

Epigenetics, Bioethics and a Developmental Outlook on Life

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Introduction

Epigenetics refers to the molecular mechanisms that control gene expression. These mechanisms are closely tied to environmental influences within the cell, the body and the environment. Epigenetics ensues naturally from genetics, the life science that dominated Western science in the 20th century. After all, it has always been known, even by the staunchest genetic determinist, that there must be mechanisms for transcribing and translating specific genes in specific circumstances. In this respect, the claim that an epigenetic approach to life and ethics offers something unheard of exaggerates the truth. Indeed, for a long time, scientists and ethicists have investigated and discussed environmental influences. However, in this chapter, I argue that epigenetics in a Waddingtonian sense urges us to rethink the object and scope of bioethics and the relationship between ethics and science in general. I hope to demonstrate that thinking about the historical meaning of epigenetics and its relationship to the concept of development can teach us something about the role that bioethics could play in biomedical research projects. In order to do so, I draw on my work on the ethics of research in developmental diversity such as autism. First, I look at the meaning of epigenetics and the closely related term epigenesis. I demonstrate that, in addition to providing insights into molecular mechanisms regulating gene expression, a focus on epigenetics also supports a developmental view of life. I then give an overview of existing bioethical reflections on epigenetics. I suggest that a developmental approach may require some fundamental changes in ethical considerations. Rather than focusing on epigenetics as an alternative to genetics as a cause of phenomena

and disorders, a developmental approach may imply emphasis on dynamics, context and experiences in normative reflection. To illustrate this, I explore what epigenetics means for research into developmental diversity in general and autism specifically. Finally, I return to the role that bioethicists could play in thinking with and about science, and make some suggestions as to what the role of bioethicists could be in relation to the aims and subjects of responsible science.

What epigenesis and epigenetics have in common is that they presuppose a developmental perspective on life. Epigenesis is a much older word than epigenetics. The term itself was coined in the 19th century by C.V.F. Wolff, although developmental perspectives on organisms have a much longer history, as the term *peri-genesis*, coined by Aristotle, suggests (Wessel, 2009). Epigenesis is a view of the development of organisms, and is often contrasted with preformation. If you hold a preformationist view on life, you consider that an organism's form is already there at the very start, from conception onwards. The preformationist view is closely linked to the idea of the homunculus, i.e. a tiny but fully formed human that lives inside the sperm and is merely enlarged during the organism's development within the uterus. Many 20th-century geneticists, in emphasizing the importance of genes rather than the environment, may be viewed as preformationists. After all, they seem to share the view that everything a person or an organism can become, minus some minor adaptations related to lifestyle and environment, is already there from the beginning. Today, few would question the environment's role in the development of organisms. However, some common assumptions in bioethics retain a dash of preformationism, such as the discussion around the non-identity problem (see Chapter 4). Several examples that Parfit uses in his famous book *Reasons and Persons* (Parfit, 1984) imply that what matters for identity is numerical identity: what happens at conception. At this point, we become who we are.

Nowadays, preformationist thinking seems to be out of fashion to the point that calling someone a preformationist may even be an insult. At the same time, the idea that there is some point in our developmental history when our identity becomes fixed, is something many can relate to, and that is assumed in many discussions about responsibility to (future) offspring.

The epigenetic landscape is a way to describe two mechanisms: canalization and plasticity. Canalization is the adjustment of developmental pathways to bring about a uniform developmental result despite genetic and environmental variations. Imagine the cell as a little marble rolling through the canals or valleys of the epigenetic landscape. Depending on the landscape (or the environment), it is sent through specific channels, ending up as a specific cell type or with a specific function. But there is also plasticity. Suppose that the landscape shuffles a bit: a minor rearrangement may have

little effect on the cell's trajectories because they are canalized. However, if the landscape is completely rearranged, this will significantly affect the phenotype. Hence, plasticity and canalization are not opposites, but work together. Canalized development enables the organism to adapt to different circumstances. Furthermore, adapting to different circumstances implies that the organism is stable enough to withstand complete disruption. Thus, dynamics and stability are two sides of the same coin (Jablonka and Lamb, 2014; Jablonka, 2016).

