

# The many meanings of autism: conceptual and ethical reflections

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This article is commented on by Graf on page 994 of this issue.

## PUBLICATION DATA

Accepted for publication 26th April 2019.

Published online 17th June 2019.

Autism is a polysemous concept. It is defined as a neurodevelopmental disorder that is diagnosed based on an assessment of behaviour and dysfunction. Autism also refers to a specific way of information or sensorial processing. For those diagnosed with autism, it is a real and shared experience. In this paper, I sketch the moral work that biological conceptions of autism perform. They help to conceptualize the diagnosis and associated challenges as real and they remove some of the blame from the diagnosed person and/or their parents. But such approaches also risk neglecting the role of behaviour as a meaningful reaction to experiences. In thinking about the ethics of autism research, diagnosis of autism, and autism care, the recent findings of epigenetics and systems biology may help us overcome the dichotomy between biology and psyche, and point the way to a more nuanced and ethical view.

Autism as a phenomenon has raised a plethora of ethical questions, both for clinicians and diagnosticians as well as for researchers.<sup>1–3</sup> For example, how should clinicians respond to the feeling sometimes expressed by certain scholars and in the media that ‘too many children are given a psychiatric diagnosis nowadays’?<sup>4</sup> What if a child is officially in the so-called subclinical range for autism but an autism approach would be of great benefit to the child? Should a diagnosis be withheld? Which terms should be used to explain autism to people who have recently received a diagnosis for themselves or their child? It may be helpful to use biological terminology (‘a differently wired brain’), but should clinicians also convey the existing uncertainties regarding the aetiology of autism? Autism researchers and those who fund autism research may be confronted with questions related to how to set research priorities, and with sometimes incompatible views among stakeholders (parents of autistic children, adults with a diagnosis of autism, clinicians). Should research on autism be focussed on finding its biological origins, or on finding treatment? And does treatment consist of finding a ‘cure’ for autism for some of its more challenging behavioural expressions, or of finding better ways in which autistic people can flourish in society. Moreover, as some authors have argued, what wellbeing actually *is* for an ‘autistic person’ may very well not be the same as what wellbeing is for the more typically developing population.<sup>5,6</sup> In this paper, I will use identity-first language (‘autistic person’, ‘autistic people’), as research suggests that this is the formulation that the majority of autistic people prefer.<sup>7</sup>

In what follows, I will not tackle these questions as such; answering these questions presupposes that we first find a common ground about how to talk about autism. Therefore, I will first describe the conceptual challenges that

ethicists face when making sense of the ethical questions surrounding autism. I will then give an overview of the normative function of biological explanations of autism in the debate. Finally, I use the idea of epigenetics, and the thinking of French medical doctor and philosopher Georges Canguilhem to suggest a non-reductionist way of looking at autism that considers the lived experience of autistic people as scientifically relevant.

## AUTISM: HETEROGENEOUS AND POLYSEMIOUS

The heterogeneity of autism is well documented, but is mostly meant to denote differences in behavioural phenotype, suggesting that there are many ways in which an underlying cognitive or biological reality can express itself.<sup>8</sup> But the meaning of the term autism in itself has different layers, and as such ‘polysemous’ would also be an adequate term to describe autism. Such a polysemic approach to autism acknowledges that autism has many meanings, and that these meanings cannot necessarily be reduced to one another. People from different professions may mean different things when they talk about autism. The diagnosis of autism spectrum disorder is done by the observation of behaviour and on an assessment of dysfunctioning, which is based on how autism spectrum disorder is defined in the DSM-5,<sup>9</sup> or the International Classification of Diseases-11th Revision. (Interestingly, other classifications such as Tic disorder do not include the criterion of dysfunctioning, and these diagnoses can in principle be given based on behavioural phenotype alone). Hence, for psychiatrists and child neurologists, a diagnosis of autism spectrum disorder is never solely the description of certain behavioural characteristics of an individual; it is always linked to the challenges the individual experiences in his or her life. The diagnosis offers some guidelines as to how to

