsibility derives its moral salience from its potential to help bring about a desirable state of affairs in the world (Smiley 2022).

An ascription of (collective) forward-looking responsibility equals a call to action. It is designed to focus on bringing about a certain desirable state of affairs in the future. This does not mean that there is no connection to the past. Indeed, the relation between forward- and backward-looking responsibility is presumed to be close. Van de Poel, for example, argues that backward-looking responsibility-as-accountability can not only be based on the breach of a duty that caused a certain negative consequence, but also on not properly discharging a forward-looking responsibility (Van de Poel 2011).

Although most philosophers working on collective responsibility focus on notions of backward-looking responsibility, the concept of forward-looking collective responsibility (FLCR) has been gaining ground in the past two decades. FLCR is often invoked as a kind of remedial responsibility, aimed at remedying certain harms. Climate change and colonialism are oft-cited issues: see for example Darby & Branscombe (2014), Lyons (2004) and Young (2011) on racism and Van de Poel et al. (2012) and Björnsson (2021) on climate change. But this is not the only function FLCR can have. As Smiley notes, the concept can also be about ensuring moral, social or political progress (Smiley 2014).

I propose that speaking of FLCR may help to show that the participants in the platform debates actually agree on much. The platformists seem to have the future-oriented dimension of responsibility in mind when they talk about the responsibility the collective should take for bringing the revolution to a successful end. They are primarily interested in bringing about this desirable future and only engage in analysing which agents are responsible for their political situation in function of this forward-looking approach.

Moreover, Smiley's version of FLCR as a way of ensuring moral, political and social progress certainly seems to apply to the aim of the Anarchist Union proposed by the platformists. Interpreted as such, the collective and its members are collectively responsible for a future state of affairs in relation to not only a moral, but also a political normative standard, as we saw before when discussion Neuhäusers political standard of responsibility.

An advantage of FLCR is that it "does not present us with any serious metaphysical challenges" (Smiley 2014, 3). Since FLCR is not designed to capture an agent's will, but instead to distribute moral labor, it does not require that all conditions of more individual and/or backward-looking responsibility are fulfilled (Smiley 2022). This would allow us to glance over passages in Makhno's defense of the Platform where he speaks of "a collective spirit" and "a collectively responsible will" as metaphorical language, and to focus instead on what it is the anarchists wish to achieve with their union: a society without oppressive hierarchies that place excessive limits on individual freedom.

FLCR can be compatible with various social anarchist values and principles. One of those is the commitment to decentralised organising, aimed at minimising power differentials within an organisation. Anarchist organisations can be understood to bear a collective responsibility to ensure that the responsibility of no individual becomes much more crucial for the collective enterprise to succeed than that of others. Knowing that others in the collective are just as responsible for the realisation of their common aims might also have psychological benefits: it might help to relieve individual members of an overwhelming sense of responsibility.[21]

On what grounds could the platformist anarchists defend their principle of collective responsibility? To put it differently, on the basis of which criteria is this responsibility ascribed to the Anarchist Union? Forward-looking responsibility can be ascribed to collectives on the basis of various considerations. In the past two decades, various lists of sources and criteria have been compiled for ascribing forward-looking collective responsibility or similar kinds of responsibility (e.g. Miller (2007) on ways to identify remedial responsibilities). A helpful list of sources of what they call 'normative responsibility' is that of Björnsson & Brülde (2017), who were also discussed in detail in the previous chapter.[22] They describe normative responsibility as follows: "If one is normatively responsible for something [...] one might be liable to be *held responsible* for certain states of it [...] or for not taking reasonable measures to prevent these states" (Björnsson and Brülde 2017, 15). As was already shown before, they identify six sources of normative responsibility that may help us to determine who should be held responsible for certain states of affairs. These are: capacity and cost; retrospective and causal responsibility; benefiting; promises, contracts and agreements; laws and norms; roles and special relationships.

At least three of these sources can be easily retraced in the Platformist arguments: 'capacity and cost', 'retrospective and causal responsibility' and 'promises, contracts, and agreements'. The Platformists argue that collective responsibility is essential for a collective of a sufficient size to be *capable* to resist counterrevolutionary forces. As we discussed before, the anarchist principle of responsibility is also not devoid from any considerations of *retrospective* or backward-looking responsibility. Both proponents and opponents of the Anarchist Union are concerned with the consequences individual members would have to

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[21] I owe this thought to Sonia Rose Havill, a participant of a book club on the Platform discussion held in Leuven in February 2020.

[22] Although the authors do not explicitly identify 'normative responsibilities' as possible instances of forward-looking collective responsibility, they do 1) describe their prospective character (they are "often grounded in what can be done rather than what has been" (14) and 2) argue that they can be attributed to corporate agents and groups of people.

face when they violate the principle of collective responsibility, e.g. by acting in defiance of the Union’s programme. Furthermore, the Platformists make it quite clear that collective responsibility only applies to the collective consisting of members who voluntarily *agreed* to join the collective and *promised* to agree with its political line. Arsinov writes that “those who do not recognise these basic principles, cannot become, and besides would themselves not want to become a member of the organisation” (Arsinov 1928).

4. Conclusion

Confronted with the notion of collective responsibility, Malatesta worried what that notion could “ever mean from the lips of an anarchist” (Malatesta 1929). In this chapter, I argued that certain interpretations of the Platformist principle render it compatible with anarchist values. I discussed both an anarchist political normative standard of responsibility and an anarchist application of the concept of forward-looking collective responsibility. These suggestions were not exhaustive, but they were intended to show that collective responsibility does not need to be inimical to everything anarchists stand for.

Surprisingly enough, at the end of his conversation with the Platformists, Malatesta seems to have changed his position somewhat. He concedes that their discussion on the PCR may have been mostly a question of words and expresses the belief that “behind the linguistic differences really lie identical positions” (Malatesta 1930). Indeed, Malatesta and the platformists have more in common than their first exchanges may have suggested. The platformists seem to introduce the PCR as a kind of aspirational or motivational principle.[23] Perhaps it is not something they wish to fully adhere to in every instance, because they value individual autonomy too much to let that be compromised by coercive discipline. However, the principle guides them in their organisational endeavors.

What Malatesta and the platformists have in common is not only a belief in the importance of organisation, but also a recognition of the general tension underlying many anarchist debates on organisation. Social anarchists are adamant proponents of the idea that “community and individuality, as they

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[23] I owe this characterization of the platformists’ use of collective responsibility to Dimitrios Zachos, who was one of the participants of the online Social Ontology Conference 2020.

develop, intensify each other and coalesce" (Ritter 1980, 29). At the same time, they see the risks of social organisations for the freedom of the individual.

This general tension between individual freedom and collective revolutionary efficiency remains central to many contemporary anarchist discussions. Thomas, for example, writes the following on what he calls 'anarchist accountability': "Once democratic structures and organisational practices are developed and utilised, then anarchist accountability demands that decisions made collectively must be respected and collectively implemented" (Thomas 2010). Another recent expression of the tension was formulated by the anarchist Kollektiv Bremen (2016). They note that those wanting to organise may "encounter internalised capitalistic and individualistic modes of thinking and behavior [...], which contradict collective processes or make them more difficult." They go on to argue that "to organise is to develop the ability to compromise, to think collectively and also be able to restrain oneself." In order for an organisation to succeed, individuals need not give up their convictions and beliefs. Rather, "it is necessary to distinguish between fundamental beliefs, which need to be discussed and, if necessary, argued about, and the fact that one does not always have to decide, determine or influence everything" (ibid., 18).

Finally, a more practical example of the role of the individual in grassroots revolutionary movements can be found within the Kurdish militant organisation PKK.[24] Journalist Fréderike Geerdink summarised their practice of holding each other accountable as follows:

> The PKK as an organisation is as good as every fighter is individually. Or, as a fighter said to me: 'Everyone is personally responsible for the whole PKK'. Criticism [of oneself and others] and discipline are essential to keep everyone sharp and focused all of the time. From relatively minor transgressions [...] which are immediately put right, to major transgressions which are never tolerated. [...] That does not mean that nothing ever goes wrong. But every

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[24] The pertinence of this example also comes from the context of the PKK's armed struggle, since this context shows similarities with the situation Nestor Makhno had in mind when he defended a kind of revolutionary military discipline. It also needs to be noted that when I talk about the PKK as a grassroots organization, I have in mind its development in recent years, in which it has been influenced more and more by the anarchist philosopher Murray Bookchin.

> fighter knows that he or she will never, ever get away with it. (Geerdink 2018, 254, own translation from Dutch)

In this chapter I aimed to show that theories and distinctions developed in social ontology and analytic philosophy are capable of elucidating discussions in (anarchist) political theory. This can be especially useful for those anarchists today who are inspired by the Platform. As Klien (2010) notes, platformism “continues to be a vibrant tradition within the global anarchist movement.” According to him, the PCR is not much more than “the very basic idea that if a group of people come to an agreement that something should be done *then they should do it*!” (Klien 2010). The Northeastern Federation of Anarcho-Communists takes the PCR to mean “that each member should take part in the collective decision-making process and respect the decisions of the collective” (NEFAC 2003). Klien suggests adding some substance to this rather thin principle by stressing the supportive and enabling character of a good organisation. He concludes that “a concern for the support and well-being towards other members ought to form a part of this collective responsibility”.

This chapter can serve as an additional input to the thought processes of those contemporary organisations who explicitly refer to the principle of collective responsibility. But I hope this chapter has not only been of interest to anarchists. I believe that social and political philosophy can draw inspiration from the rather unfamiliar political theory of social anarchism, as well as from other grassroots organisations and activists groups struggling with the same issues.

Chapter 5

Moral Reasoning About Future Generations

Chapter 5 Moral Reasoning About Future Generations

This part of my thesis is concerned with the question 'towards whom are we responsible?' applied to matters of epigenetic health. Remember that one of the ethically salient characteristics of epigenetically mediated health effects is that they seem to be potentially *transgenerational:* in chapter 1, I discussed the extent and limitations of claims about transgenerational epigenetics in more detail. Now, since epigenetic markers triggered by environmental factors can be inherited by offspring, the answer to the 'towards whom' question of epigenetic responsibility seems to include members of future generations. The ways in which individuals and collectives - such as parents, policy makers and governmental agencies – act upon (or fail to act upon) knowledge about the epigenetic connections between exposures and health outcomes does not only have an impact on themselves or on the members of currently existing generations. Those decisions also seem to influence people who do not yet exist. In the past few decades moral philosophers such as Derek Parfit have pointed out that when the people that are impacted by our choices do not yet exist, this may seriously complicate our moral reasoning about those choices. The tension between those complications and our intuitions is generally referred to as the Non-identity problem.

Because the Non-identity problem has at least some bearing on thinking about epigenetic responsibility towards future generations, this chapter of my thesis is devoted to its discussion. First, I will give a short explanation of what is at stake. I will then discuss existing literature on epigenetics and the non-identity problem. Then, I will discuss some appealing solutions, although I do not have the ambition to present the reader with an exhaustive overview of the vast amount of literature dedicated to solutions to the problem, let alone develop one myself. Finally, I reflect on the findings of experimental philosophy studies on the topic and their relevance, and suggest some future directions for qualitative research.

1. Description of the non-identity problem

To begin to understand the Non-identity problem, consider the following two cases.[25]

> **Mary** is one month pregnant, and is told by her doctor that, unless she takes a harmless, simple treatment, the child she is carrying will later have a lower quality of life. Mary decides not to take the treatment. Her child later lives a life worth living, but less so than when she would have taken the treatment.
>
> **Josephine** is about to stop taking contraceptive pills so that she can have a child. She is told that she has a temporary condition such that any child she conceives now will later have a lower quality of life; but that if she waits three months the quality of life of her then conceived child will not be affected. Josephine decides not to wait. Her child later has a lower quality of life.

The difference between those two cases is the following. In Mary's case, her decision affects someone who already exists (albeit as a fetus in utero). In contrast, Josephine's decision does not merely affect a person, but rather affects which person comes into existence in the first place. This idea is based on a genetic conception of identity. If Josephine and her partner conceive three months later than initially planned, a different ovum and a different sperm cell will merge, thus creating an embryo with a different genetic identity. This is what Rob Lawlor calls the non-identity effect: the biological claim that a different moment of conception results in a different child (Lawlor 2015).[26]

In Mary's case, the person her choice has an impact on already existed before her decision, so she does not influence the (genetic) identity of her future child. This is not so for Josephine: her decision brings someone into existence, which means

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[25] Those cases are based on the original cases of *The Two Women* formulated by Derek Parfit in his 1976 paper *Rights, Interests and Possible People,* in which he first discusses the non-identity problem (Parfit 1976). However, readers familiar with Parfit's work may recognize significant differences. This has to do with Parfit's use of disability. In the next chapter, I discuss extensively why I do not mention disability here, as well as why I made some other minor changes.

[26] As I will mention in a bit more detail later, this claim is not uncontested.

that it is identity-affecting. The difference between the two cases can thus be referred to as the Identity-Affecting Difference (IAD).

Does this difference change our moral judgment of such cases? Is there a *moral* difference between what Mary and Josephine did? According to Parfit, even after having the difference explained to them, most people hold the 'No-Difference View' (NDV), and so does he. In short, the NDV entails that there is no moral difference between choices that affect who comes into existence and choices that merely affect already existing people. Those who hold the NDV judge both cases in the same way and do not ascribe less blame or responsibility to Josephine because her choice was identity-affecting. Kuhse and Peter Singer agree that "it is significant that spelling this [identity-affecting difference] out does not lead people to modify their judgment that the woman should wait before becoming pregnant" (Kuhse and Singer 1985, 538).

The Non-identity problem and its various elements have been formulated in many different ways. Parfit himself describes it as a problem arising from a discrepancy between the two elements described above: the Identity-Affecting Difference (IAD) and the No-Difference-View (NDV). The problem lies in the difficulty we may have to explain the intuition that there is no moral difference between cases that nonetheless have an identity-affecting difference. 'Harm' cannot easily serve as a foundational concept here. Because there is no prior existence in the second case, we cannot say Josephine harmed her child if we use 'harmed' in the ordinary, comparative sense of the word. Her child would not have been better off if she had not made the choice she made. It would simply not have existed. One might deviate from this standard counterfactual notion of harm and defend some kind of impersonal harm, as we will see later, but this is no easy task.

Put differently, the non-identity problem is the problem of solving the apparent paradox between the fact that most believe it is morally wrong to bring someone deliberately into a flawed existence and the difficulty of finding moral ground to support this intuition (Lawlor 2015; M. A. Roberts 2020). The problem does not only manifest in 'micro cases' such as the ones above, in which prospective parents take decisions that influence which individual child comes into existence. It is also highly relevant in 'macro cases' where for example policy decisions may have identity-affecting implications for whole generations.[27] In his (unfinished) 2017 paper, Parfit himself explains that moral reasonings about the effects of climate change may need to deal with the paradox that is the non-identity problem:

> [Suppose] that we and the other members of some large community could choose between two energy policies, one of which would be cheaper but would increase global warming, thereby having various effects that would greatly lower the quality of life that would be had by very many people in several later centuries. Some of the effects of our policy - such as floods, droughts, heat waves, and hurricanes - would kill many of these future people. (Parfit 2017, 122-123)

Parfit argues that the intuition of many people is that choosing the cheap but unsustainable energy policy is wrong. He believes that this intuition cannot be changed or explained away by an appeal to the fact that the flawed nature of these people's lives is the very condition of their existence. Arguably, each energy policy would have far-reaching implications for people's lives, including the moment at which they conceive of their children. According to Parfit, people believe that it would make no moral difference that these choices and acts would be worse for no one.

The non-identity problem can also add a new level of complexity to a subset of macro-case debates: namely those on historic injustices that impact multiple generations, such as slavery and the Holocaust. When I characterized epigenetic injustice as a kind of historical-structural injustice in chapter 3, I conveniently left out the likely identity-affecting nature of many past decisions. But Andrew Cohen argues that if we take the non-identity problem serious in debates on reparations and justice, we need to deal with the question "How can any person have a claim to compensation for a wrong that was a condition of her existence?" (Cohen 2009, 81). Enslaved people and people suffering from the effects of e.g. malnutrition and trauma during the Holocaust who had children would probably have conceived at different moments (or not at all) if their circumstances were different. Thus, at first sight it may seem problematic to base claims for reparations made by descendants on them being worse off than they otherwise would have been.

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[27] I take the distinction between micro and macro cases in this context from (D. T. Wasserman 2009).

2. The non-identity problem and epigenetics

It is not hard to see why the non-identity problem has been considered relevant by those thinking about the ethics of intergenerational epigenetics in both micro and macro cases. Choices or exposures that cause or avoid epigenetic alterations that change already before conception the make-up of a (potential) future child may be characterized as being identity-affecting, depending on one's conception of identity. There are at least three papers devoted to epigenetics and the NIP (Bode 2017; Del Savio, Loi, and Stupka 2015; Räsänen and Smajdor 2022), and several others that touch upon it (including Chiapperino 2018; Loi and Nobile 2016; Hens 2022; Roy, Dupras, and Ravitsky 2017; Boniolo and Testa 2012). In what follows, I will discuss how those authors have engaged with the non-identity problem to illustrate the (perceived) relevance of this debate to the ethics of epigenetics.

In his literature review on social sciences and humanities scholarship engaging with epigenetics, Luca Chiapperino argues that the non-identity problem is 'particularly cogent' in relation to transgenerational epigenetics, noting that "especially in the case of epigenetic effects transmitted through the gametes [...] claims in favour of procreative and parental epigenetic responsibility appear to fall into a philosophical paradox" (Chiapperino 2018, 55). Issues are further complicated by the 'mismatch hypothesis' (cf. chapter 2.2 of this thesis), because "epigenetic predispositions assume a positive or negative health-related value only when certain environmental conditions are met" (Chiapperino 2018, 55).

Loi and Nobile do not only consider epigenetics, but discuss choices made in the general context of DOHaD, the developmental origins of health and disease (Loi and Nobile 2016).[28] They give the example of an obese woman planning to have a child to illustrate their point that DOHaD choices can have identity-affecting consequences. If the woman receives information on the increased likelihood of adverse health effects in the offspring of obese mothers, she might postpone her pregnancy to lose weight first (Reynolds et al. 2013). She then conceives at a

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[28] As mentioned in the introduction, this field studies how the early life environment can impact the risk of chronic diseases, for example through epigenetic mechanisms (Bianco-Miotto et al. 2017).

different time than she would otherwise have planned, resulting in a different child being born.

Philipp Bode zooms in on a few specific difficult cases related to the non-identity problem in the ethics of epigenetics. He refers to the famous Överkalix study to discuss whether and how one should weigh the interests of one's children against those of potential generations of (great)grandchildren (Bode 2017; Pembrey et al. 2006), if it turns out that what would be a good diet for one generation might increase the risk of adverse health effects in the next one. Similarly, Kristien Hens gives the example of the pesticide DDT, the use of which protects the current generation's health but affects that of future generations negatively (Hens 2022).

Some authors do not only explain why and how the non-identity problem might be relevant for the ethics of epigenetics, but also describe a solution or a way of dealing with the problem. Roy and colleagues, for example, are concerned with the non-identity problem in the context of the epigenetic effects of assisted reproductive technologies (ART) (Roy, Dupras, and Ravitsky 2017). Arguably, the choice of conception method changes which child comes into existence. They 'bite the bullet' and conclude that failing to minimize epigenetic risks of pre-conception ART is not something that violates a principle of non-maleficence. Thus, they conclude that "with respect to the NIP, healthcare professionals and prospective parents should not be considered to violate the principle of non-maleficence when using pre-conception ART" (ibid., 439). However, this discussion of the non-identity problem seems to rest on a flawed understanding of the problem. The problem lies in trying to find solutions that allow us to deal with the fact that our intuition may be that there is some kind of moral obligation here. As Rob Lawlor notes, 'biting the bullet' is just one of many proposed solutions (Lawlor 2015). In his reply to authors such as Savulescu and Hope, who seem to make the same mistake, he notes that this approach is not at all an uncontroversial solution to the problem. Indeed, "Parfit himself does *not* take the non-identity problem to give us a compelling reason to change our judgement about particular cases" (ibid., 894).

Lorenzo Del Savio and colleagues take a different approach and look for "rights-based obligations supervening on intergenerational epigenetic programming" (Del Savio, Loi, and Stupka 2015, 580). They defend a solution that rests on the fact that future generations are linked to ours by a chain of overlapping generations. Even in many cases of intergenerational justice, they believe it possible to justify "restricting the liberty of present generations for the sake of future ones" (ibid., 581) on the basis of person-affecting views of morality. If environmental exposure of existing people (F0) will affect the health of their not-yet-existing grandchildren (F2) through epigenetic programming, this would also have implications for the generation of their children (F1). Generation F1 might face increased costs to address the condition of F2 in the future, and this 'burden' on already existing generation F1 might generate obligations upon F0.

Even though the authors discussed above may disagree about the best way to deal with this idea, all of them have made it clear that choices related to epigenetic alterations before conception may have identity-affecting implications in the sense Parfit and others had in mind. Some authors, however, connect epigenetic knowledge to the non-identity debate in quite a different way. They use insights from epigenetics to question the very notion of numerical-identity-as-established-at-conception that is often taken from granted in this debate.