In describing the epigenetic landscape, Waddington discussed the development of cells in different cell types within the body during phenotype development. He was not suggesting that this represents a general account of the influences of lifestyle and environment on organisms. However, it is easy to see how the ideas of dynamics and stability, plasticity and canalization, can apply to an organism's interaction with its environment throughout its lifetime. For example, Jablonka and colleagues have used the idea of Waddington's epigenetic landscape to provide a way to think about culture. They argue that we can think of the social landscape as a Waddingtonian landscape: a dynamic pattern of life in a particular community where customs and practices become canalized (Tavory et al, 2014; Jablonka, 2016). Moreover, Waddington himself was very aware of the implications of complex systems thinking for science and society at large, as is apparent in his books *The Scientific Attitude* (Waddington, 1948) and *Tools for Thought* (Waddington, 1977). In what follows, I investigate the bioethical implications of a Waddingtonian approach, focusing on autism.

Epigenetics and bioethics: a marriage made in hell?

Bioethicists have discussed the ethical aspects of epigenetics at length. They have asked themselves how, if at all, epigenetics is different from genetics. However, I argue that the relevance of epigenetics is not so much its novelty. Instead, a Waddingtonian approach suggests a different view of organisms than the one that bioethicists may too often have taken for granted. The various meanings of epigenetics described previously have some things in common. Epigenetics, as a molecular mechanism regulating gene expression and as the more general idea of plasticity and canalization in development, gives biology a history. What happens in an organism's life, what it encounters and experiences, resonates in its biology. All interpretations of 'epigenetics' stress development and how organisms come into being, gain form and interact throughout their lives. From an epigenetic point of view, organisms 'lay down a path in walking', to use the words of the enactivist thinker Francisco Varela (Varela et al, 1992). The concept of epigenetics, in all its interpretations, emphasize the entanglement of organisms with their environment. Epigenetic changes occur in response to environmental

influences. However, it would be wrong to see the environment and the genome as two different spheres with equal explanatory power. ‘The environment’ may mean many things: the location of a cell in the body, lifestyle choices such as those related to food and exercise, physical influence such as environmental pollution, and psychological influences such as stress and nurture. All these spheres influence gene expression in distinct ways. Moreover, as is apparent from Waddington’s idea of a network of genes, the question is not one of either/or. Genes and various environmental factors, epigenetics and microbiomes all play a role in the complicated workings of the cell. A developmental view of life is hence not so much a challenge to the central dogma of genetics per se as a challenge to views that consider genes to be the primary or exclusive causes for behaviour, traits and diseases. Moreover, as I argue below, it would be a mistake to look at environmental factors as exact causes, in the way that some consider genes to be. If we conceive of organisms as developing through life in response to input from the environment, this introduces an element of chance, unpredictability and uncontrollability. In light of these chance encounters, canalization and plasticity come into play: we can then conceive of organisms as balancing between maintaining their form and adapting to circumstances.

Many bioethical discussions of epigenetics have explored the relevance of epigenetics to the question of responsibility. For example, what are we to make of the fact that men’s behaviour can influence their future offspring’s health, long before conception? What does it mean, normatively, that a woman’s smoking may affect the respiratory health of her grandchildren? Should a pregnant policewoman quit the stressful job that she enjoys because it has been shown that stress during pregnancy may increase the chance that her child will be hyperactive (Ronald et al, 2010; Dupras and Ravitsky, 2016; Hens, 2017)? These are essential questions, and other contributors to this volume have eloquently written on this topic (see Chapters 2 and 5). However, a shift from genes to environment, from genetic determinism to epigenetics, does not automatically offer an escape from a view of life that tries to reduce phenomena such as behaviours or diseases back to simple explanations. The idea that we are not only defined by our circumstances and lifestyle and by the genes that we inherit from our parents, but also by the experiences of our grandparents and perhaps further generations back in time may lead to an even more reductionist and deterministic view on life. For example, some studies suggest that the trauma of enslaved people lingers in the epigenetic marks of their descendants (Grossi, 2020).

Rather than genetic determinism, we can now talk of epigenetic determinism. Furthermore, there is another danger here. It has been suggested that with the rise of genetic knowledge and since the discovery of CRISPR/Cas9 (a gene editing technology) in 2012, the possibility to select and alter the genes of *in vitro* embryos will open the way to designer

babies and eugenics. However, so far, neither genetic knowledge nor genetic technology is currently sophisticated enough to accomplish this. Understanding the mechanisms that govern gene expression may also lead to use of technologies such as CRISPR/Cas9 to amend the epigenetic layer, such as methylation patterns (Nakamura et al, 2021). Changing this epigenetic layer may be technically easier than changing the underlying genes.

In this sense, the idea that the epigenetic layer is malleable may open a more straightforward way into what Juengst and colleagues call epigenetics (Juengst et al, 2014). Moreover, as explained in the Introduction to this volume, the related discipline of developmental origins of health and disease (DOHaD) investigates and stresses the importance of environmental influences at conception and *in utero*. The popular media has already reported on some of these findings, such as the claim that eating bacon and eggs during pregnancy will make your child smarter (Mehedint et al, 2010). Brain plasticity research often stresses the importance of the first three years of human life in which everything happens. After that, the window of opportunity closes (Wastell and White, 2017). I am not questioning these findings. The first three years of a child's life are indeed important for further development, and policy makers should ensure that parents and other caregivers have sufficient support to provide the best circumstances for their children. In that respect, such research is informative. However, it would be wrong to think that, if children grow up in sub-optimal circumstances, they are doomed for life, or, conversely, if you get the first three years right, everything will fall inexorably into place. I suggest that Waddingtonian epigenetics urges us to consider the idea that the course of life is unpredictable and offers obstacles and chances at any age. Development is not something that solely happens *in utero* or during the first three years; instead, canalization and plasticity play a role from birth to death. Development and life itself are based on experiences and chance as much as on genes or direct environmental influences.

In the next section, I use the example of autism research to show what such a developmental approach to life can mean for research and ethics in this field and beyond.

Autism research: putting the development back into developmental disorders

I choose autism research to illustrate what the adoption of a developmental and complex systems view on life can mean, for several reasons. First, autism is classified as a 'developmental condition', which is good reason for using it as a starting point for reflection on developmental approaches. Second, for a long time, autism research has focused on genetic causes of autism, and ethical questions have often focused on the desirability of using genetic

screening for autism in reproductive medicine (Hens et al, 2016). Third, this focus on causes and explanation has neglected the lived experiences of autistic people.

Research has primarily looked at autism as a developmental disorder in a genetic sense, as something that is caused or at least originates in the prenatal phase. However, if we take the lived experience of autistic people seriously, this means that we should look at autism through the prism of Waddingtonian epigenetics: autistic people have unique life trajectories, and their support needs and wellbeing are highly dependent on the environment in which they live. Researching these dynamics is not only interesting from a scientific point of view, but also goes hand in hand with acknowledging that responsibilities towards autistic people should be assessed on a case-by-case basis and defined by and with autistic people themselves. Hence, an ethics of autism research should not primarily focus on questions of cure, prevention or what to do with genetic knowledge, but rather ensure that what is researched conveys the complexities and situatedness of the autistic experience and is relevant to the flourishing of autistic people.