Boniolo and Testa, for example, give a thorough explanation of epigenetics in order to bring epigenetics to bear on philosophical debates on identity. They argue that all living beings are what they are because of the epigenetic processes that have regulated the expression of their genomes (Boniolo and Testa 2012). Thus, the persistence of identity of an individual (i.e. its numerical identity through time) rests on the continuity of those epigenetic processes. They conclude that their approach "shows once more that genetic essentialism is totally unconvincing since it completely neglects all the intergenerational and intragenerational epigenetic processes that [...] are fundamental to exhaustively grasp biological individuality" (295).

Räsänen & Smajdor make a similar move. In their commentary to an article on gene editing by Robert Sparrow, they discuss potential implications of epigenetics for thinking about identity and the non-identity problem (Räsänen and Smajdor 2022; Sparrow 2022). They contend that epigenetic changes may be at least as important to our identity as genes are, and perhaps even more so, "since they determine which of our genes are actually expressed" (40). This has at least two important implications. First, "If we accept the idea that identical twins are different people for largely epigenetic reasons, it seems that we must also accept that any intervention in the expression of genes also results in the creation of a new individual, rather than benefiting that organism" (41). That is, epigenetic alterations then seem to be identity-affecting. And secondly, since such alterations happen throughout our whole lifetime, a conception of identity based on genetics and epigenetics combined implies that "our identities are profoundly unstable, in a constant state of flux, altered by all we experience" (41).

Kristien Hens also takes issue with the conception of identity that underlies the assumption that our (numerical) identity is fixed at conception (which is the very assumption that gives rise to the non-identity effect and the non-identity problem). Invoking epigenetics in a similar way to Räsänen and Smajdor, she suggests that "discussions about future people should not only hinge on genes remaining the same but also consider the entire development of an organism, from conception until death, and encompass all its experiences and chance encounters" (Hens 2022, 62). Thus, Hens herself favors a developmental perspective on identity, speculating that this might "allow us to forego these technical discussions on numerical identities and focus on other things, such as the importance of experience and context for identity" (ibid.).

I am sympathetic to approaches such as the ones above that rely on insights from epigenetics to challenge long-held philosophical beliefs such as those about numerical identity. Such approaches do not always directly engage in the search for solutions to the non-identity problem, but they can shed a refreshing new light on the formulation of the identity-affecting difference and thus the problem itself. They form interesting alternatives to other criticisms of assumptions of genetic essentialism underlying the account of personal identity used in the reiterations of the non-identity problem. Such criticisms, namely, sometimes have rather counterintuitive metaphysical implications.

One example is that of Anthony Wrigley, who explains how much of the debate about the problem relies on a specific theory of modality. The Non-identity problem only arises if one accepts the genetic essentialism that it is based on. The modal claim that is assumed in Parfits account is that in every possible world where a person exists, they have the same genetic origins. But Wrigley points out that "there are alternative accounts of modality that do not require identity across possible worlds to be determined so rigidly by actual genetic origins" (Wrigley 2012, 179). He himself proposes Lewis' Genuine Realism. On this account, it is someone's *counterparts* (individuals inhabiting other possible worlds) that can be identified as possible ways they might be. Wrigley explains this account further and points out that it allows us to hold on to a person-affecting conception of harm when we reason about actions such as those of Josephine. When we adopt this alternative modal account, we could argue that "there is some possible world that is similar in all respects except that the counterpart of the actual individual with the harmed condition does not possess the condition because an alternative course of action was chosen" (184).

This is a solution to the non-identity problem, because it allows us to regard decisions affecting future generation as person-affecting. However, not everyone is willing to accept the metaphysical implications of this approach.[29] Thus, epigenetics-informed approaches to identity may be alternatives worth investigating. To be sure, such approaches that argue our identities are 'in a constant state of flux' may have serious metaphysical implications too. Some rigorous research on the implications of such approaches would be very valuable.

3. Appealing approaches to the problem

After the overview of discussions of the non-identity problem in philosophical and social sciences literature on epigenetics in the previous section, this section zooms in on some philosophical solutions to the problem itself. It is not my intention nor is it within my capacity to summarize and evaluate all solutions that have been proposed in the few decades of lively debate on the subject (see Roberts 2020 for a good and relatively recent overview). Instead, I will highlight some related approaches that I believe might be appealing to invoke in debates on the ethics of epigenetics. Those approaches have in common that they see moral relevance in the role or positionality of the agents and/or in their relationship with the (potential) future person(s). Such approaches fit well with my commitment in this thesis to forward-looking responsibility and role-related concerns. I will first explain a technical distinction that undergirds many of those approaches to the non-identity problem, before describing in more detail what characterizes a few of them.

So-called 'descriptive proposals' rely on insights in philosophy of language in their search for a solution to the non-identity problem (Roberts 2020). Those solutions make use of the fact that the same definite description can pick out distinct people in distinct scenarios. Most of them rely on the technical distinction between *de dicto* (literally: about what is said) and *de re* (literally: about the thing).[30] Harming

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[29] However, Wrigley himself argues that at least in scenarios of genetic selection and embryo selection, the use of his counterpart theory does not give rise to implausible and counter-intuitive accounts of harm.

[30] Some take a slightly different approach. For example, Kavka proposes a modified categorical imperative that includes the people we are talking about in identity-affecting cases: "do not treat rational beings *or their creation* (that is, their being brought into existence) as a means only, rather than as ends in themselves" (Kavka 1982, 190).

or benefiting someone in the *de re* sense means that you harm or benefit a particular individual. But one can also harm or benefit someone in the *de dicto* sense, by acting in such a way that the person that has certain characteristics or stands in a specific relation to you is affected, whoever this person might be. If someone says that she wants her future partner to be funny and caring, she has not picked out one specific individual to take up the role of 'future partner'. What authors such as Caspar Hare, Chelsea Haramia and Joona Räsänen want to point out by making this distinction, is that there are possible actions that make things *de dicto* worse or better in some way, without making them *de re* worse or better in that way (Hare 2007; Haramia 2013; Räsänen 2021).

Let us apply this distinction to the cases of Mary and Josephine (in the first section of this chapter) to understand the difference and its bearing on the non-identity problem better. If the pregnant woman Mary does not undergo treatment, her unborn child will arguably be harmed in a relatively straightforward, *de re* sense. The very same living being will be worse off than it would otherwise have been. Matters are not as clear-cut in the case of Josephine, who decides not to postpone becoming pregnant. In this identity-affecting case, Josephine does not harm anyone in a *de re* sense. But Hare and others argue that in her case, we could argue that she makes things *de dicto* worse for the wellbeing of her child. As Räsänen puts it, while Josephine and her partner "do not harm any particular genetic individual, they harm their child – whoever he or she will be" (Räsänen 2021, 72).

According to Parfit, the *de re* sense of harm is the only sense of harm that matters, morally speaking. We might still think something is wrong in identity-affecting cases such as that of Josephine – indeed, this is the No-Difference View that Parfit believes most people hold. But the idea is that such an intuition cannot be explained by an appeal to an account of harm that does not yield counterintuitive conclusions. However, some authors disagree and argue that *de dicto* considerations are in fact sometimes (Hare) or even most of the time (Haramia) morally significant (Hare 2007, 516). I will now explain why they think so.

Caspar Hare argues that it is the agent's *role* that determines whether or not it is appropriate to expect her to care about making things *de dicto* better (or, presumably, not *de dicto* worse) (Hare 2007). Consider his case of the Safety Officer:

> **The Safety Officer**. Tess is a state safety officer, whose job it is to regulate those features of the automobile that protect its occupants in the event of

> a collision [...]. Noticing that people in her state are not wearing safety belts, she implements some tough new regulations and, a year later, is pleased to discover evidence that they have been effective, that the severity of injuries sustained in automobile accidents has been reduced as a result of people belting up. She gives herself a pat on the back. (Hare 2007, 516)

With this case, Hare asks us to consider that a policy decision can influence which specific persons are affected, in such a way that there is a clash between *de dicto* and *de re* senses of harm. To see this, imagine that Tess is being accused of harming the victims of car accidents in a *de re* way in the following way:

> **A response to Tess**. Accidents involve split-second timing. If you had just made it illegal to wear a safety belt, then most of those people would not have fumbled with the clip for five seconds before pulling out of their driveways, and, for most of them, the momentary, unhappy combination of conditions [...] that led to the accident would never have arisen. (Hare 2007, 520)

But we feel that such a reply would be wrong, and that Tess does indeed have reason to be proud. Her job is namely to make things better for the victims of car crashes. Unfortunately, she is only able to fulfill this role in a *de dicto* sense.[31] Thus, Tess could reply to her critics that her job was to ensure "that last year's accident victims were, collectively speaking, healthier than those people who would have been last year's accident victims would have been if I had acted otherwise. [...] And I did just that." (518)

If we agree with this example, Hare thinks we should agree that there are situations in which we expect certain people to *care* about making things *de dicto* better in some way, rather than *de re*, in virtue of the causal circumstances a person finds herself in. He concludes that "there's a real psychological attitude that involves caring, not that the occupant of a certain role be as well off as possible, but that a certain role be filled by someone as well off as possible" (519). We can appropriately expect that attitude of safety officer Tess, but also of Josephine and other agents that make identity-affecting choices. We might say,

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[31] Admittedly, the fact that we are comparing benefiting and harming might also have an impact on our intuitions about this case, since there are reasons to assume that our moral reasoning about those is asymmetrical (Benatar 2006; Magnusson 2019).

for example, that it is appropriate for Josephine to care about the wellbeing of her children, whomever they turn out to be.

Chelsea Haramia goes a step further and argues that *especially* in cases in which the non-identity problem arises, we should prioritize *de dicto* readings over *de re* considerations of harm (Haramia 2013). When we reason or judge in the *de dicto* sense, we are concerned with what she terms 'the office' that future people will come to fill. Haramia contends that "we can appeal to a person-affecting principle insofar as we recognize *that* persons will come to fill a particular office, whoever they might be, and that we must make things better for these moral subjects whenever we stand in the correct responsibility to the office they will come to fill" (ibid., 256). She gives many examples of situations in which we hold people such as parents, teachers or leaders of state responsible to care for people in a *de dicto* sense. When teachers prepare their lessons for the next year, for example, they do so with the aim of benefiting their new students, whoever they might be. We have moral expectations for them to care about making those under their responsibility better off (or at least not worse), even though the identities of those people are not yet known. If they fail to live up to their responsibility, we can coherently say that this affects the office holders in a *de dicto* sense.

Now, Haramia states that in identity-affecting cases it is particularly appropriate to think about the agent's responsibility in a *de dicto* sense. This is so because in such cases, we have widely shared moral expectations of the responsibilities of the agents involved. The idea that people who desire to have a child try to make sure that things go well for whoever this child will be, is commonly agreed upon.[32] Thus, we may agree that future parents have strong moral reasons to make things better for the office holder of 'their future child'.

In short, Haramia and Hare argue that it depends on our understanding of the appropriate role or responsibility of an agent whether or not the *de dicto* sense of

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[32] Note that this seems to be a variant of the claim about the No-Difference-View being widely shared. This is a claim that will be challenged in the next section. However, I think that Haramia's approach remains valuable nonetheless, because it points to something useful about the grounds on which we decide whether or not *de dicto* considerations are relevant.

harm is relevant or important.[33] There are more approaches to the non-identity problem that suggest we shift the focus of our moral evaluation away from discussions about the possibility of the 'object' being harmed in identity-affecting cases towards considerations related to the situation of the *agent*. Such approaches ask us to consider whether the act of an agent is right or wrong, permissible or impermissible in virtue of their role, their attitudes and intentions, or their relation towards the person or people that are affected by their choice. For example, when evaluating a case we can ask ourselves whether "the agent is motivated by an appropriate level of concern for the needs and interests of (among others) the future person" (Roberts 2020). 'Among others' implies that the beliefs and moral principles of the agent herself can be of importance as well, as this example of Roberts shows:

> **Parental concerns.** The parent may have a principled objection against pre-implantation genetic diagnosis but also have an appropriate level of concern for the child’s plight. In that case, the parent’s producing the impaired child in place of the better-off but nonidentical child does not wrong the impaired child. (Roberts 2020)

Such views may have the implications that there may be nothing wrong, in some situations, in choosing to have a predicably less happy child rather than a happier one. One of those is that of David Wasserman. On his view, whether or not an act of future parents is permissible depends not so much on how we evaluate the balance of expected good and expected bad, but rather on whether or not those parents have carefully determined how those balance against each other (Roberts 2020; Wasserman 2005). This approach is acceptable as long as the agents deliberating do so from partial concerns towards the future person or persons they create. Wasserman gives the example of a couple that will conceive of a mildly cognitively disabled child unless they wait for a year. He lets us suppose that those people *want* to have a child with such a cognitive disability "because their closeness with their own mildly impaired parents has given them a strong affinity with, and partiality towards, people with similar impairments. [...] In light of their close relationship with their own parents, they are confident that they would be

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[33] Cf. Haramia: "Note that when this responsibility does not obtain, *de dicto* considerations often diminish in importance. Consider the fact that, in our everyday lives, we harm people in the *de dicto* sense all of the time. This harm is usually morally permissible insofar as we bear no legitimate responsibility to the persons who come to fill the office in question" (Haramia, 254). She then gives some good examples.

devoted and skillful caregivers" (278). The fact that they have certain reasons and the intention to conceive of this particular child, rather than acting carelessly, seems to make their choice less open to criticism. Wasserman summarizes his position as follows:

> If an agent acting from [...] partial concerns creates people with shorter or more disadvantaged lives than others she might have created, she will not wrong those people as she would have if their creation had resulted from purely selfish or other ulterior motives. (Wasserman 2009, 267)

Such an approach suggests that whether or not agents do something wrong depends on the reasons they have for acting in the way they do, rather than on some counterfactual notion of harm that is part of the Non-identity problem. As such, this approach seems a way to 'circumvent' the problem or at least to downplay its importance for our moral reasoning.

Wasserman admits that this appeal to the partiality of the agent seems to be more appropriate in micro-cases than in macro-cases. We typically expect future parents to care about the person they may bring into existence in another way than we expect policy makers to care about the persons whose creation their decisions may affect. However, he thinks that policy makers can and do sometimes also act with a degree of partiality. For example, politicians may have some partiality towards members of their own political community or culture (Wasserman 2009, 268). We may find the reasons behind such partiality to be not particularly good or admirable (Wasserman speaks of 'suspect partiality'), and criticize the policy makers for this. But the policy maker's partiality would make it so that the affected future individuals, once they exist, have less reason to criticize the decisions that brought them into existence.

Let us take stock for a moment. We discussed various approaches that use the *de dicto/de re* distinction in their attempts to find a way to allow for the *possibility* that someone who does not yet exist can be harmed. Then, as I just explained, some approaches argue that our evaluation of whether or not a wrong or a harm has actually been done should depend on an evaluation of the intentions, role or attitudes of the agent. Although they may lead to nuanced conclusions, these approaches still assume that we are well-placed to formulate a judgment about the choices made from an external perspective (i.e. distinguish good reasons from bad ones).

In micro-cases involving prospective parents as agents, Peter Herissone-Kelly challenges this very assumption. According to him, it can be fitting and appropriate for prospective parents to take up an internal perspective where "the transpersonal welfare judgements of the external perspective will find no foothold" (Herissone-Kelly 2017, 162). His position relies on the claim, made by Dancy, that considerations that function as reasons in one context will not necessarily function as reasons in all contexts in which they obtain (Dancy 1993). Thus, according to Herissone-Kelly, reasons that are appropriate in an 'external perspective' can become not just overridden, but *silenced* in an internal perspective.

Specifically, he argues against the Principle of Procreative Beneficence (PPB), coined by Savulescu, which holds that parents are at least prima facie obliged to select the child, out of a range of possible children they might have, who will be likely to lead the best life (Savulescu 2001). According to Herissone-Kelly, agents have no obligation to select for a child with the best life.[34] The PPB is an external-perspective principle, which mean that it entails comparing the lives two possible persons by drawing back from both perspectives. But the internal perspective, from which prospective parents make their choice, seems to be fundamentally different:

> **Internal perspective.** In thinking about the life of a possible person A*, we adopt the internal perspective when we (i) 'imaginatively inhabit' that life, imagining what it would be like to live it, and (ii) make the sort of 'better' and 'worse' judgements that we would make about A*'s life *if we were A**. (Herissone-Kelly, 160)

This perspective is not only appropriate for prospective parents faced with identity-affecting choices to take up; it is often even *expected* of them to do so (although Herrisone-Kelly emphasizes that they are not *obliged* to do so). It is appropriate for someone like Josephine to feel an "extremely close identification with the possible subject of each life she imagines – so close that it will include and give weight to the sorts of assessments that each child would be likely to make of his own life" (162). Remember that the reiterations of the identity-affecting difference stipulate that the life of Josephine's child will, although less worth living, still be

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[34] That is, if it were even possible to test for 'the best life', which might never be the case (Parker 2007).

worth living. Thus, it makes sense for a prospective parent to take that expected assessment of the child into account.

Debates on the non-identity problem usually take the external perspective for granted. For macro cases, this may be the only good perspective to take up. Herissone-Kelly believes that it is obligatory for policy makers to do so and to "positively eschew the internal perspective" (162). To many procreative ethicists or philosophers involved in (normative) ethics about micro cases of some kind, the internal perspective is not yet or will never be available. This does not mean that we should refrain from thinking critically about cases such as those of Josephine. But it may remind us to sometimes show some epistemic humility when discussing difficult cases in procreative ethics (Roberts and Wood 2003). Approaches based on the roles and attitudes of agents leave sufficient room for an individual's judgements and principles to play a role. As such, they fit well with the account of normative responsibility developed by Björnsson & Brülde discussed in chapters 3 and 4. In identity-affecting cases, as in many other cases, future parents have requirements to care about their prospective child in an appropriate way. How this care materializes depends on more factors than just the expected quality of life of this child. In chapter 7, I discuss in more detail what we might (or might not) expect of future parents in light of epigenetic knowledge.

4. Questioning the urgency of the problem

The solutions in the previous section are all subject of ongoing debate. Some commentators may find that those approaches do not sufficiently deal with the philosophical problem at hand, or find other flaws in them. As things stand, I cannot confidently defend one solution to the non-identity problem in order to have one less worry on our mind when discussing the ethics of transgenerational epigenetics. This section, then, takes another approach to the problem in hope of finding a way out. It discusses what people actually think about the non-identity problem. So, it discusses which moral intuitions lay people have in identity-affecting cases versus cases that do not affect who comes into existence, and which implications such findings might have. I will start by presenting the results of existing experimental philosophy on the non-identity problem. I will then discuss potential implications of their findings and specifically of the variety in their findings. Finally, I will suggest that the best way forward in debates on the non-identity problem is to focus on qualitative research that investigates the reasons behind the opinions and intuitions of people. I will suggest a few research themes that might be relevant.

Quantitative experimental philosophy

To date, there are three quantitative studies in experimental philosophy investigating public opinions related to the non-identity problem (Moormann forthcoming; Doolabh et al. 2019; Kopec and Bruner 2022). One of those is my own study, of which the next chapter in this thesis is an edited version. Although they use different methods and have their own emphases, the three studies have in common a core focus on the No-Difference View. Remember that the discrepancy between the No-Difference View and the Identity-Affecting Difference, and thus the problem status of the Non-identity problem, is asserted on the basis of at least one empirical claim. This is the claim that most (Parfit) or perhaps all (Kuhse and Singer) people who are confronted with cases such as those above judge them to be morally similar (and thus hold the No-Difference View). Neither Parfit nor Kuhse and Singer performed any systematic studies regarding their versions of this claim, but it can be tested. In what follows, I discuss how these experimental philosophy studies did this, and what their findings are.

Keyur Doolabh and colleagues lay out how the relevance of the non-identity problem to questions of public health policy is illustrated by some responses to the Zika epidemic (Doolabh et al. 2019). Two possible ways of dealing with the outbreak of this virus, and particularly its impact on fetuses, are mosquito control and contraception. In non-identity terms, the mosquito control is the person-affecting option: it involves handing out mosquito repellant to pregnant women so that they and their already existing fetuses are not harmed by the virus. Contraception, on the other hand, is the 'impersonal' or identity-affecting option. By providing couples with the means to delay pregnancy until the seasonal peak of Zika transmission has passed, this policy changes the moment of conception and thus which people come into existence.

The authors set up an experimental philosophy study in order to help philosophers and policy-makers grappling with the non-identity problem, arguing that "it may help public health policy-makers to come to a provisional stance on the non-identity problem if they understand the moral intuitions of the general public" (Doolabh et al. 2019, 5). They presented an online survey to readers of Aeon, an online magazine of ideas and philosophy. After receiving some information about Zika and potential strategies to deal with the pandemic, participants were asked to indicate on a scale whether they preferred the Mosquito Repellent strategy, the Anticonception strategy, or neither of them, and explain why. On average, participants slightly preferred Mosquito Repellent over Contraception. Subsequently, they were presented with an explanation of the non-identity problem, followed by the task to share their preference with this new knowledge in mind. The explanation did not change the average preference for Mosquito Repellent over Contraception. But the authors do report a significant change in the mean preference towards Mosquito Repellent after the explanation, which seems to come from participants who moved from a preference of Contraception towards having no preference.