Autism is classified as a ‘developmental disorder’ or developmental disability in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Many autistic people object to their condition being called a ‘disorder’ (Kapp et al, 2013). Hence, I shall not use that term to refer to it further in this chapter. At the same time, it is vital that we take a closer look at what is meant by ‘development’. In the diagnostic manual, there is not much explanation about what developmental disorders are. For example, the website of the US Centers for Disease Control and Prevention ¹ states that ‘Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime’. Developmental disabilities include autism, attention-deficit hyperactivity disorder, Tourette’s and developmental coordination disorder (dyspraxia). However, it is unclear from this definition what is meant by ‘the developmental period’, and thus the definition is open to a variety of interpretations. It suggests that the impairment at least starts in this developmental period, which is taken to be early in childhood, although that is not specified. However, it is also unclear whether the impairment is caused by something that happens in this period or whether it just becomes apparent in that period. This distinction is not trivial, as is apparent from the history of autism research. During the 1950s and 1960s, it was sometimes argued that autism was caused’ by the distant behaviour of parents, especially mothers, and thus a logical ‘treatment’ would be to remove autistic children from their families and

institutionalize them (Nadesan, 2005). Such an approach was harmful to those families for obvious reasons.

Partly as a reaction to the harmful mother-blaming discourse of the 1950s and 1960s, autism has been considered to be a childhood affliction with a primarily genetic cause from the last decades of the 20th century onwards. More recent autism research has hence focused on finding the genes that cause autism. However, in genetic research in general, there has been a shift away from a search for simple genetic causes for traits, dispositions or behaviours. Nowadays, the search for a genetic ‘cause’ for autism has led to the acknowledgement that ‘causes’ of autism are complex and cannot be attributed to genes alone (Waterhouse, 2013). Genetic and biological explanations can often help autistic people and their parents accept the diagnosis as an intrinsic part of who they are. At the same time, autistic people have expressed worry that there is an agenda of eugenics behind the promises of genetic research into autism. They fear that the discovery of ‘autism genes’ could lead to the inclusion of these genes in panels for non-invasive prenatal tests (Sanderson, 2021). Nevertheless, the suggestion that developmental phenomena such as autism may also have an environmental component is often not welcomed by autistic people and their parents. This reluctance is probably due to the lingering ghost of the ‘refrigerator mother discourse’ (Nadesan, 2005), and the view that many hold that, if something has an environmental component, it can easily be cured, or the person in question is somehow able to change their behaviour at will. An approach to autism inspired by the post-genomics and epigenetics era in biology may help resolve this conundrum.

The fact that autism is understood as a ‘developmental disorder’ with a strongly genetic component has been taken to mean that the first ‘symptoms’ arise early in childhood, as this is a criterion in DSM-5 (American Psychiatric Association, 2013). In another diagnostics manual, ICD-10 (World Health Organization, 2004), autism is defined as ‘lifelong’. However, what is meant by this innateness and lifelong nature remains unclear. For example, does this mean that autistic people will satisfy the diagnostic criteria throughout their lives? Or is a particular way of being, such as a specific manner of information processing, always there in a person, like a character trait? Such ambiguity is apparent in at least two respects. First, autism research currently buys into the idea of the critical window of the first three years by investigating methods to detect autism early on, even pre-symptomatically, and by investigating what kind of early interventions would work. However, there is much uncertainty about what such interventions would accomplish. Is the aim to make people less autistic, an aim that is challenged by autistic people themselves, or to make them behave in a more typical way? Or should these interventions address the actual challenges autistic people face during their lives?

Second, as is apparent from testimonials of autistic people and their parents, such challenges may differ depending on one's life stage or specific context (Hens and Langenberg, 2018). The life stories of autistic adults demonstrate that what autism means and how it is experienced differ. The factors that contribute to challenges or flourishing depend on the path taken through life. Hence, autism is a truly developmental phenomenon in a Waddingtonian sense: there may be a behaviour or a specific way of being that is canalized and persistent, but, at the same time, it is flexible and dependent on changing circumstances. This implies that research investigating autism as a developmental phenomenon should extend beyond the first three years of life. Waddington's epigenetic landscape and the discussion on epigenesis versus preformation can help to make sense of a developmental approach to developmental disability. In the same way that epigenetics has challenged the 20th-century idea of the gene as a blueprint and has firmly anchored biology as being entangled with the environment, the idea of autism as developmental in a Waddingtonian sense could challenge the research focus on causes and explanatory models to one on interactions and experiences. Such an approach to autism research, querying experiences of stability and change in interaction with what one encounters over the course of a lifetime, could yield a more complete view of the phenomenon of autism but is largely still missing.

A developmental approach to biomedical research does not imply that genetic research has now become obsolete. The move toward a post-genomic and systems biology approach to health needs to factor in life's dynamics to understand the dynamics of genes. At the same time, understanding experiences and life stories can tie in with biological research. In order to understand life, and autistic life in this specific case, biology, environment and experience should be studied not as separate fields but as necessarily entangled. Unfortunately, even though autism researchers acknowledge this context relativity and the dynamics of how autistic people experience their diagnosis, and the importance of studying the dynamics of gene expression in addition to the informational value of genes, there is not much research that incorporates these aspects.

Longitudinal studies investigating the meaning and experience of autism throughout a lifetime are still relatively scarce. A developmental approach also suggests that questions regarding the support of autistic people should be posed differently. Indeed, biomedical science in general should not be seen as separate from societal values; it can influence them, and vice versa. A developmental approach to autism in society means recognizing needs, duties, responsibilities and obligations on a case-by-case basis. It also means adopting a fundamentally inclusive approach to autism management.

It may seem as though I have been attacking a straw man up to this point. Geneticists or other scientists often contend that 'everybody knows' that genetic determinism and reductionism are misguided and that there

are environmental components to development. They argue that (post) genetic determinism is merely the result of poor scientific communication in the popular media or a lack of understanding of biology by the general public. My point is not that individual scientists have such deterministic and reductionist views on life but that they may be forced to conduct research in a reductive way.

Let us take it for granted that an important aim of clinical and psychological research is to help the people under investigation. The primary outcome of the search for the ‘autism gene’ is that there is no such gene but that many genes may play different roles, but the immediate benefit of such knowledge to those studied is uncertain. Many projects now investigate whether autism can be detected earlier using biomarkers or early behavioural observation. However, there is still uncertainty about what to do with this knowledge and how it can help autistic people or even help understand ‘autism’ as a subject of scientific inquiry. It is increasingly acknowledged that research that aims to ‘cure’ autism is not what is needed. At the same time, what could help autistic people and how this help may differ between life phases is only recently being incorporated into research. To be clear, my point is not that individual autism researchers or research groups are to blame for the fact that autism research is only now moving away from a purely biological approach. Rather, autism research is an excellent example of how scientific practice and funding today are not ready for a rich understanding of life and experience in all its dynamics and development. Many science projects aim for quick results in a short timeframe, often the time it takes to do a PhD. In order to be successful, project proposals need to be very clear about their end goal and how to achieve it. Finding a gene that is shared in some families with a particular phenotype is feasible in this context, as is identifying general trends in a large population using the statistical methods of behaviour genetics. Spending decades mapping experiences and biology in real life is not so feasible.

A genuinely developmental investigation of developmental disability in all its aspects throughout a lifetime would require a completely different approach to scientific research. It would mean that funding and personnel would have to be guaranteed for many years. Such research could use AI and molecular techniques from systems biology to study the dynamics of gene expression over time, in combination with methods suitable for querying the experiences of the research participants, and with an active engagement of the population under study to co-create research goals and provide feedback during execution of the research. Moreover, such truly developmental science would necessarily be interdisciplinary. In the final part of this chapter, I provide further details on how this approach may shed new light on the role of bioethicists in medical research.

Responsible bioethics, responsible science

In the previous sections, I have suggested that a truly developmental approach to autism in research goes beyond simple causal explanations and instead engages with experiences throughout a lifetime. This means taking lived experiences seriously and looking beyond disciplinary boundaries. In what follows, I suggest what role a bioethicist can play. In short, I argue that bioethics should not involve solely thinking about science, but with science, in a broad endeavour to understand life in all its complexity.