The authors conclude that the identity-affecting difference appeared to play a minor role in the moral decision-making of their participants. The slight average preference for Mosquito Repellent both before and after the explanation may indicate that people prioritize person-affecting solutions. For many people, the identity-affecting difference explanation did not seem to make much of a difference for their moral evaluation. Based on the answers to open questions, the researchers observe that the majority of participants "were influenced by other ethical or practical issues such as cost-effectiveness, practicality, and imposition on people's freedoms" (ibid., 14). Moreover, based on questions they asked about harm, they found that "participants seem to either misunderstand the non-identity problem, or hold non-counterfactual views of harm that do not define harm as making someone worse off than they would have been otherwise" (1).[35] In other words, many participants used conceptions of harm that do not make the non-identity problem arise, which explains why they might not be bothered by an explanation of it.

Matthew Kopec and Justin Bruner conducted an experimental philosophy study on the non-identity problem to investigate an observation from their teaching experience. They observed that many of the students they teach about the non-identity problem see a 'substantial moral difference' between identity-affecting cases and person-affecting cases (Kopec and Bruner 2022). Their students seemed to attach less moral weight to choices affecting not-yet-existing people.

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[35] The fact that of the 1313 people who started the survey only 763 or 58% of them finished it, may also be an indication of the difficulty with understanding the subject of the questionnaire itself and/or its relevance.

Kopec and Bruner hypothesize that the intuitions of their students are shared by the American public in general. To test this, they developed a behavioral economic experiment in which they present participants a version of the dictator game, in which a player (the proposer) is given some money and needs to decide how to divide this between herself and another player (the receiver). They compared the outcomes of a 'normal' dictator game, in which the proposer has to decide how much money to give to one specific person, to the outcomes of an identity-affecting version of the game.[36] Their conclusion confirms their hypothesis: "agents tend to act more selfishly when they find themselves in identity-affecting choice problems, where they seem less willing to make small, altruistic sacrifices" (Kopec and Bruner 2022, 187). Their data thus suggest that the No-Difference View is not as widely shared by the general public as may sometimes have been assumed by philosophers.

Just like Doolabh and colleagues, Kopec and Bruner also looked into the conception of harm held by their participants. They found that "substantial portions of the population seem to each employ distinct notions of harm in their normative thinking". Arguing that those findings "raise puzzling features about the public's normative thinking", they call for more empirical research on this topic.

Finally, my own experimental philosophy study also looked into the prevalence of the No-Difference View. I will only summarize some results of my own experimental philosophy study, which took the form of an online survey conducted in the winter of 2019/2020. The next chapter provides a detailed report of my methodology, analysis and the results that do not pertain to the No-Difference-View. I presented respondents with cases such as those of Mary and Josephine in the first section of this chapter. I did so twice: before and after they read an explanation of the difference between the two cases, i.e. an explanation of the non-identity problem. I expected the answers of our respondents to be in line with those of the studies discussed before. Hence, I hypothesized that people would not hold the No-Difference-View, but instead attach (a bit) less moral import to the identity-affecting case.

Before the explanation, the means of the answers to the pre-conception cases (i.e. the identity-affecting ones) were not significantly different from those to the post-

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[36] See Kopec & Bruner p. 177 for an explanation of the set-up.

conception cases. This means that, in my data set, people initially did not tend to have less outspoken, negative judgments about the behaviour of a woman who is not yet pregnant (such as Josephine) than about that of a pregnant woman (such as Mary). The explanation of the non-identity problem did have an impact on the answers of participants. After reading about the non-identity problem, participants were more outspoken about the identity-affecting, preconception cases than about the post-conception, person-affecting cases. This difference was due to a combination of increased judgment of the preconception cases and decreased judgement of the post-conception cases (cf. chapter 6.4 for an image).

The three studies have some interesting commonalities and differences. They all share the result that, at least after an explanation of the non-identity problem, the answers of participants are not in line with the No-Difference View. The identity-affecting difference (or the 'non-identity effect') *does* make a moral difference for people. Thus, these findings seem to indicate that the No-Difference View is not as widely shared as Parfit and others assumed. Because this view is one of the ingredients of the non-identity problem, such findings might mean that the problem loses at least some of its urgency.

That being said, the findings are far from conclusive with regards to the way in which the identity-affecting difference affects people's moral judgements. While people seemed to attach slightly more moral import to person-affecting cases in the studies of both Doolabh and colleagues and Kopec and Bruner, participants in our study were more outspoken about person-affecting cases. This is a puzzling result that indicates the non-identity problem is far from solved. So far, quantitative experimental philosophy does not seem to get us 'off the hook'.

Indications that people might indeed find identity-affecting cases less morally relevant are worrisome for those concerned about intergenerational issues. The authors of each of the studies referred to above are worried, too, what such a preference for person-affecting considerations might mean. Kopec & Bruner contend: "If human life is to continue on this planet, we need to motivate the public to care more deeply about the welfare of people who don't yet exist" (Kopec & Bruner 2022, 1). In an unfinished 2017 paper, Parfit himself neatly described how we find ourselves in some sort of 'double bind':

> The Non-identity problem must be either practically or theoretically important. If the No Difference View is false, this problem is practically important, since it would matter less whether our acts or policies would have these bad effects. If the No Difference View is true, this problem is

> theoretically important, since many moral theories imply or assume that this view cannot be true. (Parfit 2017, 123)

Thus, if we want to efficiently deal with the Problem, we first need to establish whether or not the No Difference View is true or false. And if it is false (i.e. not widely shared), we need to be certain that people indeed care less about the effects of their actions when they are identity-affecting, instead of the other way around. More experimental philosophy is needed to establish such a claim, and to rule out the impact of other distinctions or elements people might find relevant in thinking about non-identity cases.

I want to consider the possibility that the differences between the results of the three studies point in another direction. Perhaps it is not the identity-affecting difference that plays a major role in the moral reasoning of people, but rather a set of context-related aspects. Although the three experimental studies were all concerned with the non-identity problem, the methodologies and cases used were rather varied. Doolabh and colleagues asked participants to reason on a macro level about public health issues concerning reproductive ethics. The cases in my study were also about reproductive ethics, but they were situated on a micro level. Finally, the study of Kopec and Bruner did not present participants with cases about which they could reflect as an outsider; instead, their participants were part of a behavioural economics experiment in which they themselves needed to take an identity-affecting decision on a micro level. This variation might partly explain the differences in outcomes.

Moreover, in both my study and that of Doolabh and colleagues, participants cited a broad range of reasons and considerations that influenced their answers, most of them having nothing or little to do with the identity-affecting difference that was 'supposed' to matter most. Some might say that this merely points towards the imperfections of thought experiments and vignettes. Many contextual factors are deliberately excluded from such abstracted scenarios. If participants do turn out to include aspects in their judgments that the philosophers deem irrelevant in such cases, the correct response might be said to entail stipulating in the next version of the vignettes that those particular aspects should not be taken into account here.

However, I am skeptical about this approach. I do believe that thought experiments can have some hermeneutical value. Moreover, if they seem to reflect implicit biases that might muddle the judgements of participants even though they are orthogonal to the distinction being investigated, I believe the right thing to do is to change the vignettes (cf. my discussion of disability in the next chapter). But I think it is far from clear that we can assume that all considerations except those related to the non-identity effect are irrelevant to the cases under discussion. We need to find out what actually matters most to people. And if it would turn out that that is not the identity-affecting difference, this may be somewhat of a relief: then, our options to motivate people to care about future generations may not be so restricted after all.

Qualitative experimental philosophy

I thus suggest that the most fruitful way for research on the non-identity problem to continue is to conduct *qualitative philosophical research*. In addition to quantitative research that gives us an indication of the strength of people's judgements, conversations with lay people in either individual settings or focus groups can lead to more information on the reasons behind those judgments. Qualitative research can give us much-needed insights not only into whether or not people hold the no-difference view, but also into why they do (not do) so. The following are some suggestions for research themes or potentially relevant factors:

- **Implicit biases.** In the next chapter, I will discuss how 'disability' in thought experiments, such as those of Parfit and others concerned with procreative ethics, often serves as a placeholder for 'lower quality of life' or a 'life less worth living'. Not only is it wrong to assume this, but whether or not disability is mentioned in vignettes related to the non-identity problem may also have a unjustified, but non-negligible impact on people's moral judgments. Apart from ableist biases, other biases that are known to be common may play a role in such cases as well. For example, although it is hard to find out, it is not unimaginable that sexist biases play a role for some participants when they judge the behaviour of prospective mothers and pregnant women.
- **Conceptions of harm.** Both Kopec & Bruner and Doolabh and colleagues found that people use a variety of conceptions of harm; the latter specifically call for more research on this. Qualitative research could have a heuristic purpose here, and help inventarize the variety of conceptions used by the public.
- **Standpoints and proximity.** As I hinted at before, I hypothesize that there might be a significant difference between being the agent faced with an

identity-affecting decision yourself, and judging about or advising another (hypothetical or real) agent making such a decision. Similarly, whether or not you have ever been confronted with similar choices such as those of Mary and Josephine – whether you have ever taken up the 'internal perspective' (Herissone-Kelly 2017) may also influence your considerations.[37] And if people seem to care less about distant future generations than their own, that may also be an extension of the effect of proximity on moral issues rather than a specific effect of the identity-affecting nature of those scenarios.

- **Conceptions of identity.** Perhaps not everyone shares a conception of numeric identity based on the genetic information at conception. It may also be worth researching to what extent people let their conception of identity, whichever one it is, play a role in such cases at all.
- **Role of language.** This may require a different research method, but I wonder whether some of the issues related to the non-identity problem may be influence by the language in which it is being discussed. Dutch translations of the term 'harm' and the expression 'making worse off', for example, seem much less common in everyday language than their English equivalents.
- **Assumptions about future people's views.** Many intuitions surrounding the non-identity problem seem to assume that, as long as people find their lives worth living, they will be grateful that their parents created them, or at least evaluate as positive the decision they made to do so under specific circumstances. This is fundamentally an empirical question. Although I will not focus on non-identity issues, I will come back to the issue of the opinions of future persons about choices that affected them in the past in chapter 7 when I discuss epigenetics and parental autonomy.
- **Crosscultural differences.** Various elements mentioned above, such as conceptions of harm and identity, might also vary between cultures. Hence, crosscultural experimental philosophy might be as relevant here as it has already been in some other areas of philosophical thought.

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[37] A first attempt at investigating this hypothesis in my study by analyzing the impact of parental status, did not yield any significant differences (cf. the appendix of chapter 6).

5. Concluding remarks

Kristien Hens remarks that "the non-identity problem has puzzled reproductive ethicists for decades, to the extent that some people just choose to ignore it" (Hens 2022, 60). With this chapter, I hope to have shown that I do not ignore the problem. However, at the same time I suggested that the problem may not be so urgent that it cannot be put between brackets for the rest of this thesis. Various theorical solutions to the problem already exist (although some are more promising than others), and I discussed that approaches focusing on the role and intentions of the agent may help us circumvent the problem to some extent. Moreover, I showed that experimental research on the problem is far from conclusive. More (qualitative) research is needed, but that should not stop normative ethicists from being concerned with the wellbeing of future generations.

Finally, I am convinced that most ethical and political interventions aimed at increased intergenerational justice can be justified without solely relying on moral regard for people who do not yet exist. Climate change, for example, is not only likely to make the lives of future generations less worth living than they otherwise would have been. It also affects entire ecosystems, institutions and societal structures that are long-lasting and already present today. As Del Savio and colleagues argue in the context of epigenetics, the fact that the present and the future overlap may give us reason enough to care about the latter. Philosopher Samuel Scheffler defends this approach towards the non-identity problem in general. He argues that preventing disaster in the distant future is in the interest of those alive now, because we are involved in many meaningful endeavors that presuppose the existence of future generations (Scheffler 2018). Activities we engage in and care about today, such as philosophy, education, literature, medical research and activism, all derive at least part of their meaning from their continuation across generations.

I tend to believe that issues in transgenerational epigenetics are similar. Most of the decisions we can take to improve the epigenetic health of future generations also already benefit already existing people. Conflicts of interests between generations such as those mentioned by Bode (in the Överkalix study) and Hens (who refers to DDT) are the exception rather than the rule. This does not mean that we should not study them, but we should not treat the non-identity problem as something overshadowing all normative work on epigenetic effects. By attaching too much weight to the problem, we risk that causative agents of mass environmental pollution start using the non-identity problem to thwart the attempts of those of us concerned with achieving increased structural epigenetic justice. We should not lose sight of the fact that dealing with environmental pollution and other factors that increase chances of adverse epigenetic alteration is generally very much also in our own interest.

Chapter 6

Blaming the Mother?
A Philosophical Vignette Study
on the Non-Identity Problem,
Disability and Quality of Life

Chapter 6 Blaming the Mother? A Philosophical Vignette Study on the Non-Identity Problem, Disability and Quality of Life

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I made some very small changes to the text to increase the general coherence of this thesis. I also added references to other chapters to draw connections between this chapter and the overall structure of the thesis.

Introduction

Which obligations do we have towards possible future people whose identity and quality of life we can influence? As David Boonin explains, moral principles that we use in other contexts may suddenly yield counterintuitive or unacceptable results when we apply them to questions about future people. A problem arises, then, "of determining how, if at all, these common sense moral beliefs must be revised in light of their implications for our obligations to those future people whose identity we can (at least in part) control" (Boonin 2008, 127).

This so-called Non-identity problem, which has been discussed extensively in the previous chapter, continues to inspire and trouble many philosophers across various disciplines. Those include intergenerational ethics, procreative ethics, philosophy of medicine and the ethics of epigenetics. Some bioethicists and philosophers of medicine believe the problem has applications that will increase in the coming years (Alonso and Savulescu 2021), or that it has practical implications for the duties of physicians faced with identity-affecting requests (Hope and McMillan 2012). This prominent role warrants a critical discussion of the problem in experimental philosophy fashion. This chapter reports an experimental philosophy study that aims to investigate whether the central role of the problem is justified given lay people's intuitions about related vignettes. For a very short introduction to experimental philosophy, I refer the reader to the Introduction of this thesis.

This chapter reports on the experimental investigation of two assumptions underlying the typical use of the Non-identity problem. Firstly, I doubt that the Problem is as deep as is often believed. The Non-identity problem is only problematic because of a supposed discrepancy between two claims: the No-Difference View and the Identity-Affecting Difference. Parfit and others believe that most people would agree with both claims because they share the intuitions that underlie them. However, in this study, I investigate whether a diverse sample of non-philosophers shares the No-Difference View. This view entails that there is no *moral* difference between choices that affect who comes into existence and choices that merely affect already existing people. If this view is not commonly agreed upon, this may be important for everyone working with the Non-identity problem and expecting their theories to be somewhat in line with most people's moral intuitions. Moreover, the Non-identity problem is often regarded as a difficult obstacle to formulating a theory of beneficence for future people. But if the problem does not really pose an obstacle for many people, perhaps procreative ethicists should pause to consider the usefulness of the problem as an argumentative tool.

The second part of this study investigates people's intuitions about disability in the context of procreative ethics and the Non-identity problem. The concept of disability is a central element of Parfit's original description of his problem and the theories and criticisms of many authors engaging with his work, including those engaged in creation ethics debates (e.g. Savulescu 2001). However, I believe that the continued employment of the concept of disability in thought experiments related to the Non-identity problem might be inappropriate and that its impact on people's judgments about identity-affecting decisions should be tested.

The use of certain terms or concepts in thought experiments might influence people's intuitions about them in ways not accounted for by the philosopher who designed them. As Eva Kittay remarks in *Learning from My Daughter*, "what philosophers rarely do is acknowledge the autobiographical origins of all intuitions that they appeal to" (Kittay 2019, 38). I suspect that people's prejudices (including, possibly, the biases of philosophers such as Parfit) about or experience with disability and quality of life may impact their intuitions about identity-affecting issues in ways that Parfit and others had not anticipated. Following other experimental philosophers (for an overview, see e.g. Alexander 2012; Knobe and Nichols 2017), I believe that intuitions about philosophical categories may systematically vary between groups of people. First- or second-hand experience with disability, gender and parental status are some aspects of individuals that might influence their intuitions on issues in creation ethics.

This chapter reports on the findings of my experimental vignette study on lay people's judgments about vignettes involving the Non-identity problem. In section 1, I sketch the philosophical background behind my research questions concerning the No-Difference View. Section 2 explains why I investigated the role intuitions about disability and quality of Life in thought experiments about the Non-identity problem. Section 3 explains my methodological choices regarding vignette design, question design, survey flow, sample population, and statistical analysis. I then interpret and discuss the results of our data analysis in Section 4. I end with some remarks on the limitations of our study and some opportunities for further research (section 5).

1. No-difference view

In his 1976 paper *Rights, Interests, and Possible People,* Parfit asks us to consider two cases of women who want to become pregnant but risk conceiving a disabled child. These are the original cases:

> ***The Two Women***. The first woman is one month pregnant, and is told by her doctor that, unless she takes a simple treatment, the child she is carrying will develop a certain handicap. We suppose that life with this handicap would probably be worth living, but less so than a normal life.
> We next suppose that there is a second woman who is about to stop taking contraceptive pills so that she can have another child. She is told that she has a temporary condition such that any child she conceives now will have just the same handicap; but that if she waits three months she will then conceive a normal child. (Parfit 1976, 373)

Parfit explains that the only difference between the two cases is that in the first case the non-disabled and the disabled child are the same child, while in the other they are not. What makes the second case different from the first is that it is identity-affecting.

As we saw in the previous chapter, Parfit and some others believe that most people generally hold a No-Difference View, which entails that they see no moral difference between the two cases. He believes that an explanation of the Person - Affecting (or Identity-Affecting) Difference does not alter people's views.[38] This discrepancy between the No-Difference View and the Identity-Affecting Difference lies at the heart of the Non-identity problem. It is crucial to understand that this discrepancy, and thus the problem status of the Non-identity problem, is asserted on the basis of at least one empirical claim. This is the claim that most (Parfit) or perhaps all (Kuhse and Singer 1985) people who are confronted with cases such as those above judge them to be morally similar.

I believe this empirical claim should be tested. Based on my experiences of explaining the Non-identity problem and the No-Difference View, I suspect the claim may not be true. I think that the No-Difference View is not as widely shared as Parfit *cum suis* assume. Instead, I hypothesize that most people would see *some* moral difference between the cases. I also expect they will maintain slightly different intuitions on both cases after explaining the difference between the cases. Note that I hypothesize a quantitative, not a qualitative difference, in moral judgment. I do not expect people to suddenly think of the behaviour in the second case as morally right or unproblematic after they realize what the difference is. I think the respondents would find the behaviour of both women problematic, but that of the second woman a bit less so.

Our study is not the first one to experimentally investigate aspects of the Non-identity problem. Kopec & Bruner (2022) and Doolabh et al. (2019) had similar hypotheses that were confirmed in their studies on (partially) the same subject. Kopec and Bruner hypothesize that the No-Difference View is not generally shared by the public (Kopec and Bruner 2022, 1). They base this hypothesis on their teaching experience, observing that many of their students "do see a substantial moral difference between identity-affecting cases and the parallel cases that don't change who comes into existence." (ibid., 2) Doolabh and colleagues want to understand the moral intuitions of the general public about the moral relevance

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[38] In the previous chapter, I spoke of the Identity-Affecting Difference. In this chapter, I also talk about Person-Affecting Choices as opposed to choices that do not affect which person comes into existence. Those point to the same difference. Identity-affecting choices are simply those choices that are not person-affecting, and person-affecting choices are those that are not identity-affecting.

of the Non-identity problem. They hypothesize that most participants would not be influenced by the non-identity problem prior to an explanation of it, but respond in a variety of ways after they had understood the problem. However, they also expect that "the non-identity problem would play a relatively small role in participants' decision-making compared to other ethical considerations" (Doolabh et al. 2019, 5). I already explained how the methods and results of this study relate to theirs in the previous chapter of this thesis.

2. Disability, deafness, and quality of life

A novel element of this study that was not yet explored in those discussed above pertains to the role of disability in Parfit's thought experiments. He describes disability as a cause of life being less worth living than a life without disability. This does not mean he thinks all disabilities are of such a nature, of course. But it does seem to contain the assumption that disability is a good example of a cause that leads to a diminished quality of life. In doing so, Parfit seems to take for granted a 'bad-difference view' of disability. He is not alone. Elizabeth Barnes informs us that "it is often taken for granted within philosophy that some version of the bad-difference view is the default or common-sense position" (Barnes 2016, 70). This part of the study investigates (1) the impact of this assumption on people's intuitions about the person-affecting/non-person-affecting choices and (2) the intuitions of those who have experience with disability themselves.

Views on disability and quality of life

This part of the study investigates the relevance and impact of assumptions about and experience with disability on people's moral intuitions related to the difference between identity-affecting choices and choices that do not change which person comes into existence. This is important, because as Elizabeth Barnes remarks, "if we have good reasons to believe that disability is the subject of prejudice and stigma, then it seems we also have good reason to think our intuitions about disability aren't going to be particularly reliable" (Barnes 2016, 72).