Bioethics as a field is concerned to a large extent with the ethical aspects of biomedical practice. Recently, some bioethicists have critiqued what they call ‘mainstream bioethics’. For example, Henk ten Have has argued that bioethics, as it is practised now, has taken too much for granted the science that it is supposed to reflect upon, and has done so without critically reflecting upon the values that underlie scientific and everyday practice (ten Have, 2022). Similarly, it has been argued that philosophical reflection on the concepts and presuppositions of research should be part and parcel of research ethics, and that philosophy of science and bioethics should not be seen as separate endeavours (De Block et al, 2022).

Narrative and care ethics approaches in bioethics have stressed the importance of experiences and the acknowledgement of situatedness of science, practice and ethics (Lindemann et al, 2008). The example of autism research demonstrates that the kind of research that is done and the ontological commitments that it has have direct implications for the good that such research can do. Based on recent and not-so-recent findings in epigenetics and systems biology, I advocate a developmental outlook on life. Such a developmental outlook sees organisms as constantly in flux, and acknowledges the relevance of each life stage and the context in which that life stage takes place. The rise of projects in systems biology appears to corroborate this approach. At the same time, due to current funding practices in science, researchers cannot fully embrace such systemic, longitudinal and developmental approaches. As a companion to science, bioethics follows suit: many bioethics projects and questions focus on specific moments in life (birth, death, illness). Here I make some suggestions for more developmental, systems biology-ready bioethics practice.

What is the responsibility of bioethicists in research projects? From my experience, many research projects in biomedicine assume that the role of an ethicist is, in the first place, a procedural one: their responsibility is to ensure that correct ethical procedures are followed. At the same time, bioethicists can make recommendations on the ethical use of the scientific findings resulting from the research. In this role, they engage stakeholders and investigate opinions. While all these activities are worthwhile, I believe the responsibility of a bioethicist can go beyond this, and that bioethicists may play a role in many aspects of research beyond research ethics.

First, bioethicists have a responsibility to look critically at the concepts taken for granted in research projects. The complex entanglements of biology, experience, culture and society also call for a truly interdisciplinary approach whereby exact sciences, social sciences and humanities work together to make sense of life trajectories. In interdisciplinary projects, bioethicists and philosophers of science may play a role in clarifying concepts and enabling communication between fields. For example, terms such as ‘gene’ or ‘resilience’ may have a different meaning if you are a molecular biologist, a behaviour geneticist or a disability scholar. None of these meanings contains the final truth, but philosophers can help build communication bridges. Specifically, I see a role as a ‘benevolent gadfly’ for the ethicist in a research project.

Gadflies have a bad reputation, both in philosophy and in everyday life. They cause itches. They break our concentration. Bioethicists and philosophers of science can ask ‘itchy’ questions about the concepts used in research projects, such as the possibility that genes ‘predict’ autism. Specifically, when it comes to genomics research, bioethicists can uncover assumptions about genes and behaviour in research projects that are simplistic or even reductionist, even when they are not made explicit. For example, if we are engaged in a research protocol that claims to find genetic biomarkers for autism, we can keep questioning what is meant by autism in this case and the link between genes and autism. Does autism refer to a specific neurotype, a behaviour, or challenges that may or may not be associated with a neurotype, depending on the circumstances? In the light of epigenetic findings that challenge simple interpretations of the central dogma, in what way do genes ‘cause’ behaviour, and what does ‘a gene for autism’ actually mean?

Second, bioethicists have a responsibility to think critically about how knowledge is acquired. Epigenetics is the molecular proof that one’s life course and experiences are entangled with biology. The philosopher Georges Canguilhem said that ‘life is experience’ ([Canguilhem, 2008](#)). Hence, understanding aspects of life that involve people means going beyond searching for explanatory genes. Understanding experiences of wellbeing, resilience and challenges means actively engaging with people who have these experiences. Such co-creation with stakeholders may be challenging and is not always welcomed by researchers. Bioethicists should ensure that stakeholder engagement goes beyond tokenism, and that the voices of those who are often not heard are included. As one reviewer of this chapter rightly stated, many autistic people do not use verbal language, which may impede research participation. However, this does not imply that engagement is a dead end from the start. It is the responsibility of the bioethicist, who is, after all, responsible for the ethics part of the research, to ensure that we try harder to engage those who are hard to engage.