In the Two Women case presented in the previous section, Parfit talks about disability (he uses the term 'handicap') as the cause of the child having a life less worth living than a 'normal' life. He does so in multiple cases in *Reasons and Persons* as well, such as the Medical Programmes cases and The Wretched Child. But this does not seem to be a crucial element of Parfit's point. That point is just about the difference between identity-affecting and non-identity affecting choices. So we might agree with Barnes that "Parfit's assumptions about the badness of disability seem entirely orthogonal to the interesting issues of the non-identity problem" (Barnes 2016, 70). In that case, disability does not seem an essential element of the non-identity problem. Including disability in a vignette or thought experiment only complicates the vignette and leaves room for a distortion of the answers of respondents. As Eli Clare remarks, "The act of choosing disability in the white Western world is never neutral, simply one choice among many, but rather pathologized, shamed, or sensationalized. In contrast, un-choosing [a term he prefers over 'avoiding'] disability is celebrated and framed as a collective imperative" (Clare 2017, 130).

I aim to find out whether the inclusion of the term 'disability' in a bad-difference way has an impact on the way in which the explanation of the identity-affecting difference influences people's judgments. I will do so by comparing the answers people give to questions on vignettes close to Parfit's original thought experiment of the Two Women to a set of vignettes that are different from these in just one way: they do not mention disability as the cause of the life of the child being less worth living. If the disability-part is truly orthogonal to the interesting aspects of the non-identity-problem, there should be (almost) no difference in people's moral intuitions between cases.

Additionally, I will inquire people's views on the impact of being disabled on a person's quality of life as a way to see to which extent people actually hold the bad-difference view (Brillhart, Jay, and Wyers 1990; Iezzoni et al).[39] I also expect to find a positive correlation between holding negative views on disability and more outspoken (for example, blaming) intuitions in response to the vignettes that most closely resemble Parfit's original thought experiment.

Experience with and views on deafness and quality of life

The bad-difference view discussed above may not be as common-sense or widespread as Parfit implicitly seems to assume. Scholars in the field of disability studies and critical disability theory generally reject the bad-difference view of

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[39] Iezzoni and colleagues conducted a survey on physicians' perceptions of people with disability among currently practicing physicians in the United States, and found that 82% of them reported that "people with significant disability have worse quality of life than nondisabled people" (Iezzoni et al. 2021).

disability because it is not in line with the lived experience of many disabled people. Harriet McBryde Johnson is strongly opposed to saying that disabled people are simply worse off, arguing that there are too many variables at play to make such a general claim (H. M. Johnson 2006).

Empirical research also shows that people with a first-hand experience of disability often adhere to different views and report about their well-being in much more positive ways than non-disabled people would predict. Many studies found that most people with various disabilities are not less happy, or do not report a lower quality of life, than most non-disabled people (Bagenstos and Schlanger 2007 give an overview of reports of well-being of disabled people; Albrecht and Devlieger 1999 conducted dozens of interviews and found that "54.3% of the respondents with moderate to serious disabilities reported having an excellent or good quality of life" (p. 977)).[40]

In order to investigate to what extent the intuitions of those with a specific disability differ from others, I introduce another element to our study in the form of a set of vignettes about deafness. I chose deafness as a concrete disability in our study for various reasons. The fact that it is relatively common allowed me to find participants who have first- or second-hand experience with deafness with relative ease. It also meant that participants are more likely to have a sufficient grasp of what it entails and what their views about it are (as compared to very rare diseases). Finally, I wanted to have the opportunity (which I ended up using) to extend the group of (congenitally) deaf people to everyone with hearing impairments if it turned out to be difficult to find enough deaf people for our survey.

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[40] They conducted this research in order to investigate the so-called 'disability paradox': "Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence?" (Albrecht & Devlieger 1999, 977). I am not the first to observe that when disabled people describe their quality of life as good, the need to 'explain away' their testimony often arises. The ‘disability paradox’ is an example of this, and so is the adaptive preference model, which “purports to give a compelling explanation of why a person might alter their preferences toward something which is sub-optimal” and is often applied to disability (Barnes 2009, 1). Following Barnes, I am cautious not to adopt narratives as this one too easily, and believe that at least our default response to such first-person testimonies should be to accept them as valid.

I am aware of the fact that there are deaf people, such as some advocates of 'deaf pride', who do not view deafness as a disability (Barnes 2016, 34). In order to find out the stances of our research participants on this matter, one of the questions included at the end of the survey is 'Do you consider deafness a disability?'[41] I also investigate whether the answer to this question is significantly related to people's answers to the vignette questions. Finally, I included a remark on language, disability and deafness in the debriefing. This stated that the researchers do not presume a connection between a lower quality of life and disability. By this I meant that I do not think that a lower quality of life is intrinsic to disability, but my formulation in the debriefing may have been somewhat too strong. I do not wish to mimimize the extent in which ableism, not the condition of disability itself, leads to a lower quality of life for many people with disabilities. The debriefing text also acknowledged that many people in the Deaf community do not regard themselves as disabled or deafness as a disability.

Inspired by insights from philosophers such as Miranda Fricker and disability ethicists such as Jackie Leach Scully, I see it as a matter of epistemic justice to take the intuitions of deaf people into account when conducting an experimental philosophy study that concerns them (Fricker 2007; Scully 2008). I suspect that their first-hand experience of deafness may significantly inform the intuitions of deaf people about vignettes related to deafness, in the sense that they will be less outspokenly negative. I also think that this is related to their views on the impact of deafness on a person's quality of life.

This study also investigated whether knowing one or more deaf people might influence people's intuitions about the vignettes and beliefs about the relation between deafness and quality of life. I expected to find that this group has somewhat less negative intuitions and beliefs than people with no experience with deafness. I realized that some other characteristics of the participants might also inform their views and moral intuitions. For these reasons, this study also

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[41] Alison Kafer struggles with a similar question in developing her crip theory, wishing to account for "those who do 'have' illnesses or impairments, and why might be recognized by others as part of this 'disabled we,' but who do not recognize themselves as such" (Kafer 2013, 14). As a preliminary reply, she argues that it does not matter much whether such people claim the term 'disability' or not, because "much as feminist activism benefits people who want no part of feminism, disability studies and activism ideally benefit people who are not interested or invested in either." (ibid.)

investigated whether (1) men and women and (2) parents and non-parents differ in their opinion of the behaviour of the women in all three kinds of vignettes.

3. Methodology

Vignette design

Following Fitz and colleagues, I used the contrastive vignette technique for our study design (Fitz et al. 2014; Burstin, Doughtie, and Raphaeli 1980). As they explain, this approach entails that "minimally contrastive versions of a master vignette are presented to participants who then answer identical questions regarding their attitudes towards issues presented in the vignette." (Fitz e.a. 2014, 3). This approach allowed a focus on the differences in moral judgments between groups. Participants were randomly assigned to one of three sets of vignettes without knowing that vignettes with other conditions exist. The three kinds of vignettes will now be introduced in full.

Subjects were asked to consider almost the same cases as those Parfit asks people to consider in his 1976 paper. Only a few adjustments to the cases were made:

- I replaced 'handicap' by 'disability'. 'Handicap', a term meant to point out that someone is limited or held back by their condition, is a term that has become quite uncommon in the English language. This means that 'disability' is a term that more people will be more familiar with. Perhaps this has to do with the increasing influence of the social model of disability, which argues that 'disability' can be used not only for the impairment itself, but especially for the ways in with social and political contexts influence people's experience of it.[42] Parfit writes that the handicap leads to a life less worth living than a life without this handicap. I do not know whether this is the case because of medical factors, social ones, or both – and we do not need to know. I follow Barnes in using 'disability' as a broad term (Barnes 2016, 53).

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[42] On the closely-related distinction between disability and impairment, Alison Kafer remarks: "asserting a sharp divide between impairment and disability fails to recognize that both impairment and disability are social; simply trying to determine what constitutes impairment makes clear that impairment doesn’t exist apart from social meanings and understandings" (Kafer 2013)

- 'Normal' was replaced by 'non-disabled' to make the vignettes maximally contrastive.
- 'Simple treatment' was replaced by 'harmless, simple treatment' to ensure that the potential harm to woman does not influence answers.
- In the second case, 'another child' was replaced by 'a child', since it seems irrelevant to the vignette whether the woman already has other children.
- I gave the women names, because I hypothesized that distinct names might make it easier for participants to distinguish between the pre- and post-conception cases than descriptions such as 'woman 1' and 'woman 2'. Similarly, naming them might make it easier for people to recall after the explanation that they were answering questions about the same vignettes as before the explanation.
- The sentence 'We suppose that life with this handicap would probably be worth living, but less so than a normal life' was changed into 'This disability leads to a lower quality of life'. This was done to minimize the risk of variation in respondent's interpretation of 'probably'. Moreover, speaking of 'quality of life' is less contrived and more readable than 'less worth living'. Parfit himself expresses himself in favour of the phrase 'quality of life' in *Reasons and Persons* (Parfit 1984), so we think it is safe to assume that the phrase is apt in this context.[43]

We then end up with the following vignettes, to which I will continue to refer with 'Parfitian vignettes':

> **Parfitian vignette – post-conception (not identity-affecting)** Charlotte is one month pregnant, and is told by her doctor that, unless she takes a harmless, simple treatment, the child she is carrying will develop a disability. This disability leads to a lower quality of life. *Continuation after the first question:* Charlotte decides not to take the treatment. Her child is born disabled.

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[43] "I assume that one person can be worse off than another, in morally significant ways, and by more or less. But I do not assume that these comparisons could be, even in principle, precise. I assume that there is only rough or partial comparability. [...] 'Worse off' could be taken to refer, either to someone's level of happiness, or more narrowly to his standard of living, or, more broadly, to the quality of his life. Since it is the broadest, I shall often use the phrase 'the quality of life'." (Parfit 1984, 357-358)

> **Parfitian vignette – pre-conception (identity-affecting)** Lisa is about to stop taking contraceptive pills so that she can have a child. She is told that she has a temporary condition such that any child she conceives now will have a disability; but that if she waits three months her then conceived child will be non-disabled. This is the same disability as the one in the previous case, so this disability leads to a lower quality of life. *Cont.:* Lisa decides not to wait. Her child is born disabled.

Secondly, a set of vignettes was designed in which disability is left out as a cause of a diminished quality of life. Except for this change, the vignettes are similar to those above. I will refer to these vignettes as the Pure vignettes, because they are meant to exclude disability as a possible element that disrupts people's moral intuitions related to the Non-identity problem. Those are the vignettes I also used in the previous chapter.

> **Pure vignette – post-conception (not identity-affecting)** *Ma*ry is one month pregnant, and is told by her doctor that, unless she takes a harmless, simple treatment, the child she is carrying will later have a lower quality of life. *Cont.:* Mary decides not to take the treatment. Her child later lives a life worth living, but less so than when she would have taken the treatment.

> **Pure vignette – pre-conception (identity-affecting)** Josephine is about to stop taking contraceptive pills so that she can have a child. She is told that she has a temporary condition such that any child she conceives now will later have a lower quality of life; but that if she waits three months the quality of life of her then conceived child will not be affected. *Cont.:* Josephine decides not to wait. Her child later has a lower quality of life.

Thirdly, I designed a set of vignettes in which deafness, as a concrete disability, is said to be the result of the women's choices. Quality of life is not mentioned in those vignettes, the 'Deaf vignettes':

> **Deaf vignette – post-conception (not identity-affecting)** Adila is one month pregnant, and is told by her doctor that, unless she takes a harmless, simple treatment, the child she is carrying will be born deaf. *Cont.:* Adila decides not to take the treatment. Her child is born deaf.

> **Deaf vignette – pre-conception (identity-affecting)** Susan is about to stop taking contraceptive pills so that she can have a child. She is told that she has a temporary condition such that any child she conceives now will be born deaf; but that if she waits three months her then conceived child will be hearing. *Cont.:* Susan decides not to wait. Her child is born deaf.

Survey questions and flow

Participants were randomly assigned to one of three variants of the survey. They were thus presented with the Parfitian, Pure or Deaf vignette set. Otherwise, the structure and questions were the same for everyone.

After consenting to participate, participants were first presented with some demographical questions. They were then presented with the first vignette, the non-person-affecting or after-conception variation. In order to get a robust view of the moral intuitions of participants with regard to the prospective mother's behaviour, they were asked four different questions about it. Each question matches a deontic category that has been considered relevant to philosophical thinking about Parfitian issues before.[44] After reading the first part of the vignette, participants answered the following question: 'To what extent do you agree with the following statement: '[The woman] should [take the treatment/wait]?' This first question asks participants to think about which choice they believe the women should make, just as Parfit asks this question to his readers in the Two Women cases and similar ones, such as that of the Medical Programmes (Parfit 1984).

The Likert-scale answer options range from strongly agree (1) to strongly disagree (7). The participants then read which choice the woman made and what the consequence was. They were asked to answer three additional questions, presented to them in randomized order. Parfit (1976, 1984) thinks "it would be wrong for [the] woman" to make the choice that results in the birth of a disabled child. Thus, we asked: 'To what extent is what x did wrong or right?' (very wrong (1) to very right (7)).

The survey also included a question about harm, because it is exactly the presumed difficulty of talking about harm in identity-affecting cases that makes the Non-identity problem into a problem. According to Parfit, we cannot explain what is wrong about the identity-affecting case by appealing to our standard

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[44] When analyzing my data, I also compared the means of answers between those four different questions. The means of the four deontic categories turned out to be very similar, with the exception of the statement 'x should [...]', where the mean is lower. A difficulty in interpreting this result lies in the fact that the structure of the first question is different from that of the other three. Indicating to what extent you agree or disagree with a given statement is different from answering a more direct question. I do not have alternative explanations for this result.

comparative account of harm, i.e. by saying that the child is worse off than it otherwise would have been. The question is: 'To what extent is what x did harmful or beneficial to her child?' (very harmful (1) to very beneficial (7))

Finally, it seems that 'blame' is a relevant deontic category as well. Parfit explains that 'blame' is not a redundant category because it does not always overlap with 'harm' in our ordinary understanding of making someone worse off: "we can deserve to be blamed for harming others even when this is not worse for them" (Parfit 1976: 371). Thus, participants were asked: 'To what extent is x blameworthy or praiseworthy because of what she did?' (very blameworthy (1) to very praiseworthy (7)).

I wanted to allow for the possibility that some of these categories would come apart because of some previous findings in experimental philosophy. For instance, Inbar and colleagues demonstrate that harm and blame can come apart, by designing studies with vignettes "where no harm is caused or intended, yet individuals are nonetheless deemed worthy of blame." They found that this is specifically the case when those individuals "engage in actions that enable them to benefit from another's misfortune" (Inbar, Pizarro, and Cushman 2012). However, because the mothers in my vignettes are not really benefiting from their choices, I did not expect to find similar results. Indeed, when analysing my data the means of the four deontic categories turned out to be very similar. The exception is the statement 'x should [...]', where the mean is lower. A difficulty in interpreting this result lies in the fact that the structure of the first question is different from that of the other three. Indicating to what extent you agree or disagree with a given statement is different from answering a more direct question. I do not have alternative explanations for this result.

Participants continued to read the second vignette, the identity-affecting or before-conception variation. All questions were the same. After having answered the questions for both vignettes, participants were asked to consider the explanation of the differences between the vignettes. They received a modified version of the explanation Parfit gives in his 1976 paper:

> **The Explanation** Did you consider that the choice of Charlotte might be less straightforward than that of Lisa? We might ask whether Charlotte has really affected her child for the worse by refusing to wait. It seems to be the case that her child could not claim, when it grows up: 'If my mother had waited, I would have been born three months later, as a non-disabled child.' If Lisa had waited, the child would not have been born at all; she would have had a different child. The child is not worse off than it would have been,

> because it wouldn't otherwise have existed. So the difference between the cases of Charlotte and Lisa is the following: in Charlotte's case, her choice influences one and the same child. In Lisa's case, her choice influences which child exists.[45]

As explained before, this study was also intended to find out whether people answer differently after they have been confronted with an explanation of the difference between the vignettes. Therefore, after the explanation participants were presented with exactly the same set of vignettes as before the explanation. The participants were aware that this was the case. They were explicitly encouraged to take some time to reflect on the cases and to decide whether the information they read made any difference for their moral judgments.

After the vignettes, participants answered a few additional questions on deafness and disability. They were asked whether they were congenitally deaf, and whether they knew anyone who is deaf (the answer options ranged from 'no' to 'more than three people'). They were asked to indicate whether they consider deafness as a disability ('yes'/'no'/'I don't know'). The final two questions asked: 'What effect do you think [deafness/being disabled] generally has on a person's quality of life?' and could be answered on a scale from 'very negative' (1) to 'very positive' (7).

Finally, participants were offered participants a debriefing in which I explained the aims and set-up of the study, as well as some remarks on language, disability and deafness (see the Appendix for this debriefing). If they wished, participants could leave a comment, question or remark before completing the survey.

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[45] Original explanation: "But if the second woman does deliberately have a handicapped child, has she harmed him - affected him for the worse? We must first ask: "Could he truly claim, when he grows up, 'If my mother had waited, I would have been born three months later, as a normal child'?" The answer is, "No." If his mother had waited, he would not have been born at all; she would have had a different child. The second woman's handicapped child is, then, not worse off than he would otherwise have been, for he wouldn't otherwise have been. Might we still claim that in deliberately conceiving a handicapped child, the woman harms this child? We might perhaps claim this if the child's life would be not worth living-would be worse than nothing; but we have assumed that it would be worth living. And in this case being handicapped is the only way in which this child can receive life."

Survey format

Sample population & size

Participants were selected and paid through the online platform Prolific. When they signed up for our study, they were redirected to Qualtrics to fill out the survey. Participants could only participate in the study if they were at least 18 years old and proficient in reading English. The study excluded professional philosophers, because the focus was on participants not yet familiar with the non-identity problem and Parfit's thinking. Participants were not excluded based on their level of education. The majority of the participants (147/200) has had at least some college education.

One of the aims of this study was to compare the differences in answers between two groups of people: deaf and hearing people. However, I was unable to select deaf participants by using Prolific's prescreening criteria. Moreover, I expected that finding a sufficient amount of deaf participants who are a representative sample of the population in other aspects (e.g. age, gender, parental status) would be very challenging. Thus, I decided to select two groups of people based on the Prolific criterium 'long term health condition or disability: hearing impairment'. I set an ideal sample size of 100 participants who did not meet this criterium, i.e. who did not have hearing impairments, and 100 who did. Because participants would be distributed among three variants of the vignette survey, I aimed at a minimum sample size of 60 participants for the hearing-impaired group. After running the survey for a few weeks, I ended up with 140 hearing participants and 60 hearing-impaired participants. This means that each variation of the survey (Parfitian/Pure/Deaf) was filled out by 46 or 47 hearing participants and 20 hearing-impaired participants. In the survey itself, people were asked whether or not they are congenitally deaf. Seven of the 60 participants with hearing impairments indicated that they were.

Statistical analysis

Data were analyzed using SPSS. It was assumed that the answers on the 7-point Likert scales can be treated as continuous variables. It was always checked whether variances were statistically different or not. The responses were compared with appropriate statistical tests. Often, I compared the outcomes of parametric and non-parametric tests, especially when sample sizes were rather small. The following parametric tests were used: paired samples t-test (for comparing within-subject answers, such as before/after the explanation or on vignettes with behaviour before/after conception), independent samples t-test and ANOVA. The non-parametric equivalents I used are, respectively: Wilcoxon signed-rank tests, Mann-Whitney U tests, Kruskal-Wallis tests. Unless mentioned otherwise, non-parametric testing did not yield different results with regards to the significance of the differences. For categorical data (i.e. considering deafness a disability compared between hearing and between groups that know various amounts of deaf people), I used a Pearson's chi squared test.

As a multiple testing corrective, the False Discovery Rate method ((Benjamini and Hochberg 1995) was used. I found that p-values smaller than 0.005 survive this FDR correction. Thus, only those p-values < 0.005 will be reported as being significant. The data were uploaded to an Open Science Framework page, where readers can consult them.[46]

4. Results and discussion

No-difference view

It was first investigated whether people's opinions on the women's behaviour in the vignette differ based on whether the behaviour described takes place before or after conception. As explained before, I expected a slight difference for all four questions – specifically, lower scores for the after conception-vignettes. The bars on the left of every set in Figure 1 show the means of all (n = 200) answers to the four questions of the post-conception and pre-conception vignettes before the explanation.

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[46] Link OSF: https://osf.io/n32yu/

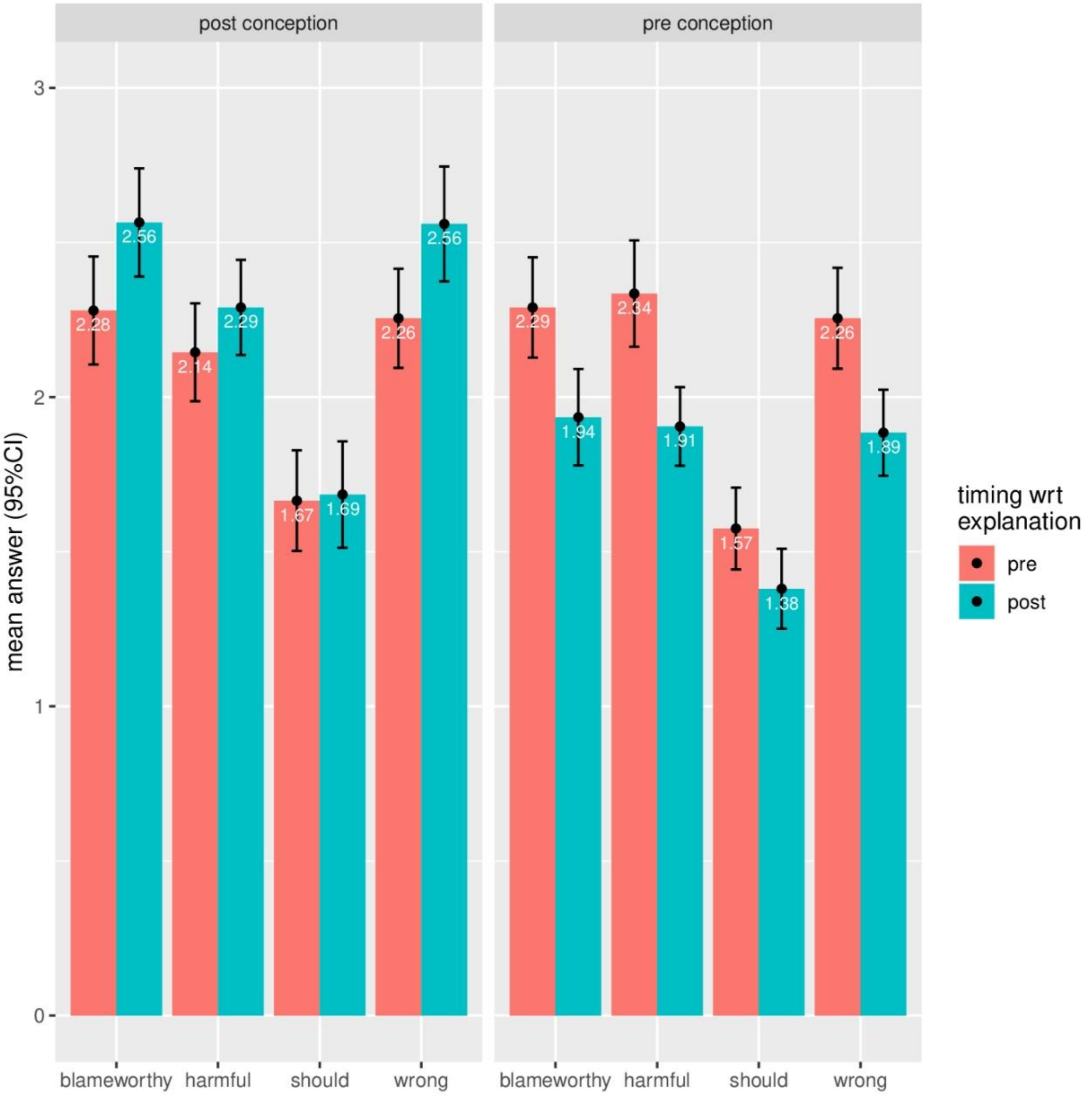

Figure 1- Mean answers of all participants before they were presented with the explanation of the Person-Affecting Difference © Erik Fransen

A paired samples t-test that paired each pre- and post-conception question gave the following p-values: *p* 0.002 (x should, t 3.10), 0.000 (wrong, t 8.23), 0.000 (harmful, t 6.12) and 0.000 (blameworthy, t 8.42). A Wilcoxon signed rank-test yielded similar results. The results were similar when studied per vignette condition.

This means that in all mean comparisons, the mean of the answers to the pre-conception vignettes were significantly ($p < 0.005$) lower (which means more outspoken) than those of the post-conception vignettes. This means that, in this data set, people tend to have more outspoken, negative judgments about the behaviour of a woman who is not yet pregnant than about that of a pregnant woman.

This means two things with regards to the No-Difference View. It does confirm our hypothesis that the identity-affecting difference actually makes a moral difference for people. But, strikingly, the order is completely different from what was expected. Based on own experience and the findings of Kopec and Bruner, I expected people to attach a little less moral import to the identity-affecting, pre-conception cases. I thus expected the scores for the pre-conception vignettes to be somewhat higher (i.e. less outspoken) than those for the post-conception vignettes, but this is consistently not the case.

It is unclear how this result should be explained. There is a small possibility that it has to do with the difference between what the women are supposed to do: taking a harmless treatment in the post-conception case, and waiting three months in the pre-conception case. Even though the word 'harmless' was deliberately included to mitigate this effect, people may have taken account what they perceived as potential risks of the two options. They may have judged milder on the treatment case because there might be a risk involved for the mother, whereas waiting sounds quite risk-free. Two comments at the end of the survey points in this direction: "I think Mary should be blamed a little less than Josephine, because she might be scared of taking that medication, maybe thinking it was harmful" and "[..] the responses do not allow for the mother's confidence in the treatment. She may have had very good reason to refuse; perhaps worries about the safety of the drug being administered."

Additionally, I investigated whether the opinions queried above were influenced by an explanation of the identity-affecting difference. The difference in the means of all (n = 200) answers to the four questions of the vignettes before the explanation on the one hand, and those after the explanation on the other, is made visible in Figure 1.

A paired-samples t-test that compared each pre- and post-explanation question gave the following p-values for post-conception vignettes: 0.772 (x should, t 0.29), 0.000 (wrong, t 4.56), 0.003 (harmful, t 3.00) and 0.000 (blameworthy, t 4.76), as well as the following p-values for pre-conception vignettes: 0.012 (x should, t -2.54), 0.000 (wrong, t -5.49), 0.000 (harmful, t -5.48) and 0.000 (blameworthy, t -5.47). A Wilcoxon signed ranks-test yielded similar results. The p-values of the paired-samples t-test that compared the pre- and post-conception questions after the explanation are as follows: 0.369 (should, t 0.90), 1.000 (wrong, 0.000), 0.042 (harmful, t -2.05) and 0.909 (blameworthy, t -0.11).

In order to be in line with Parfit's thinking, the explanation of the difference between post- and pre-conception cases should not alter people's judgments on the pre-conception cases. I expected, however, that there would be at least a small difference, in the sense that people would judge somewhat milder (i.e. higher scores) after the explanation. We found that almost all mean answers on the pre-conception vignettes were significantly higher (i.e. less outspoken) after the explanation. This means that our hypothesis is confirmed.

I want to note a peculiar additional result. As we saw above, before the explanation, people judge significantly more harshly about the pre-conception cases than the post-conception cases. However, after the explanation the pattern is less clear: it depends on the question whether people have more outspoken opinions on the pre- or post-conception cases. Only one question was answered differently: people were significantly more outspoken about the harmfulness of the behaviour in post-explanation, post-conception cases than in post-explanation, pre-conception cases.

Disability and quality of life

Investigating the No-Difference View is only what half of this study is about. The second part, of which the findings will be discussed now, is concerned with the influence of concepts such as 'disability' and 'quality of life' on people's intuitions about identity-affecting choices. I wanted to find out which impact the elements of disability and quality of life in Parfit's thought experiments have on people's judgements about them. As explained before, this study contained three kinds of vignette conditions: the Parfitian, Pure, and Deaf vignettes. I expected a difference in answer scores between the Parfitian vignettes on the one hand and the Deaf and Pure vignettes on the other. In particular, the expectation was that people blame the the women in the Parfitian vignettes somewhat more (lower scores) for her behaviour than the women in the Pure and Deaf vignettes.

The means of the answers between the three tracks - Parfitian (n=67), Pure (n=66) and Deaf (n=66) – were compared using ANOVA. In a quarter of the cases, the differences in answer means were significant ($p < 0.005$). The order of differences is the same for almost all variances: the scores are the lowest (i.e. most outspokenly blaming/harmful) for the Parfitian vignettes, followed by the Deaf vignettes, and highest in the Pure vignettes.[47] A nonparametric test, the Kruskal Wallis Test, yielded similar results.

The vignette condition did not significantly influence the answers to any of the precon/preex vignette questions, while it did influence one (harm: 0.000, F 10.6) of the postcon/preex and one (harm: 0.000, F 6.43) postcon/postex questions, as well as two answers to the precon/postex vignette questions (harm: 0.000, F 10.73; blame: 0.000, F 1.31). For at least those questions it seems justified to conclude that the conditions do influence people's answers, such that a Parfitian vignette can be associated with lower scores than the Deaf vignette. This result is in line with the hypothesis, but it also seems to show more than was predicted. Namely, people judged the behaviour described in both of these tracks to be more harmful than that of the prospective mothers described in the Pure vignettes, in which neither deafness nor disability was mentioned (instead, a diminished quality of life was mentioned). This might imply that whether or not disability is mentioned in the vignettes has a bigger impact on people's moral evaluation than whether or not quality of life is mentioned. However, the results are far from conclusive since they are only really significant in a subset of the vignette-question combinations.

Experience with deafness or hearing impairments

As explained in the introduction, some participant characteristics might be salient to investigate in our vignette study. Here, I shortly discuss the potential correlation between people's experience with deafness or hearing impairments and their judgments about the vignettes. In the Appendix, I also discuss gender, parental status, and knowing deaf people. Answers to the vignette questions were compared between congenitally deaf (n=7) and hearing (i.e. not hearing-impaired) participants (n=140). Because the number of congenitally deaf participants is so small[48], it was only possible to use a non-parametric test, the Mann-Whitney U Test. This test yielded no significant results (i.e. every p-value > 0.005).

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[47] The minor exception is postcon/postex/blame: there the Deaf mean is 2.11 and the Parfitian mean 2.12.

[48] Moreover, it is unfortunately even less reliable because the congenitally deaf people are not equally represented in each vignette condition – 5 of them were presented the Parfitian one, and the Deaf and Pure ones were each presented to only 1 of them. – I used exact significance instead of asymptotic significance due to this partly extremely small sample size.

Because of the small number of congenitally deaf participants, I also compared the results of hearing-impaired (n=60) and not hearing-impaired (n=140) participants. An Independent Samples T-test did not detect any significant differences, neither across different vignettes, nor within specific vignettes. The non-parametric Mann-Whitney U Test yielded similar non-significant results.

The hypothesis was not confirmed. I did not find a significant difference between the answers of deaf and hearing people. Moreover, there is no significant difference between the answers of hearing-impaired and hearing (i.e. not hearing-impaired) people.

5. Limitations and further research

It is in order to note few limitations of this research and make some suggestions for other studies in experimental philosophy of medicine that deal with identity and/or disability.

A first limiting aspect of this study is that it was unable to incorporate aspects of decision-making under *uncertainty and risk*. Dealing with probabilities and chances of negative outcomes is, however, essential to almost any real-life case of procreative choices and decisions involving disability and quality of life. The deterministic character of the vignettes arose out of necessity to keep them as simple as possible, but perhaps it is removed too far from reality to make the results very reliable or meaningful for discussions about people's opinions about real cases. I believe that the primary focus of my research, the differences between groups and vignette conditions, is not affected by this tension. Nonetheless, a vignette study that focuses on elements of uncertainty and risk would provide valuable additional insights in people's moral reasoning on cases in creation ethics.

A second element that deserves further (empirical) study is constituted by the assumptions about identity behind our study. In order to stay close to the origin vignettes and Parfit’s ideas behind them, the genetic understanding of identity they represent was not put into question. The reasoning behind the Non-identity problem is based on understanding the moment of fertilization, when the fusion of genetic material occurs, as the cut-off point for identity-affecting choices. All choices made after fertilization can only influence the future child in a non-identity-affecting way, the reasoning goes, as opposed to choices made before fertilization. However, the assumption that identity is strongly connected to genetic make-up might not be as widely shared as Parfit and most of the scholars working on reproductive ethics seem to believe (cf. section 4 of previous chapter). As said before, I think it would be worthwhile to experimentally investigate people's intuitions about identity and conception. These intuitions might vary. Perhaps they are also culturally dependent.

Relatedly, I did not have the time and the room in this study to engage with potential *cultural differences*. The negative programme of experimental philosophy has been providing interesting insights in the extent in which supposedly universal assumptions turn out to be culturally determined.

With regards to the *sample population,* I would have preferred a much bigger sample of congenitally deaf participants. Because it was hard to reach an otherwise diverse group of deaf people, however, I opted to broaden the group to those who are in some way and to some extent hearing-impaired. Of course, however, this is really not the same. There is probably a wide variety with regards to the nature of the impairment and the period of time people have been living with it. It might be interesting to conduct similar studies with other groups of participants, particularly with disabled people. Moreover, additional studies could be designed with a focus on other physical and/or mental disabilities.

Finally, potential *survey design flaws* should be pointed out. The order of the vignettes may have had an undesired influence on the answers of the participants. To avoid confusion, the post-conception vignette was always followed by the pre-conception vignette. However, I cannot exclude the possibility of order effects.

As some attentive participants pointed out in the comment section, I made a typo in the explanation of the difference between the Deaf vignettes. Instead of 'Did you consider that the choice of Susan might be less straightforward than that of Adila?' I wrote 'Susan' twice. However, it is unlikely that this made a noticeable difference in people's opinions, as the rest of the explanation made clear I was talking about Adila and Susan.

It needs to be remarked that perhaps the term 'quality of life' is not ideal, even though we deemed it to be better than alternatives such as 'a life worth/not worth living'. The term may be understood differently by people depending on their backgrounds and familiarity with the term.

Comments and qualitative research

In the open comment section, some participants remarked that they found it difficult to convey the nuance of their intuitions in this survey format ("it is difficult to make an assessment without all the information', 'the answer scheme makes it difficult to respond with nuance", "I wasn't able to answer properly to the last question because the quality of life mainly depends on how a person defines his life"). Someone else pointed out that "women have complete rights over their own bodies and it is not up to anyone else to judge how they behave". I admit that the abstract, somewhat contrived nature of the vignettes may have made it difficult for participants to give answers to their own satisfaction. Moreover, I am fully aware that this study only measured the strength of people's judgments, not the reasons behind them.

As was discussed in the previous chapter, qualitative research may be a promising avenue to find out more about the thoughts behind people's opinions. Such research has been conducted rather sparely by experimental philosophers. A qualitative follow-up to this particular study might take the form of focus group conversations. From these conversations, we might learn more about the elements and contextual factors people consider to be relevant when judging cases such as those described in our vignette. For example, perhaps some respondents might also want to know whether the woman in the Deaf vignettes is deaf herself, because this might mean the child could more easily be introduced to Deaf culture. Or perhaps people's conceptions of health, rather than those of disability, influence people's moral judgments.[16] As was mentioned before, worries about the safety of the treatment might also be considered relevant.

6. Conclusion

The results of this experimental study are relevant for philosophy of medicine both from an epistemic and a moral perspective. Its epistemic goal was to investigate the prevalence of some intuitions that underpin the theories of Parfit and others concerned with benefiting future generations. I found that the non-philosophers in our sample do not hold a No-Difference View. Instead, they attach more moral import to identity-affecting, pre-conception choices than to those made by a woman who is already pregnant. The mean answers on the pre-conception vignettes were also found to be significantly higher after the explanation of the difference between pre- and post-conception cases. Those results do not only diverge from Parfit’s intuitions, but also from previous experimental findings

(Kopec and Bruner 2022; Doolabh et al. 2019). The findings are important for those in procreative ethics who use the Non-identity problem to analyse practical challenges, as well as for those who use it as an obstacle for certain theories or concepts.

Similar epistemic concerns informed the second part of our study. I critically engaged with the use of *disability* in thought experiments related to the famous Non-identity problem and found that aspects of the stories which Parfit seems to deem morally irrelevant are actually considered to be relevant by other people. In particular, I found that both Parfitian vignettes (about disability in general) and Deaf vignettes (about deafness) are associated with lower scores than the Pure vignette, in which neither deafness nor disability was mentioned. Hopefully, this part of our study is one of the first of many studies in experimental philosophy of medicine that deal with disability.

Furthermore, this second part does not only have a general epistemic benefit of showing that various populations might have different intuitions than Parfit and others have been assuming. It also has moral value, because the voices, opinions and intuitions of various of these groups - disabled people especially - are still underrepresented in philosophy. Many thought experiments on identity-affecting choices feature disabled people. Following the disability activists' principle 'nothing about us without us', I tried to investigate the intuitions of deaf and hearing-impaired people themselves. This study can thus be seen as part of a broader philosophical project that strives towards epistemic justice. As Miranda Fricker argues, this means that we need to be aware of how their social identity might impact the judgments of all involved differently.

With regards to the participants, I found no significant difference between the intuitions of deaf and hearing people, and almost no significant differences between those of hearing-impaired and hearing people. The gender and parental status of the participants did seem to correlate with different answer means in some cases, albeit to a limited extent (cf. Appendix).

But it is not only the identity of research participants we need to take into account. As philosophers, we need to be aware that our desire for universalizable theories and generalizable claims does not obscure the influence of our own social identities on our work. Fricker calls for a "distinctly reflexive critical social awareness" (Fricker 2007, 91). For bioethicists and philosophers of medicine, this may be interpreted as a call to critically investigate their own assumptions about disability and its relation to issues such as quality of life, cure and procreative beneficence. Experimental philosophy can be an excellent starting point for such an investigation.

Appendix

This appendix contains the results of a few additional analyses.

Gender

Figure 2 shows the differences between the mean answers of men and women.

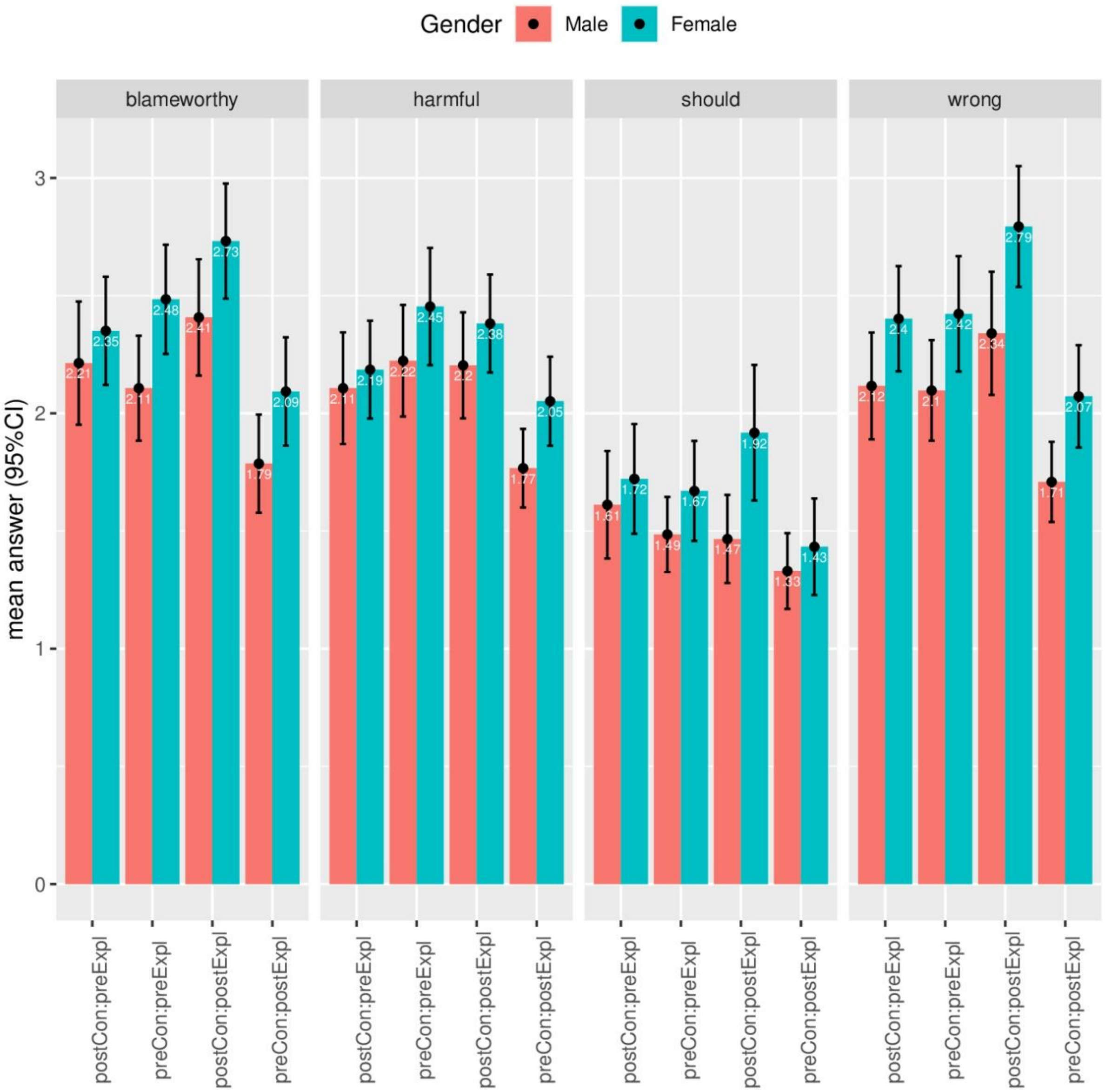

Figure 2 - Differences between the mean answers of men and women © Erik Fransen

An independent t-test was used to compare the answers of men (n=103) and women (n=97) on the four questions about the behaviour of the prospective mothers across all three vignettes. Initially, the differences were significant ($p < 0.05$) for about half of the questions, but none of them survived the FDR correction (which required $p < 0.005$). In all but one of these cases[49], the mean scores of female respondents were higher than those of men.

The judgments of women are somewhat milder, especially in the Deaf condition. One might speculate that this generally is the case because women are more likely to be mothers themselves or to imagine the possibility of having to make the same choices as the women in the vignettes, which might lead empathy to play an increased role in their answers. However, this would not serve as an explanation for the fact that the difference is mostly present in the Deaf vignettes as opposed to the Parfitian and Pure ones.