Third, bioethicists have responsibilities that go beyond scientists and research participants. Scientific practice, specifically in the biomedical field,

aims (or should aim) to benefit humankind and life at large. The responsibility of ethicists is therefore also to think about the aims and impact of science and the benefits for stakeholders and society. Hence, bioethicists should scrutinize research proposals and not be afraid to ask *cui bono* (who benefits) (Haraway, 1997). For example, what benefit does genetic research on autism offer those being researched? The question *cui bono* is not meant to provoke. It should be asked of both the scientists and the relevant stakeholders to ensure that everyone is on the same page right from the project's inception. Facilitating this communication and co-creation of research aims with those affected by the research should be considered part and parcel of an ethicist's work.

The bioethics gadfly is a benevolent one. It is a friend of science. Rather than stalling or impeding, the benevolent gadfly thinks *with* the scientist. In the end, we may hope that both bioethicists and scientists have the same goal: challenging an old-fashioned reductionist and deterministic view on life and ultimately making science 'better' in many ways for relevant stakeholders.

In this chapter, I have suggested how taking the concept of development seriously and engaging with the complexity of organisms offers a different perspective for bioethics. I want to end with two observations for the reader to ponder. First, the distinction between a preformationist and epigenetic approach, as for related ideas such as nature versus nurture, innate versus acquired, and so on, may be a specifically Western one. It may very well be that certain native American relational ontologies can help us grasp the implications of complexity theory and developmental approaches to life (Cordova, 2003; Cordova, 2007; Gare, 2017). The direction I propose should engage with these ontologies and be inspired by them, otherwise we risk reinventing the wheel. Second, as hinted at in the example of autism genetics, a Waddingtonian approach to (epi)genetics may challenge more than Western preformationist assumptions in bioethics. In fact, it may challenge the very premises of ethical thinking in Western philosophy, such as harm or causality. Given how these concepts are usually linked with common moral standards of responsibility, this should give us pause.

Note

¹ <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

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References

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, Washington DC: American Psychiatric Association Publishing.

- Canguilhem, G. (2008) *Knowledge of Life*, New York: Fordham University Press.
- Cordova, V.F. (2003) 'Ethics: the we and the I', in A. Waters (ed), *American Indian Thought. Philosophical Essays*, Hoboken, NJ: Wiley-Blackwell, pp 173–81.
- Cordova, V.F. (2007) *How it is: The Native American Philosophy of V.F. Cordova*, Tucson, AZ: University of Arizona Press.
- De Block, A., Delaere, P. and Hens, K. (2022) 'Philosophy of science can prevent manslaughter', *Journal of Bioethical Inquiry*, 19: 537–43. <https://doi.org/10.1007/s11673-022-10198-4>.
- Dupras, C. and Ravitsky, V. (2016) 'The ambiguous nature of epigenetic responsibility', *Journal of Medical Ethics*, 42(8): 534–41.
- Gare, A. (2017) 'Chreods, homeorhesis and biofields: finding the right path for science through Daoism', *Progress in Biophysics and Molecular Biology*, 131: 61–91.
- Grossi, É. (2020) 'New avenues in epigenetic research about race: online activism around reparations for slavery in the United States', *Social Sciences Information*, 59(1): 93–116.
- Haraway, D.J. (1997) *Modest_Witness@Second_Millennium.FemaleMan_Meets_OncoMouse: Feminism and Technoscience*, New York: Routledge.
- Hens, K. (2017) 'The ethics of postponed fatherhood', *International Journal of Feminist Approaches to Bioethics*, 10(1): 103–18.
- Hens, K. and Langenberg, R. (2018) *Experiences of Adults Following an Autism Diagnosis*, Berlin: Springer.
- Hens, K., Peeters, H. and Dierickx, K. (2016) 'The ethics of complexity. genetics and autism, a literature review', *American Journal of Medical Genetics*, 171(3): 305–16. <https://doi.org/10.1002/ajmg.b.32432>.
- Jablonka, E. (2016) 'Cultural epigenetics', *The Sociological Review*, 64(suppl 1): 42–60.
- Jablonka, E. and Lamb, M.J. (2014) *Evolution in Four Dimensions, Revised Edition: Genetic, Epigenetic, Behavioral, and Symbolic Variation in the History of Life*, Cambridge, MA: MIT Press.
- Juengst, E.T., Fishman, J.R., McGowan, M.L. and Settersten, Jr, R.A. (2014) 'Serving epigenetics before its time', *Trends in Genetics*, 30(10): 427–9.
- Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E. and Hutman, T. (2013) 'Deficit, difference, or both? Autism and neurodiversity', *Developmental Psychology*, 49(1): 59–71.
- Lindemann, H., Verkerk, M. and Urban Walker, M. (2008) *Naturalized Bioethics: Toward Responsible Knowing and Practice*, Cambridge: Cambridge University Press.
- Mehedint, M.G., Niculescu, M.D., Craciunescu, C.N. and Zeisel, S.H. (2010) 'Choline deficiency alters global histone methylation and epigenetic marking at the Re1 site of the calbindin 1 gene', *The FASEB Journal*, 24(1): 184. DOI: 10.1096/fj.09-140145.