Parental status

An independent t-test across tracks was performed to study the differences in opinion between parents (n=49) and non-parents (n=151). The differences between the answers of parents and non-parents were most outspoken in the following two cases: postcon/postex/wrong (*t* 2.23, *p* 0.027) and postcon/postex/blameworthy (*t* 2.28, *p* 0.024). In both cases, the mean scores of non-parents were lower than those of parents.

Subsequently, I split the data for the different tracks and again performed an independent t-test to study the previously found differences in more detail. Most of the greater differences are located in the Deaf vignettes. Specifically, they are all related to the post-conception, post-explanation Deaf vignettes. The results of the non-parametric test, the Mann-Whitney-U-test were very similar. In all but one of these cases[50], the mean scores of parent-respondents were higher than those of non-parents.

It seems to be the case that parents sometimes differ from non-parents in their opinions about the behaviour of the prospective mothers in our vignettes, in the sense that their judgments are somewhat milder. This might be explained in a similar way as the difference between men and women, i.e. a difference between

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[49] Precon/postex/wrong: the average answer of women is 2.42, whereas that of men is 2.10.

[50] Pure vignette, precon/postex/blameworthy: the average answer of parents is 2.07, whereas that of non-parents is 2.83.

the two groups in the likelihood of them being or having been in a similar situation. This does not explain, however, why the differences are bigger in some cases (most notably, the Deaf postcon/postex cases) than in others.

Knowing deaf people

A majority of othe participants, 126 out of 200 people, do not know anyone who is deaf. Out of those 126 people, 109 consider deafness a disability, compared to 42/50 of those who know one person, 10/12 of those who know two, 2/2 of those who know three and 9/10 of those who know more than three people who are deaf. The results of a Chi-Square Test were non-significant. At least in this data set, there seems to be no correlation between knowing deaf people and considering deafness a disability. The hypothesis that knowing deaf people is positively correlated with not considering deafness a disability is not confirmed.

I also could not find any evidence for the hypothesis that knowing more deaf people is correlated with milder judgments, at least about the behaviour in the Deafness vignettes. An ANOVA test and a Kruskal-Wallis test were performed on the differences between the answers of the groups of people knowing no, one, two, three and more than three deaf people. On the basis of this data set, the hypothesis needs to be rejected. I found no significant difference between the answers of those who do not know any deaf people and those who know one, two, three or more.

Views on disability, deafness and QoL

The hypothesis that most people consider deafness a disability is confirmed. Out of the 200 participants, 172 people consider deafness a disability. Of the others, 19 do not consider deafness a disability, and nine do not know. Most (53/60) hearing-impaired participants consider deafness a disability, two do not, and five do not know. Six out of seven congenitally deaf participants consider deafness a disability, and one does not know. These findings do not quite support the hypothesis that deaf people are more likely not to consider deafness a disability.

Returning to the answers to the vignette questions, it was investigated whether people's views on the impact of respectively disability and deafness on the quality of life influence their opinion on the behaviour of the prospective mothers in the vignettes. For both sets of comparisons, an ANOVA test was performed across all vignettes.

With regard to the relation between views on *disability* and moral judgments about the vignettes, a significant difference ($p < 0.005$) was found for about half of the questions. When looking at the specific vignettes, I found that all of those differences are located in the Deaf vignettes. A Kruskal-Wallis test yielded similar results.

In all cases, this difference entailed that those who gave more negative responses to the question on the relation between disability and quality of life were more outspoken (i.e. disapproving) about the behaviour in the vignettes. In other words, the mean scores to the vignette questions of someone who thinks disability has a very negative impact on quality of life are likely to be lower than those of someone who is less convinced disability has a negative impact on quality of life.

The general part of the hypothesis seems to be confirmed: there is a positive correlation between holding negative views on disability and more outspoken (lower) scores on the vignettes. However, I expected this pattern in the responses to the Parfitian vignettes in particular, because these are the vignettes where a non-descript disability is mentioned as the cause of a lower quality of life. Instead, I found that the pattern is most pronounced in the responses to the Deaf vignettes. Perhaps the more concrete nature of those vignettes makes it easier for people to have outspoken ideas or opinions about them.

With regard to the relation between views on *deafness* and moral judgments about the vignettes, I found a significant difference ($p < 0.005$) for about a quarter of the questions after performing an ANOVA test across the three kinds of vignettes. All significant differences were found to be located in the Deaf vignettes. A Kruskal-Wallis test yielded similar results. The pattern is the same as with the previous comparison: those people who gave the most negative responses to the question on the relation between deafness and quality of life tend to be more outspoken about the behaviour in the vignettes.

The results are somewhat in line with the hypothesis: in response to a subset of the questions of the Deaf condition, people with (very) negative views on the impact of deafness on quality of life give significantly lower (i.e. more outspokenly critical) scores than those who have a less negative view.

Chapter 7

From Parental Responsibility Towards Mutual Understanding: Reimagining the Employment of Epigenetic Knowledge

Chapter 7 From Parental Responsibility Towards Mutual Understanding: Reimagining the Employment of Epigenetic Knowledge

Introduction

In this final chapter of the section on responsibility towards future generations, I zoom in on a specific group of agents: (prospective) parents. Findings in intergenerational epigenetics give rise to a 'temporal expansion' of normative discussions about parental responsibility (Chiapperino 2018; Mansfield and Guthman 2015; Mansfield 2017). Thus, if the findings on epigenetic inheritance are to be trusted, factors influencing the health of future generations would include "predispositions acquired by prospective parents throughout their whole life course and would also extend to those they have inherited from their own parental lineages" (Chiapperino 2018, 54).[51] In light of such findings, questions of parental responsibility arguably become more acute (Hens, Cutas, and Horstkötter 2017). The lifestyles, behaviours, circumstances and exposures of people who are planning to have a child, or are already pregnant, are indeed subject to intense normative scrutiny in both scientific and popular discourse.

However, in order to properly evaluate claims about the epigenetic responsibilities of individual parents and their communities alike, we first need to take a step back. Claims about responsibility can never be unequivocally derived merely from biological findings about the workings of epigenetic mechanisms. Epigenetic knowledge itself cannot simply be regarded as either a burden or a blessing, but at best as a “double-edged sword” (Meloni 2016, 212). The translation from epigenetic knowledge into moral and political realms can happen in a variety of ways, depending on the values, commitments, priorities and biases, of those doing

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[51] For an overview of recent research in intergenerational and transgenerational epigenetics, see chapter 1.

the translating. As Müller and Kenney note, “biosocial narratives are neither inherently liberatory nor inherently oppressive” (Müller and Kenney 2020, 2). Maurizio Meloni plainly points out that it is also quite hard to predict how epigenetic narratives will be taken up in the future: “We can’t yet say whether epigenetics will fulfill its liberating potential or instead further racist or classist [or sexist] agendas. [...] even the best conceptual framework is open to unpredictable socio-political outcomes. Today, as throughout history scientific theories do not decide political values” (Meloni 2016, 223).

Thus, we need to distinguish between epigenetic knowledge, agency and responsibility. It is generally agreed upon that more knowledge only benefits agents if this knowledge is actionable to them. Firstly, this depends on the kind of epigenetic knowledge. While in this chapter I primarily have in mind knowledge on the level of public health, i.e. knowledge about associations, one might also think of epigenetic risk scores on an individual level. Moreover, agency is a necessary condition for responsibility, but it is not a sufficient one.[52] For example, we might hold that an agent needs to have sufficient autonomy or self-governance with regard to her choices. Furthermore, the mere fact that an agent is able to act on obtained knowledge does not imply that she should do so. Moral responsibility can only be ascribed to moral agents, but whether a particular moral agent should take up specific responsibilities may depend on many other considerations than just the capacity to do so (cf. chapter 3).

This is not to say that I believe epigenetic knowledge is an 'objective' starting point for such normative translations. As was already touched upon earlier in this thesis the process of scientific knowledge creation is itself already an endeavour imbued with different kinds of values, and choices made in this process are context-dependent. Going into the complexities behind epigenetic knowledge itself, however, is largely beyond the scope of this chapter. It focuses instead on the perspective of (prospective) parents and broader society in relation to epigenetic knowledge once it has been produced, particularly in the form of responsibility claims. How should this knowledge be communicated, and how should it be taken up by public health organizations, parents and politicians? Which recommendations do epigenetic scientists themselves make, and how is this knowledge taken up by public health bodies and politicians, translated into the

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[52] Another way to put this: 'ought' implies 'can', but 'can' does not imply 'ought'.

moral and the political realm, particularly in the form of responsibility claims, and how should this be done?

The literature I discuss in the first section of this chapter almost unanimously points out worrisome tendencies of epigenetic knowledge inspiring policies and discourses that lead to blaming and stigmatization of individual parents and women in particular. But other routes from epigenetic knowledge towards responsibility ascription are at least possible. Inspired by insights from non-ideal theory, in section 2 I discuss how social determinants of health and causal uncertainties complicate the relationship between epigenetic knowledge, autonomy, and responsibility. I argue that rather than risking getting stuck in debates about (backward-looking) responsibility distributions, we need to dwell more on the potential positive effects of epigenetic knowledge for parents and their children. Thus, in section 3 I propose a novel way in which we could employ epigenetic knowledge positively based on ideas from the philosophy of education. The central claim of this chapter is that epigenetic knowledge can contribute to the construction of the narrative identity of children and families. The integration of epigenetic knowledge in a shared narrative identity may benefit mutual understanding and self-knowledge. This way, epigenetic knowledge can be used in a framework that goes beyond deterministic etiologies to embrace the complexities and interrelatedness of all factors influencing the health of future generations.

This chapter focuses mostly on epigenetically mediated influences in the perinatal period. Although such influences are of course also possible in later stages of child development and the human lifespan in general, this focus stems from the fact that most of the existing literature concentrates on ethical issues surrounding epigenetic influences before conception and during pregnancy. I acknowledge that discussions of paternal and maternal epigenetic influences are crucially limited in scope. The focus of this chapter on biological influences does not do justice to a wide variety of family arrangements in which one or more parents of the child are their social, but not their biological parent. Moreover, I also admit that simplistic talk of paternal and maternal factors glosses over the wide variety of assisted reproductive technologies in which multiple people might be involved in reproduction in various ways. In surrogacy, for example, the maternal genetic material and the gestating environment do not belong to the same person. I will discuss and nuance the risk of an epigenetics discourse tapping into 'bionormativity' later in this chapter.

1. Blame and burdening

Most of the literature on the potential ethical and social implications of epigenetic discoveries for procreation and parenthood takes a cautionary approach (Dupras, Saulnier, and Joly 2019). The articles can generally be categorized as criticizing one or both of two tendencies they observe in the scientific and popular discourse on epigenetics: an increased responsibilization of individual (prospective) parents (with the exception of Räsanen 2021) and reinforcement or intensification of a disproportionate focus on maternal (as opposed to paternal) behaviour during and before pregna+ncy.

Individual and collective responsibilities

As we saw in chapter 3, there is no lack of criticisms of individualizing epigenetic responsibility in ELSI literature on epigenetics. In this section, I add concerns related to individual *parental* responsibility in particular.

Many commentators have warned against the premature translation of research findings in animal experiments (Kenney and Müller 2018; Wastell and White 2017; Richardson et al. 2014; Juengst et al. 2014). Findings of transgenerational epigenetics in mice and rats cannot simply be extrapolated to human models. Rushed and simplistic science communication that attaches normative implications for human behaviour to research in animals is not only epistemologically problematic but also risks making "impossible demands on prospective parents" (Juengst et al. 2014, 427).

Various authors point out that expecting individual (prospective) parents to prevent disease or suboptimal epigenetic transmission in their offspring by minimizing every possible risk factor seems to ignore the extent to which exposures, diets and stressors are shaped by "socioeconomic and sociopolitical forces" (Juengst et al. 2014, 428; Richardson et al. 2014; Kollar and Loi 2015; Chiapperino 2018). Thus, they emphasize the importance of collective responsibility in this context. Daniela Cutas argues that the environmental aspect of epigenetic mechanisms implies that all agents who causally contribute to a child's environment being a certain way might together bear some collective responsibility for their wellbeing (Cutas Forthcoming; Hens 2017).

Another concern is the personal nature of "individual and familial decision-making about childbearing and child-rearing" (Juengst et al. 2014, 428; Hens, Cutas, and

Horstkötter 2017). Although dealing with the inequities that shape the lives of individuals and their children requires societal change, it is far from clear which amount of state influence should be allowed. For example, M'hamdi and colleagues argue in favour of 'other-regarding nudges': public health campaigns and policies that would nudge people towards certain decisions out of concern for the health of their future children (M’hamdi et al. 2017). As we will see in the next section, others point out that especially prospective mothers are already overburdened by expectations that do not always seem to take their own needs and interests into account. I will return to this issue in the final section of this chapter, when I discuss whether epigenetic knowledge might help us to argue for increased parental autonomy or 'discretionary authority', rather than being used to limit it.

Finally, even if we believe that not only individual (future) parents but also collective agents should take up epigenetic responsibilities towards future generations, it is far from clear which goal they should have in mind. Excessive blaming of individuals is a potential downside of claims of heightened individual responsibility. If parents are unable to fulfill the increasing forward-looking responsibilities with regard to the health of their child, they may be held responsible for failing to do so in a backward-looking sense. On the other hand, increased social pressure and state interference might be a downside of an approach that focuses on collective responsibility without clearly delineating the object of this forward-looking responsibility. It may be true that "one cannot dispute the benignancy of the aspiration to purge the next generation of debilitating and often deadly disease" (Wastell and White 2017, 178). But the line between preventing harm and optimizing or enhancing an outcome is not at all easy to draw, especially in the context of parental responsibility (M’hamdi et al. 2017; Hens, Cutas, and Horstkötter 2017; Wastell and White 2017). Epigenetic findings might be employed to intensify societal pressure on individual parents (and especially women) to have healthy children, thereby "maximizing human capital and productivity" (Wastell and White 2017, 178). Some commentators even worry about the risk of 'epi-eugenics' through "increased social pressure on prospective parents to undergo preconception and prenatal testing for epigenetic alterations" (Juengst et al. 2014, 428).

In summary, most ELSI scholars and philosophers working on epigenetics have seen it as their task to criticize, either explicitly or implicitly, a scientific and societal discourse that excessively attributes responsibility for epigenetic alterations in offspring to individual people, particularly mothers. Joona Räsänen (2021), however, takes a different approach and defends an 'epigenetic responsibility thesis' to "remind prospective parents that they are sometimes responsible for their children's diseases because of epigenetic inheritance" (Räsänen 2021, 54). I will come back to his approach in section 2.

Maternal and paternal influences and responsibilities

Gestation, and thus women's bodies and behaviours, seem to have become the main target of intervention suggested in epigenetic literature (e.g. Mansfield and Guthman 2015; Hens 2017b). While epigenetics expands the temporal window of potential influence, this overemphasis on maternal influence itself on the health of a fetus, baby or child is nothing new (Waggoner 2017; Richardson 2021; Juengst et al. 2014; M'hamdi et al. 2017; Kenney and Müller 2018).

There seems to be a growing consensus among commentators that the overemphasis on maternal influences in epigenetic risk messaging is unfair because it risks ascribing excessive blame to women. In an influential paper, Richardson and colleagues compellingly show how narratives about epigenetic findings risk perpetuating "a long history of society blaming mothers for the ill health of their children" (Richardson et al. 2014, 131). They give examples such as panic concerning Fetal Alcohol Spectrum Disorder (FASD), media hysteria around 'crack babies' in the United States, and the popularity of theories about 'refrigerator mothers' whose 'cold' parenting style supposedly caused autism in their children.[53] They warn us that although the scientific findings underpinning those societal blaming practices are often rather moot or have been proven to be plain wrong, women still experience harmful effects until this day.

Thus, researchers should be aware of existing biases and moralizing tendencies in society when they share their findings to minimize the risk that their findings inspire unfair blaming practices. But the problem seems to be situated on a more fundamental level than the biased language in science communication. The attention and resources science has been directing toward maternal influences, specifically in the perinatal period, should also be critically questioned. As I noted in the introduction, ethical considerations regarding epigenetics should not just

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[53] For a thorough sociological analysis of the moral panic surrounding the diagnosis of FAS(D) in the first three decades after its invention, see Armstrong 2003.

pertain to the uptake of epigenetic knowledge, but also to the construction of this knowledge itself.

The focus on maternal influences seems to be a continuation of the centuries-old "bewitching idea that the environment in which you are gestated leaves a permanent imprint on you and your future descendants" (Richardson 2021, 1). Sharp et al. (2018) highlight how the focus of DOHaD research (including epigenetics) on maternal exposures around and during pregnancy is based on some "implicit assumptions about the 'causal primacy' of maternal pregnancy effects" (Sharp, Lawlor, and Richardson 2018, 20). However, epigenetics offers an opportunity to strike a new balance in parental responsibility between contributors, because it helps to show how not only influences *in utero* play a role in offspring health. Because they are concerned about a looping effect in research, Sharp and colleagues urge researchers to address this imbalance by looking more into paternal factors and postnatal exposures in later life.

Many others have addressed the need to research paternal influences (e.g. Hens 2017b in the context of postponed fatherhood). In recent years epigenetics researchers seem to have heeded such calls, for example by creating a POHaD paradigm (paternal originals of health and disease) that researchers the impact of paternal lifestyle and exposure and their impact on for example sperm quality (Mayes, Lawson-Boyd, and Meloni 2022). However, venturing into this new area requires researchers to be cautious of the contexts in which fathers find themselves. Epigeneticists can do so by for example taking an interdisciplinary approach that includes insights from disciplines such as sociology and history (Mayes et al.) or by fostering collaborations with critical humanities (Kenney and Müller 2018). Translation of these new findings could reduce some of the burden currently placed on mothers, but we should also be careful that the discourse about paternal influences does not simply replicate the stigmatizing and blaming tendencies that are currently present in the discourse about maternal influences Hens 2017b).

Researching resilience factors

Shifting the focus from maternal to paternal influences is not the only redirection of epigenetic research that is being suggested. Towards the end of her paper that explains what epigenetics might add to understanding health disparities, Alexandra Shields remarks that "nearly all extant epigenetics studies focus on adverse exposures" (Shields 2017, 226). She urges researchers to investigate 'sources of resilience', calling for more research on epigenetic effects that are positive to one's health or at least help one be more resilient in the face of adversities:

> Little research to date has focused on positive mediating influences such as social support, coping and spirituality that might offset the adverse effects of stress or adverse life circumstances and promote resiliency and health. Focusing on positive mediating influences has the benefit of often being more tractable and amenable to intervention than adverse influences, such as psychosocial stress at the individual or community level. (Shields 2017, 226)

Epigenetics research focusing on factors of resilience might be a welcome addition to the emphasis that is often placed on risk factors.[54] Moreover, resilience can remind us of the collective responsibility to ensure that our societies provide the environments in which individuals can take control of their own health and that of their offspring in ways they see fit.

2. Epigenetic knowledge, autonomy and responsibility

The literature reviewed in the previous section shows how epigenetic knowledge might be or is already being employed to responsibilize prospective parents and particularly pregnant women. However, findings in epigenetics themselves do not hold any political or moral implications. How one chooses to use epigenetic knowledge in those domains depends on a host of values and considerations. In this section, I take a step back from debates on responsibility to dwell on the possibility of ameliorative ways of dealing with epigenetic knowledge.

Positively using epigenetic knowledge rests on the assumption that epigenetic knowledge actually can offer more clarity rather than obfuscate matters, as Chiapperino and Testa remind us. They point out that it is "debatable whether epigenomics will actually be able to disentangle the contribution of lifestyles to health from that of other environmental factors" (Chiapperino and Testa 2016,

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[54] An example of this move is embodied by the newly launched R2D2-MH project. This interdisciplinary European project strives for a paradigm shift in mental health and developmental disability: 'from risk to resilience'. See http://www.r2d2-mh.eu/.

214). In chapter 2, I already explained in more detail some of the problems with causality claims in epigenetics. For the sake of the philosophical exploration I stipulate here that increased knowledge will at least allow us to disentangle those to some extent, but I admit that this is merely an assumption. In the final section of this chapter, I will develop an approach that attempts to depend less on etiological claims.

Recognizing and ameliorating the nonideal

Even if the causal contribution of each habit, action or amount of exposure to the health of the agent and/or that of their offspring would ever be established, this alone would not be sufficient ground to ascribe responsibility to this agent. Epigenetic knowledge needs to be actionable, and it does not suffice that epigenetic knowledge is *generally* or in principle actionable: it depends on the context of the receiver of this knowledge whether they can do something with it. A fair responsibility ascription requires (among other things) that the intended agent has sufficient autonomy to take up this responsibility (in a forward-looking sense) or be truly liable to blame or praise (in a backward-looking sense). Thus, autonomy is a necessary condition for being an appropriate subject of moral responsibility claims.

Because we know that in most if not all current societies the burdens of (prospective) parenthood and procreation are not equally shared, we may worry about responsibility claims 'adding insult to injury' (Meloni and Testa 2014). We should avoid unjustly burdening with individual responsibility those for whom epigenetic knowledge may not be available or, when available, be actionable at all. The first step in doing so consists in taking a **nonideal approach**. In contrast to ideal theory, such an approach does not assume just background conditions and tries to avoid idealization or abstractions that misrepresent or exclude all aspects in which our moral and political reality are currently not ideal (O'Neill 1987; Haslanger 2020; Michelle Ciurria 2019; Mills 2005). Mills adds that in order to work towards an improved situation, we do not only need to recognize the actual nonideal one. We should also be careful not to assume that ideal or non-ideal in our theorizing because such theories would not be applicable to our actual situation and thus only allow the nonideal situation to persist (Mills 2005).

In the context of epigenetics, taking a nonideal approach implies sufficiently taking into consideration the role of social determinants of health and disease in the triggering of adverse epigenetic effects in parents and offspring. Social determinants of health are conditions in the social and physical environments of people that influence health outcomes throughout their life course (Mancilla et al. 2020; Notterman and Mitchell 2015).[55] Those conditions are not distributed equally, and they are hard to change for any individual parent or couple.

I will illustrate what I mean by this in dialogue with Räsänen's Epigenetic Responsibility Thesis, which is intended to remind prospective parents of their responsibility towards future children. Although I do not categorically disagree with his thesis that prospective parents are sometimes responsible for the health of their child, this thesis and its defense exemplify an ideal approach that is somewhat out of touch with our nonideal world.

Some of the hypotheses Räsänen formulates do not apply equally to all prospective parents. First of all, he argues that "since epigenetic transmission through our diet is something over which we have at least some control, we should act in a way that would not harm our future children" (Räsänen 2021, 63). This statement ignores the sometimes stark differences in control between privileged and underprivileged individuals and communities. When Räsänen argues that prospective parents can avoid severely harming their genetic children without significant cost to themselves, he seems to ignore that the means of people to secure a healthy food intake can be seriously limited by e.g. socioeconomic and geographical conditions (they could live in so-called food deserts). And even if prospective parents could have avoided harming their future children but failed to do so, it does not automatically seem warranted to me to claim that they wronged those children. People might be unaware of the (full scope of the) consequences of their actions, which at least seems to mitigate the extent to which they are wronging their children.

The claim also seems be more limited in scope then it may appear at first sight. For example, Räsänen admits that his argument is only directed at those who plan to have a child. Although certain eating habits may cause harm regardless of whether or not a pregnancy is planned and wanted, he does not believe that it is fitting to ascribe moral blame to a pregnant woman in cases of unwanted or accidental pregnancies (54). But since nearly half of all pregnancies worldwide are

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[55] In chapter 1, more is said about the relation between social determinants of health and epigenetics.

unintended, this important nuance robs the claim of much of its force (United Nations Population Fund, 2022).

Finally, not all of his assumptions about harm and disability seem to be warranted. For example, he assumes it to be 'obviously true' that diseases are harmful. He describes how diabetes leads to a reduced quality of life and may lead to an early death to illustrate his point that causing disease is severely harming. He then extrapolates to all diseases of developmental origin. However, developmental conditions are too varied to be lumped together like this. The meaning and negative impact of effects such as reduced life quality and early death are also not as straightforward and uncontested as is assumed here, as becomes clear from the experiences of disabled people (Liddiard et al. 2022; Albrecht and Devlieger 1999; Iezzoni et al. 2021).

In short, I doubt whether defending the Epigenetic Responsibility Thesis is strategically the right thing to do. Pregnancies are often unintended; gender inequality still means that women often bear (or are expected to bear) most of the responsibilities surrounding the health of future generations; and discourses individualizing procreative responsibilities flourish. Even though, for example, Räsänen makes an effort to emphasize that his claim pertains to both parents, and that he by no means intends to blame pregnant women, one might whether this nuance would survive translation into public and political discourse. Most parents do not *need* reminding of their responsibilities; but they might lack the means to fulfill their role as well as they want to.

Where to go from here? Given the nonideal situation of epigenetic and other social injustices we find ourselves in, how can we use philosophy to argue for changes that benefit parents and children? One possibility, that has been defended by various feminist philosophers, is to subscribe to an **ameliorative project** as described by Sally Haslanger (Haslanger 2006). As Mich Ciurria explains, an ameliorative approach first asks "What is the point of having the concept in question?" before constructing a definition of the concept in reference to ameliorative goals or a set of emancipatory aims (Ciurria 2019, 30). Haslanger, for example, uses this approach to define concepts such as 'race' and 'woman' in such a way that they acknowledge existing racial injustice and sexism. Ciurria takes up the ameliorative project in her development of a normatively adequate theory of blame and moral responsibility theory intended to "underscore, and seek to ameliorate, oppression and adversity as experienced by the marginalized" (ibid., 31). Her ameliorative approach to responsibility seeks to radically change the responsibility system that currently is insufficiently capable of reflecting the structural nature of injustice (Ciurria 2022, 160).

Epigenetic knowledge has the potential to paint an increasingly clear picture of how social determinants of health shape the health of (prospective) parents and their children. Interconnected existing social injustices express themselves in health disparities that can partly be called epigenetic injustice. How can we think of ways in which we can take up an ameliorative project in this context? Can epigenetic knowledge potentially be employed or (re)conceptualized to benefit especially the most vulnerable communities? In the remainder of this section, I discuss whether the concepts of empowerment and procreative autonomy can be usefully employed with this goal in mind.

Empowerment and procreative autonomy

A first possible way to think positively about epigenetic knowledge in an unequal society might be to see it as a tool in striving toward the **empowerment** of individual citizens and communities. There is no consensus about the definition of empowerment. It is usually understood as the process of enhancing people's capacities to control the determinants of their own quality of life ('empowering people'), and/or as the state that results from this process ('empowered people') (Tengland 2016; Vanaken 2022).

Chiapperino and Testa present a critical analysis of the use of empowerment in healthcare, arguing that both empowerment-based healthcare reforms and molecular epigenomics lie at the basis of the rising personalized medicine (PM) discourse (Chiapperino and Testa 2016, 203). They observe that epigenetic knowledge is frequently employed as providing the "epistemic correlates and legitimisation" (211) for a neoliberal project of individualizing responsibility for health. Language of empowerment can be used to serve such a political project that seeks to devolve responsibility for health from the state to individual citizens and expects this move to make the healthcare system more economically sustainable (207).

However, Chiapperino and Testa do not rule out the possibility of using empowerment as part of a more emancipatory discourse. They refer to a more radical history of the concept, for example in the tradition of liberatory pedagogy (Freire 2000). Epigenetic knowledge can be insightful if it manages to show agents how social determinants and environmental exposures affect their health and that of their offspring. What an empowerment discourse should be mindful of, then, is that agents also need to be sufficiently free from financial, social and material constraints to act on this knowledge.

Such an emancipatory project could be served by a sufficiently refined concept of **procreative autonomy**, that is the right of people to decide whether, when and under which circumstances to procreate (Harris, Søren, and Holm 1998). Although this definition seems to treat procreative autonomy as something that one either has or does not have, I think that both parental and procreative autonomy can be understood in a more gradual sense as something that one has to a certain degree or under certain circumstances. How autonomous an agent is, depends not only on their capacity for self-governance, but also on the extent in which she is socially and politically recognized to have authority to make decisions that impact herself and the power to act on this authority (Hutchison, Mackenzie, and Oshana 2018). Epigenetics is relevant to both parental and procreative autonomy. Particularly, I want to think about ways in which epigenetic knowledge can be employed to minimize inequalities in procreative autonomy. How, if at all, can epigenetic knowledge benefit vulnerable (potential) parents-to-be?

One way to direct our collective endeavors towards epigenetic and procreative justice is to think about them as supporting **'procreative flourishing'** (Davis 2022). Emmalon Davis takes issue with the 'moral gaze' of much ethical and political philosophy about procreation, because it "presumes the salience of concepts, characterizations, and presuppositions that bear the markings of dominant and controlling ideologies" (ibid., 20). Philosophical and political analyses that seek to place moral responsibility for a social problem with individuals who are also harmed by this very problem, uphold the social injustice by reproducing it in their descriptions. As Davis summarizes it, "where and with whom one locates the 'problem' is itself a matter of justice" (21). She herself focuses on the discourse surrounding the reproductive lives of black women and girls in the United States. This discourse needs to be informed by these women and girls themselves, not only at the level of evaluating the (il)legitimacy of various policies, "but in our very conceptions of what it means to exercise reproductive agency while one is young, poor, and black" (21).

For Davis, this pursuit can only succeed if we shift "from a framework of reproductive responsibility to a framework of reproductive flourishing" (21). Unfortunately, she does not elaborate on what such a shift might mean for moral philosophy or political practice. However, I believe that the perspective of procreative flourishing is a promising one, that could help us to focus less on isolating individual contributors or responsible agents, and more on nurturing environments that allow for flourishing. As the suggestion of Davis above seems to show, such an approach would need to include efforts to listen to the lived experience of the very people that our research seeks to benefit, starting from the research design. This call is not only directed at empirical researchers such as epigeneticists, but also at philosophers whose research is more conceptual in nature.

In the rest of this chapter, however, I will stick to autonomy terminology. I wish to engage with existing literature that uses the concept, and I do not want to appropriate the concept of Davis in this chapter without knowing how she intends it to be used. To heed Davis' call for awareness of the social structures that impact procreative autonomy, I do want to emphasize that I use autonomy in an inherently relational sense. Proponents of relational autonomy also take a non-ideal approach, recognizing that the social contexts in which agents develop and exercise their autonomy are often 'far from ideal' (Hutchison, Mackenzie, and Oshana 2018). The term is premised on the belief that persons are "shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity" (Mackenzie and Stoljar 2000, 4).

Note that procreative autonomy is not necessarily beneficial to a (future) child. When we emphasize the right of future parents to make choices about procreation and pregnancy, we need to acknowledge that those choices need not always be good from the perspective of the fetus' or future child's health. Behaviours engaged in by parents themselves with limited state intervention or nudging may well lead to worse health outcomes for future children or go against their interests more broadly construed. However, some room for making bad choices may need to be allowed in order to protect people from arguably more harmful far-reaching public involvement in the private sphere.

Arguments in favour of procreative and parental autonomy can be split into at least three groups. Most of them appeal to how this is the right of or benefits the subjects of this autonomy: for example, (future) parents or pregnant people. Some of those arguments invoke the interests of (potential) future children. In discussions about abortion, for example, pro-choice defenders may argue that if someone is pregnant with a fetus that she does not want to or is unable to carry to term or provide with a good upbringing once it is born, it may be better for this child to never be born at all. Finally, some arguments for procreative and parental autonomy can appeal to the interests of both 'parties' at the same time. This can be done by referring to potential benefits that autonomously made choices with regards to procreation may bring to the future parent-child relationship. In the next section, I draw inspiration from the philosophy of education to propose a way of employing epigenetic knowledge to strengthen the narrative identity of the child and the family, thereby placing it in this third group.

3. Narrative identity

In the book *Family Values: The Ethics of Parent-Child Relationships,* Harry Brighouse and Adam Swift argue for the value of the family. They understand the family not in a narrow conservative sense, but as "an arrangement in which some small number of adults is charged with continuing responsibility for paternalistic treatment of a child" (Brighouse and Swift 2014, 67). According to them, the family so defined is the only child-rearing arrangement that will adequately promote and protect the interests of the child.

They argue that one of the reasons the family is valuable for the child is that it is, at least ideally, an arrangement "in which those adults are granted very considerable authority over her, and discretion in carrying out the tasks associated with raising her" (67). This discretionary authority means that parents need to have sufficient freedom to raise their children as they see fit. It means that if they robotically follow state-sanctioned instructions about breakfast routines and bedtime stories, they are generally not parenting as well as they would be if they chose how to deal with those issues themselves. Such manual-following would not be the kind of loving guidance that tends to induce identification with the authority figure.

This discretionary authority should strengthen the loving parent-child relationship. They assume that it is good for children to know that how they are raised is a result of the persons who love and care about them taking decisions to raise them as they think is best.[56] This helps the child to identify with the parent. This may lead to imitating them and learning important skills such as regulating responses, and in general increased self-knowledge. It is important that child and carer know

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[56] As my colleague Daniela Cutas pointed out, this assumption should be backed up by empirical research. I will return to the importance of empirical work later on.

each other well, in order to strengthen their loving relationship as well as the child's development.

The line of argument of Brighouse and Swift only applies to child-rearing. But perhaps the argument that parental discretionary authority or, more generally, parental autonomy benefits the child can be extended in time to include the prenatal and even preconception stage. The argumentation can be broken down into two steps:

> 1) **Epigenetic knowledge -** Shared knowledge (between parents and children) of the choices those parents made and the circumstances they lived in that (potentially) impacted their future offspring in some way may help parents to create a strong parent-child relationship and benefit the child in terms of self-knowledge. This knowledge can include epigenetic knowledge about the complex and interconnected associations between the lifestyles and exposures of future parents and the phenotype of the child.
>
> 2) **Procreative and parental autonomy -** A certain level of procreative and parental autonomy of (future) parents is necessary (but not sufficient) for these beneficial effects to be possible.

Epigenetic knowledge

As a first step towards explaining my first hypothesis, let us extend the argument from Brighouse and Swift to the stages of conception and gestation. How might knowledge about the choices their parents made in these stages, or the circumstances they had to deal with, benefit future children? We might imagine that some children at some point have conversations with their biological parents about the decisions they made before their birth. It might be valuable for them to know their parent's considerations with regard to family planning, prenatal testing, and a host of other issues, such as food intake and changes in habits (or a lack thereof) such as smoking. This might strengthen the mutual knowledge component of a parent-child relationship. Children might learn about what their parents value and how they deal perhaps with unexpected situations or difficult choices. Moreover, such conversations might help a child to understand their own biological makeup better knowing some of the in-utero influences they were exposed to. Although epigenetics need not necessarily play a role here, knowledge of epigenetic mechanisms might provide some added insights.

To think about whether or not this line of argument holds any plausibility, consider the following case.

> **Alex and his mother Farah.** Farah is a postdoc researcher at a prestigious university. She loves her job and considers being an academic an important part of her identity. At the same time, various elements of her job are causing her quite some stress. When Farah gets pregnant, she makes a conscious decision to continue working her stressful job, even though she is aware of the potential influence that the stress she experiences (as well as that she has experienced before) might impact her offspring. Ten years later, her child Alex receives a diagnosis of ADHD after experiencing some difficulties in home and school settings. Although he sometimes continues to struggle with some aspects of his ADHD, throughout his teenage years Alex starts to consider this diagnosis as an integral part of his identity that he would not want to change.

A few epigenetic studies have already found mechanisms implying a causal connection between stress during pregnancy and ADHD in offspring (Bock et al. 2017; Pineda-Cirera et al. 2019). Suppose that Alex learns about these studies, for example when he is in college, and talks with his mother to learn more about the decisions she made before and during her pregnancy. What might his reaction be? And how, if at all, might that reaction be impacted by the knowledge that his mother's past choices may have made some contribution to his ADHD *through epigenetic mechanisms*?

A possible response Alex might have is to blame his mother for letting herself, and once pregnant her fetus too, be exposed to the stress she experienced. But I think it is at least conceivable that Alex might (also) have a different reaction, one of increased understanding. Getting to know more about Farah's reasons and values behind the choices she made, and about the circumstances that perhaps constrained them, may provide Alex with information that he could use when facing similar choices later in life. Furthermore, the fact that the knowledge about epigenetic mechanisms leads to a few honest conversations between mother and son may (admittedly, in ideal circumstances) also be valuable to the parent-child relationship itself. Moreover, knowing that there may be some connection between the choices and experiences of his mother and his ADHD, which he considers important to his identity, may contribute to his developing *narrative identity*. I will say more about this later.

Now, I want to take one more step and try to expand this line of thought back in time even further. Might there be any value for the child or the parent-child relationship in having shared knowledge of elements of the lives of parents before they were even thinking of conceiving, but that nonetheless may have impacted the child's biological make-up? Epigenetic knowledge then can play a contextualizing role, suggesting that aspects of the child's health or personality are not isolated from actions, behaviours or exposures of their parents in the past. Consider an example related to environmental pollution to think about this. It differs from the first example in an additional way: prospective parent Farah in the above example had a considerable amount of agency, but influencing the chances of certain health outcomes materializing is often not so accessible to future parents. The example of Jenn and her parents intends to reflect this reality.

> **Jenn and her parents.** Two people who together intend to have children have both grown up in a poor neighborhood close to a polluting factory. They are aware of this pollution and its potential health effects on themselves and their future offspring. Although this is far from easy, they manage to move to another part of their city with relatively clean air. There, they conceive and later become the parents of Jenn. However, the marks of them having lived in the polluted neighborhood may to a certain extent still have been inherited by Jenn.

Would it be valuable for Jenn to know this? And if so, how might she react? Jenn might be thankful that her parents decided to move away from a place that they were very attached to for her sake. She might gain a better sense of appreciation of their considerations (although it is not unthinkable that she might also feel guilty for being the reason they made such a drastic and costly change). Moreover, knowledge about epigenetic mechanisms might help Jenn understand why she is more prone than others to certain conditions such as asthma than others. Conversations about the way in which social determinants of health affect both Jenn and her parents may lead to a sense of mutual understanding.

In short, the power of epigenetic knowledge might lie in helping people to integrate their biography and their biology. Epigenetic knowledge can serve as a 'biological interface' (Chiapperino 2018) that may help people such as Jenn and Alex to construct a 'somatic sociality' to make sense of their 'embedded body' (Niewöhner 2011, 279). Another way to put this is that parent-child conversations on such topics help the child to create their own narrative identity. A narrative identity can be understood as an "internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life" (McAdams 2011, 99). So-called 'life stories' or 'personal myths' explain how someone is the person she currently is (McAdams 1993). Narratives lie at the heart of autobiographical thinking because they "elaborate on connections between past events and current self-understanding" (McLean 2017, 328). Kate McLean argues that storytelling is something in which families usually engage often, thereby helping the child to build its earliest and most lasting understanding of self (McLean 2016). Interestingly, McLean also describes how stories that parents tell their children about their personal experiences and choices might shape not only the identity of their children but also that of themselves. Sharing personal stories such as those in the examples above may thus affect everyone involved in the parent-child relationships (McLean 2016, ch. 7; 2017, 327). Although Sally Haslanger convincingly argues that acquaintance with biological kin is not necessary for a healthy narrative identity, information about the lives and circumstances of biological relatives may be one source of such a story (Haslanger 2009; Velleman 2005).

What epigenetic knowledge adds explicitly to this project of biological-narrative identity formation, compared to other biological knowledge, is that it broadens the scope and the timeframe in which potentially relevant factors can be found. Of course, as has been pointed out by many authors mentioned in previous chapters, claims about epigenetic mechanisms often come with high degrees of uncertainty. It is very difficult to isolate the contribution of specific causal factors from each other, and this may in fact never become fully possible. But for the construction of a narrative identity, absolute certainty is not required. Leni Van Goidsenhoven, for example, convincingly summarizes that we need a broad notion of narrative that allows for departures from traditional, coherent linear stories if we want to do justice to all kinds of life stories (Van Goidsenhoven 2017). David Velleman, in describing his own family narrative, also admits that "it's all imaginative speculation. But such speculations are how we define and redefine ourselves" (Velleman 2005, 377).

The child's interest in procreative and parental autonomy

In order to really apply the Brighouse and Swift dual-interest argument in favour of parental discretionary authority here, I need to argue for more than the potential benefits of epigenetic knowledge. This implies arguing for the second claim posited before: a certain level of procreative and parental autonomy of (future) parents is necessary in order for these beneficial effects to be possible.

Although Brighouse and Swift mainly think about parental authority vis-à-vis the state, I already discussed in the previous section that I take a relational understanding of procreative and parental *autonomy* to imply limited interference of the state as well as minimalized constraints by adverse circumstances.

Would it be valuable for a child to know that their parents made choices that impacted them autonomously rather than being limited by state regulations, public health policy or the constraints that come along with poverty or social discrimination? Would it have made a difference for Alex, for example, if his mother Farah would have lost some child benefits by deciding to continue working until giving birth? Knowing that she made this choice based on her own values rather than fear for financial repercussions might make some difference to him, although it seems hard to imagine that it would matter much. Would Jane gain anything by learning that her parent's decision to move to a cleaner neighborhood was enabled by public housing policy that ensured the availability of some affordable homes in such an otherwise expensive neighborhood? She might be thankful that such a policy existed, but the added value of this knowledge to her sense of self-knowledge or narrative identity seems rather limited.

Employing epigenetic knowledge to increase or safeguard procreative and parental autonomy does not seem easy to defend on the grounds of the benefits this might have for their future children. However, arguments of such autonomy being in the interest of the adults themselves still remain their force and need to be articulated. Although findings in epigenetics can be employed by policy-makers in positive ways that support parents and children, exaggerations and over-simplifications could "increase surveillance and regulation of pregnant women" (Richardson et al. 2014) and "invite moral judgment into areas of people's lives in ways that we may not see as justified" (Hens, Cutas, and Horstkötter 2017, 4). Faced with the "temptation for policy-makers to police private lives in the name of future interests, future goods, or of the public good" (ibid.), we need a continuing emphasis on the interests of people in having their procreative and parental autonomy respected.

Complications

Although I have explored a novel way to employ epigenetic knowledge to defend procreative autonomy with an eye on the interests of the future child, I am not sure those arguments succeed. I will shortly discuss two worries: 1) attaching too much weight to etiology and 2) playing into bionormativity.