- Nadesan, M.H. (2005) *Constructing Autism: Unravelling the 'Truth' and Understanding the Social*, London: Routledge.
- Nakamura, M., Gao, Y., Dominguez, A.A. and Qi, L.S. (2021) 'CRISPR technologies for precise epigenome editing', *Nature Cell Biology*, 23(1): 11–22.
- Parfit, D. (1984) *Reasons and Persons*, Oxford: Oxford University Press.
- Ronald, A., Pennell, C.E. and Whitehouse, A.J.O. (2010) 'Prenatal maternal stress associated with ADHD and autistic traits in early childhood', *Frontiers in Psychology*, 1: 223.
- Sanderson, K. (2021) 'High-profile autism genetics project paused amid backlash', *Nature*, 598(7879): 17–8. <https://doi.org/10.1038/d41586-021-02602-7>.
- Tavory, I., Jablonka, E. and Ginsburg, S. (2014) 'The reproduction of the social: a developmental system theory approach', in L.R. Caporael, J.R. Griseimer and W.C. Wimsatt (eds), *Scaffolding in Evolution, Culture and Cognition: Vienna Series in Theoretical Biology*, Cambridge, MA: MIT Press, pp 307–27.
- ten Have, H.A.M.J. (2022) *Bizarre Bioethics: Ghosts, Monsters, and Pilgrims*, Baltimore, MD: Johns Hopkins University Press.
- Varela, F.J., Rosch, E. and Thompson, E. (1992) *The Embodied Mind: Cognitive Science and Human Experience*, Cambridge, MA: MIT Press.
- Waddington, C.H. (1948) *The Scientific Attitude*, London: Penguin Books.
- Waddington, C.H. (1977) *Tools for Thought*, London: Cape.
- Waddington, C.H. (2012) 'The epigenotype. 1942', *International Journal of Epidemiology*, 41(1): 10–13.
- Wastell, D. and White, S. (2017) *Blinded by Science: The Social Implications of Epigenetics and Neuroscience*, Bristol: Policy Press.
- Waterhouse, L. (2013) *Rethinking Autism: Variation and Complexity*, Cambridge, MA: Academic Press.
- Wessel, A. (2009) 'What is epigenesis? Or Gene's place in development', *human_ontogenetics*, 3(2): 35–37.
- World Health Organization (2004) *ICD-10: International Statistical Classification of Diseases and Related Health Problems – tenth revision* (2nd edn), World Health Organization. Available from: <https://apps.who.int/iris/handle/10665/42980> [Accessed 3 May 2023].