Firstly, I worry that the arguments above might attach too much importance to etiology, which is exactly what I argued against in chapter 2. Is knowing more about the causes of their diseases or conditions really necessary for people such as Jenn and Alex in order to act on them or improve their lives? Does Alex really need an explanation of a causal chain of events in order to be able to live well with his condition? In general, knowing the cause of something may be a first step towards either preventing it our developing a cure, but this is not always desirable. Autism is just one example of a condition for which more and more researchers advocate moving away from simplistic searches for biological causes or biomarkers (Hens and Van Goidsenhoven 2023). Yet, many autistic people still welcome the search for biological certainty as a basis of diagnosis (Hens and Langenberg 2017). Thus, although knowledge of causes can be valuable, we cannot simply assume that it is meaningful for everyone. This worry might be mitigated if we focus not on the potential of epigenetic knowledge to provide insight about the exact extent to which each factor played a contributory role. Instead, insights from epigenetics and postgenomics more generally can be regarded as opportunities to appreciate how the health and life story of every individual is embedded in a broad biological and social context.

A second set of worries pertains to the normative risk of drawing normative conclusions from biological knowledge. Brighouse and Swift repeatedly stress that their arguments really do not just apply to biological parent-child relationships. I agree wholeheartedly with them that "nothing important need be lacking, from the child's point of view, if she is raised by an adult without this [biological] connection" (Brighouse and Swift 2014, 79). But tensions arise when I extend their argument to the prenatal stage. For example, it might arguably matter less to adopted kids than to kids living with their biological parents which choices those biological parents made before their birth (although this is really an empirical question). Neither do I, by introducing a biological argument, want to downplay the relationship that adoptive parents, step-parents etcetera can have with children, and the influence on their upbringing and understanding of self that they can have. I disagree with David Velleman, who argues that knowledge of biological ancestors and knowledge by acquaintance are so important for the development of one's sense of self and narrative identity that they warrant regarding the biological nuclear family as preferable (other things being equal) compared to non-traditional family-making such as closed adoption. I do not at all want to defend that – in no way do I believe that it is necessary for Alex or Jenn to develop a healthy identity to have the knowledge of their parents' past choices and circumstances and the epigenetic mechanisms that may have connected those with their biological make-up. I merely want to argue that 'epigenetic self-knowledge' may be of some value in constructing one's narrative identity.

Perhaps the 'epigenetic narrative identity argument' made in this section unintentionally taps into a sense of bionormativity or "culturally dominant biologism" (Haslanger 2009, 93). Employing epigenetic knowledge in an emancipatory way may even be understood as a kind of 'strategic biological essentialism' (Warin, Kowal, and Meloni 2020). But maybe, as Daniela Cutas points out, epigenetic knowledge can rather help us see that the category of biological parenthood may need to be broadened: it seems safe to assume that everyone who is closely involved in raising a child influences their environment and experiences and also modulates their molecular biology in doing so (Cutas forthcoming). She suggests that those people may not have parental or procreative responsibilities, but based on their epigenetic contributions they might have a biological 'responsibility for shaping'. Seen from that perspective, epigenetic knowledge production "brings closer together or altogether blurs the margins between parental, non-parental, primary, secondary, individual and collective responsibilities for children" (ibid.).

4. Conclusion

After an overview of existing literature about procreative and parental responsibility and epigenetics, I concluded that most of the existing work points out the dangers of employing epigenetic knowledge in such a way that it overburdens (prospective) parents or blames them unfairly or disproportionally. Although such warnings are important and necessary, later in this chapter I explored whether there might also be more positive or emancipatory ways of thinking about new developments in epigenetics. I explored how the concepts of procreative and parental autonomy could be employed in an ameliorative project that takes into account the complexities of our nonideal world. Then, I considered whether the interests of the (future) child might provide us with additional arguments in favour of parental and procreative autonomy. First, I argued for the potential benefits of shared (epigenetic) knowledge between parents and children that points to a potential causal connection between the choices or exposures of parents before conception and the health of their children. Then, I also suggested that the procreative autonomy of future parents might be a necessary condition for such benefits to be possible. I concluded that it is at least conceivable that children might benefit from gaining such epigenetic self-knowledge that they might integrate in their narrative identity.

Readers may not be very convinced that these specific hypotheses are worth pursuing further. But given the fact that knowledge about epigenomics is rapidly increasing and will continue to do so, it is important to contemplate and imagine its potential positive impact. We should not be afraid to do so in creative ways or by looking for insights in research fields that we might not quickly consider relevant to the ethics of epigenetics. Philosophy of education is just one of the many possible sources of inspiration. Another suggestion is to look once again towards empirical research that reports on the experiences and attitudes of people with regard to the relationship between epigenetic knowledge, agency, autonomy and responsibility. A first step could be to look into empirical literature about the opinions or attitudes of (adult) children about choices or behaviours of their parents that took place before they were born but impacted them in a health-related way, such as drug use. Conducting novel research on the attitudes of people toward potential epigenetic influences in particular could be a next step. This research could include questions that address the worries of bionormativity (e.g. 'how do children in non-traditional families think about how their biological parents may have shaped them not only genetically, but also epigenetically?') and etiology (e.g. 'do people value knowing causes of their conditions?').

To close this chapter and this thesis as a whole, I want to bring our attention back to responsibility issues. Arguably, being less constrained by external circumstances and having more autonomy comes with an increased individual responsibility. I disagreed with Räsänen about the extent to which we can currently hold individual parents, especially mothers, responsible for the health of their children, but I do not disagree with ascribing any responsibility to parents at all. This does not contradict the emphasis on collective responsibility that can be observed in my earlier chapters. Rather, collective responsibility towards the health of future generations needs to be taken up not only to benefit those generations themselves but also to enable their parents to take up their responsibility in ways they see fit. Understood in this sense, the collective responsibilities of the state and healthcare organizations should be geared towards enabling future parents, especially the most vulnerable ones, to take informed and autonomous decisions about factors that might affect the health of their offspring. As Alexandra Shields puts it, "We cannot have healthy mothers without having healthy and safe social and physical environments in which they can live, work, and exercise, and without safe and healthy food that they can access" (Shields 2017, 226). Researchers (including myself) in epigenetics and its ethical and social implications should also play a role by heeding the calls for nuanced and compassionate research communication. Such communication of research findings should not easily allow for exaggerations, and perhaps even pre-emptively address existing social injustices and biases that might otherwise influence their translation into moral and political claims. Consider the following quote by Elizabeth Armstrong:

> We can look at this interrelationship of individual and collective, of private and public, as a mandate to police and control the behavior of individual women. Or we can regard the interdependence of individual and society as a moral imperative to ensure health for our entire population. (Armstrong 2003, 222)

Armstrong does not make this point in the context of epigenetics, but epigenetics makes this interdependence between individuals and society more clear than ever. Research communities, then, have a forward-looking collective responsibility to take the second route she proposes, and to create the circumstances in which parents can flourish.

Appendix

Appendix

Gender and Race Differences in Moral Judgments of Implicit Bias: an Empirical Study

This is a study in experimental philosophy that I am working on together with Kris Goffin. Below, I include the abstract of our draft paper.

Abstract: Our paper investigates gender and race differences in moral judgments and moral attitudes towards implicitly biased behavior with an experimental philosophy method. This is the first study to do so. The ideas of the paper support the feminist project of criticizing idealized notions of moral responsibility. One way to question this idealized theory of responsibility is to see whether these theories of moral responsibility are truly universal or whether there might be race and gender differences, which is what this papers aims to do. We focused on moral responsibility for implicitly biased behavior. We found that participants were on average very convinced that John is morally responsible for his behavior, even though it is not in line with his explicit beliefs. This goes against many theories of implicit bias and moral responsibility that hold that John is not, or only to a limited extent, responsible for what is unintentional. Moreover, we found quite some significant differences between participants based on their gender and race.

Paternalism, Authority and Compulsory Schooling in Social Anarchist Educational Thought

This paper was published in the Journal of Philosophy of Education in 2020 (Moormann 2020). It is the result of research I started in my research master. I here include the abstract and a link to the full article.

Abstract: This paper investigates the implications of some social anarchists' views on education for thinking about authority, educational paternalism and compulsory schooling.

In the first part of the paper, some key concepts in social anarchist theory will be introduced in order to demonstrate the importance of education for social

anarchists. The paper then discusses anarchist educational ideas with regard to the content and process of education. Potential justifications of authority and educational paternalism receive special attention. The final part of the paper revolves around a discussion of compulsory schooling understood as a paternalist practice. It aims to contribute to ongoing debates by evaluating the educational institution of the school, and the practice of compulsory schooling, from a social anarchist perspective. The pragmatic character of this approach is reflected by some final remarks on the feasibility and desirability of compulsory schooling in imagined anarchist societies and our existing societies.

This paper is aimed at anarchist and non-anarchist philosophers of education. Anarchist theory critically scrutinises all authority and hierarchy and takes no existing social structure, institution or practice in any area of life for granted. An engagement with anarchist thinking on educational issues such as authority, directiveness, educational paternalism and compulsory schooling may help anarchists and non-anarchists alike to enrich and deepen their own views on certain practices.

Full article: https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9752.12433

What Are You Reading: Kittay & Kittay letter exchange

This is a short piece with my reflections on the letter exchange 'On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with my Son' (Kittay and Kittay 2000). This piece was published in the section 'What are you reading?' of DiGeSt – Journal of Diversity and Gender Studies *(Bafort et al. 2021). I include the full text below.*

Kittay, E.F., & Kittay, L. B. (2000). On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with my Son. In E. Parens, A. Asch (Eds.), *The Ethics of Prenatal Testing and Disability Rights: A Report from the Hastings Center* (pp. 196-214). Temple University Press.

'Does the decision to abort after diagnosis of disability signal the devaluation of the life of a person with disabilities?' This complicated question is the topic of an email exchange between feminist philosopher Eva Feder Kittay and her son Leo, a philosophy major. The exchange was published as a book chapter titled *On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with my Son* (Kittay and Kittay 2000). When discussing the issue of selective abortion, Kittay combines more traditional, bioethical insights with her own perspective as a feminist, an analytic philosopher, and a mother of a disabled daughter. She argues that the choice to continue or to terminate a pregnancy must always be the woman's to make. Whether this decision is informed by a prenatal diagnosis of disability or not does not influence her stance, although she admits that making such a decision is even more poignant in such cases (p. 173). Often, reasons to abort involve reasons not to assume the burden of raising a child, which is a very heavy burden for mothers of disabled children in a patriarchal, ableist society. But even though Kittay emphasizes the autonomy of the woman, she seems to agree with her son that, in such a society, some reasons for not choosing a future as a parent of a disabled child are better, or more informed, than others. She is less concerned than her son, Leo, about the potential message selective abortion might send to existing disabled people or would-be siblings, but they both hope that such a decision would not be motivated by ableist assumptions about the value of a disabled person's life or of raising a disabled child (pp. 178-179). The focus of this conversation with Leo comes back in Kittay's more recent work, which strives to complicate the implicit assumption of disability as a negative type of difference; still a pervasive assumption in our contemporary public and philosophical discourse. In *Learning From My Daughter* (2019) she explains how her disabled daughter inspired her to challenge long-held philosophical beliefs about what it means to live a good life, the importance of cognitive abilities, and the value of independence.

The tension present in Kittay's work has been thematized by a growing number of contemporary scholars writing about disability. I aim to take up this crucial challenge in my own research on epigenetics and responsibility. Findings in epigenetics, the field of biology that studies molecular mechanisms that influence how and when genes are expressed, have implications for our thinking about health and justice. My work studies possible models and principles to divide responsibility for our health, as well as the health of future generations, since epigenetic changes may also be heritable. In doing so, I inevitably enter the field of tension explored by Kittay and others. While I agree with research that highlights the negative impact of pollution by corporations, I also contend that the cause and definition of harm in these instances is not entirely straightforward. Among the harmful results of our society's unreasonably high, and thus stress-inducing, expectations on women are the potential adverse health effects of such influences on future generations. This tension has led me to opt for a two-pronged research approach: instead of exclusively focusing on how agents can remedy the harms they have caused, which is a backward-looking focus, I also explore what it means to say that all of us, as members of an unjust society, are to some extent responsible for ensuring moral and political progress regarding issues such as women’s rights and disability rights. This means that all relevant moral agents in a society share a forward-looking collective responsibility for these problems and their potential solutions.

Eva and Leo Kittay’s exchange may remind us of the fact that complex ethical issues, such as selective abortion, always benefit from an intersectional analysis that takes in elements of class, race and disability, as well as gender. The piece also demonstrates the value of understanding the personal as political through the integration of their first-hand experiences in their arguments. As a result, their conversation urges researchers in the fields of both gender and diversity studies to view disability through multifaceted theoretical and methodological lenses.

Summary (English)

‘Who is morally responsible for what toward whom?’ This question structures this thesis on responsibility for health in light of epigenetics research. Epigenetics is the biological study of heritable regulations of DNA expression that do not entail changes in the DNA itself. Epigenetic mechanisms influence how and when our genes are expressed, and they are often triggered by environmental influences inside or outside of the body. After an introduction to epigenetics in chapter 1, the second chapter claims that those concerned with ethical and social aspects of such epigenetic findings need to move beyond mere causal understanding of epigenetic harm toward a multidimensional analysis of the concept.

The second section explores the usefulness of the concept ‘forward-looking collective responsibility’ in an epigenetics context. Chapter 3 starts with a literature review of discussions that concern the relation between individual and collective epigenetic responsibility that are ongoing in ELSA literature on epigenetics. Then, it characterizes epigenetic injustice as an instance of historical-structural injustice and provides suggestions for an integrated account of epigenetic responsibilities to address this injustice. Chapter 4 uses some conceptual tools developed in contemporary philosophical scholarship to analyze a historical debate on collective responsibility in social anarchism. It aims to show how anarchist political theory might deepen our thinking about the concept.

The third section of this thesis considers how transgenerational epigenetic inheritance might imply that we have responsibilities toward future generations. Chapter 5 is devoted to the discussion of the Non-Identity Problem in the context of epigenetics. It discusses the potential and limitations of theoretical and experimental research and concludes that we should not let this problem stop us from being concerned with the well-being of future generations. Chapter 6 reports on the findings of an experimental vignette study on lay people’s judgments about vignettes involving the Non-identity problem. Non-philosophers who took part in the study do not always share the intuitions of Derek Parfit. The chapter also critically engages with the use of disability in thought experiments related to the Non-identity problem. Finally, Chapter 7 argues that we need to direct more of our attention toward imagining the potential positive effects of epigenetic knowledge for parents and their children. The central claim of this chapter is that epigenetic knowledge can contribute to constructing the narrative identity of children and families.

Samenvatting (Nederlands)

Epigenetica en morele verantwoordelijkheden voor gezondheid: een filosofische verkenning

Wie is moreel verantwoordelijk voor wat tegenover wie? Deze vraag structureert dit proefschrift over verantwoordelijkheid voor gezondheid in het licht van epigenetisch onderzoek. Epigenetica is de biologische studie van erfelijke regelingen van DNA-expressie die geen veranderingen in het DNA zelf met zich meebrengen. Epigenetische mechanismes beïnvloeden hoe en wanneer onze genen tot uitdrukking komen. Ze worden vaak in gang gezet door omgevingsinvloeden binnen of buiten het lichaam. Na een inleiding tot de epigenetica in hoofdstuk 1 stelt het tweede hoofdstuk dat degenen die zich bezighouden met de ethische en sociale aspecten van dergelijke epigenetische bevindingen verder moeten gaan dan een louter causaal begrip van epigenetische schade en een multidimensionale analyse van het concept moeten maken.

Het tweede deel onderzoekt het nut van het concept 'toekomstgerichte collectieve verantwoordelijkheid' in een epigenetische context. Hoofdstuk 3 begint met een literatuuroverzicht van discussies over de relatie tussen individuele en collectieve verantwoordelijkheid die gaande zijn in de ELSA-literatuur over epigenetica. Vervolgens wordt epigenetisch onrecht gekarakteriseerd als een voorbeeld van historisch-structureel onrecht en worden suggesties gedaan voor een geïntegreerde beschrijving van epigenetische verantwoordelijkheden om dit onrecht aan te pakken. Hoofdstuk 4 gebruikt enkele conceptuele hulpmiddelen uit hedendaagse filosofische literatuur voor de analyse van een historisch debat over collectieve verantwoordelijkheid in het sociaal anarchisme. Het hoofdstuk laat zien hoe de anarchistische politieke theorie ons denken over het concept kan verdiepen.

Het derde deel van dit proefschrift onderzoekt hoe transgenerationele epigenetische overerving zou kunnen impliceren dat we verantwoordelijkheden hebben ten opzichte van toekomstige generaties. Hoofdstuk 5 is gewijd aan de bespreking van het ‘non-identity probleem’ in de context van epigenetica. Het bespreekt de mogelijkheden en beperkingen van theoretisch en experimenteel onderzoek en concludeert dat dit probleem ons er niet van mag weerhouden om ons te bekommeren om het welzijn van toekomstige generaties. Hoofdstuk 6 doet verslag van de bevindingen van een experimenteel vignettenonderzoek naar de oordelen van leken over casussen waarin het non-identity probleem een rol speelt. Niet-filosofen die deelnamen aan het onderzoek delen niet altijd de intuïties van Derek Parfit. Het hoofdstuk gaat ook kritisch in op het gebruik van handicaps in gedachte-experimenten over het non-identity probleem. Ten slotte betoogt hoofdstuk 7 dat we meer aandacht moeten besteden aan onderzoek naar de mogelijke positieve effecten van epigenetische kennis voor ouders en hun kinderen. De centrale stelling van dit hoofdstuk is dat epigenetische kennis kan bijdragen aan de constructie van de narratieve identiteit van kinderen en gezinnen.

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Notes on cover art

English

Art and text by Reinout Engel

Mathematics is the language that describes everything in the cosmos. The smallest part and the largest. The language that describes how everything relates to each other. Proportion and balance. This is also what I try to instill in my work with Islamic geometric patterns. And those proportions and balance are inherent to this 14-hundred-year-old art form. Geometric principles dating back to Euclid and far before, transformed into irresistible ornamental perfection during the first Caliphates in the eighth century.

Within the concept of the patterns I work with, the smallest part fits an exact number of times into the identical but proportionally larger part. This implies an infinite potential for reduction and enlargement. And in those terms, I think we can also see ourselves in relation to the universe of which we are an unsightly small part. But as indescribably insignificant as we are in the universe, we are truly important to our environment in terms of emotional experience, identification and awareness within the social and societal fabric in which we are a structural element. Awareness of this duality between meaninglessness and importance, and acting accordingly, holds within it the seeds of one of the many possible futures we can give our children.

One of the things that makes me happy when I see people interacting with what I make is the wonder on their faces when I tell them what the underlying science, history and cultural context is. Introducing someone to something new, especially in the form of a visually appealing transferable concept, has a direct impact on their life. I firmly believe that offering individual people beauty has an impact on our collective well-being and thus also influences our collective behaviour. This turns an essentially simple visual language into a powerful medium. The beautiful and the good work together.

For more examples of, and questions about, my work, please visit:
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Dutch

Kunst en tekst van Reinout Engel

Wiskunde is de taal die alles in de kosmos beschrijft. Het kleinste deel en het grootste. De taal die beschrijft hoe alles tot mekaar in verhouding staat. Proportie en evenwicht. Dat is ook wat ik de toeschouwer probeer aan te reiken in mijn werk met Islamitische geometrische patronen. En die proporties en evenwicht zijn inherent aan deze veertienhonderd jaar oude kunstvorm. Geometrische principes die terug gaan tot Euclides en ver ervoor, die tijdens de eerste kalifaten in de achtste eeuw tot een onweerstaanbare ornamentele perfectie werden getransformeerd.

Het kleinste deel past binnen het concept van de patronen waar ik mee werk een exact aantal keren in het identieke maar proportioneel grotere deel. Dat impliceert een oneindig potentieel tot verkleining en vergroting. En in die termen denk ik dat we onszelf ook kunnen zien in relatie tot het universum waar we een onooglijk klein deeltje van uitmaken. Maar zo onbeschrijflijk nietszeggend als we zijn in het universum, zo waarachtig belangrijk zijn we voor onze omgeving wat betreft emotionele ervaring, identificatie en bewustzijn binnen het sociale en maatschappelijke weefsel waar we een structureel element in zijn. Het bewustzijn over deze dualiteit tussen nietszeggendheid en belang en het handelen ernaar, houdt in zich de kiem van één van de vele mogelijke toekomsten die we onze kinderen kunnen geven.

Eén van de dingen die me blij maken als ik mensen in contact zie komen met wat ik maak, is de verwondering op hun gezicht als ik ze vertel wat de achterliggende wetenschap, geschiedenis en culturele context is. Iemand kennis laten maken met iets nieuws, zeker in de vorm van een visueel aantrekkelijk overdraagbaar concept, heeft een directe impact op zijn of haar leven. Ik ben er vast van overtuigd dat individuele mensen schoonheid aanbieden een impact heeft op ons collectieve welzijn en zo ook ons collectief gedrag beïnvloedt. Dat maakt van een in wezen eenvoudige beeldtaal een krachtig medium. Het mooie en het goede werken elkaar in de hand.

Voor meer voorbeelden van, en vragen over mijn werk kun je terecht op:
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