proceed with tackling and alleviating these challenges, and is not solely made on certain characteristics of an individual, a certain kind of social behaviour, or a specific type of information processing. However, when asked what autism actually *is*, many people, including clinicians, will not only refer to challenging behaviours.<sup>10</sup> They will often refer to a specific way of information processing or sensorial processing that is related to how the brain works, that is innate and has a genetic origin. Such explanations may refer to neurocognitive theories for the specific workings of the autistic mind, including theories positing a deficit in theory of mind, a weak central coherence, or weak executive functioning.<sup>11</sup> More recently, theories have emerged that try to explain the behaviour of autistic persons using models that suggest specific autistic ways of low-level information processing, or differences in sensorial processing. Examples of these models are enhanced perceptual functioning,<sup>12</sup> intense world syndrome,<sup>13</sup> and high inflexible precision of precision errors.<sup>14</sup> Although the explanatory models are often still used to explain autistic behaviour, and although new theories of autism are still being developed, some autism researchers, such as Happé et al.,<sup>15</sup> have suggested that it is perhaps impossible to find one underlying explanation of autistic behaviours.

Besides a neurocognitive reality, autism is now also considered a highly biological disorder, with a strongly genetic component. But it has been acknowledged for quite some time that given the heterogeneity of the autistic phenotype, the search for one genetic cause is likely to fail, and that the heterogeneity is also present at the level of the genotype.<sup>16</sup> Moreover, besides autism's heterogeneity on the behavioural, cognitive, and genetic level, authors have demonstrated that the term autism has come to mean different things throughout its history. For example Verhoeff<sup>17,18</sup> has demonstrated that there is something fundamentally historical in the way autism is defined, and that autism's meaning has shifted several times since its first use, despite the insistence of certain scientists that an essence of autism may still be found. Authors such as Silverman, Navon, Eyal, Evans, and Nadesan<sup>19–23</sup> have all given descriptions or explanations of how and why the diagnostic category of autism has evolved and expanded.

The idea that the phenomenon of autism cannot be reduced to one underlying cognitive or genetic explanation, and may thus lack construct validity, has led some to argue that autism as a concept should be abandoned in research,<sup>24</sup> or as a diagnostic label.<sup>4</sup> However, this seems to neglect the fact that autism is also a lived and shared experience. Despite its apparent heterogeneity, autism as a concept makes it possible for people (parents of children with a diagnosis and autistic adults) to relate their shared experiences and to interpret their experiences in a meaningful way. In an interview study with people who have received their diagnoses when they were adults, Langenberg and I found that for our interviewees, the diagnosis was a valuable moment, which provided insight and it reflected a real and experienced difference.<sup>25</sup>

### What this paper adds

- The meaning of 'autism' has different layers and as such autism is a polysemous concept.
- The lived experience of autistic people matters in research.

Scholars with a background in disability studies have also stressed the importance of lived experiences, and have also suggested alternative and complementary views on disability and autism. In her book *Authoring autism: on rhetoric and neurological queerness*, Yergeau describes autism as a 'narrative condition', that is defined and redefined by how autistic people narrate about their condition.<sup>26</sup> Using the concept of 'autie-biographies', Van Goidsenhoven also describes how autistic people live with and challenge the boundaries of autism as a biomedical category.<sup>27</sup> In their paper *Reading Rosie: the postmodern disabled child*, Goodley and Runswick-Cole describe the same child, Rosie, through different lenses.<sup>28</sup> They demonstrate how it is precisely because of the different meanings that we attribute to phenomena such as autism or disability, meanings that cannot be reduced to one another, that an openness is created for a productive (and non-reductive) uncertainty. What such approaches have in common is that autism's 'realness' is not contingent on an ultimate causal explanation, but is located in a shared and lived experience, an experience that is both felt as intrinsically real as well as contextually defined, and as constantly in motion.

### THE NORMATIVE IMPLICATIONS OF BIOLOGICAL INTERPRETATIONS

I have described how autism has several possible meanings and how disability scholars have demonstrated that the fact that these meanings cannot always be reduced to one another does not necessarily have to be problematic. In what follows, I will return to what is the predominant meaning of autism: that of a neurodevelopmental disorder that is diagnosed on the basis of behavioural criteria defined in the diagnostic handbook.<sup>9</sup> Indeed, although autism spectrum disorder is defined in the DSM-5, it seems that it is one of the conditions that is considered to be more biological than for example the mood disorders. For example, a study by Ahn et al.<sup>29</sup> has shown that clinicians conceptualize cognitive disorders along a single continuum spanning from highly biological disorders (e.g. autistic disorder) to highly non-biological disorders (e.g. adjustment disorders). Already in his original text on infantile autism of 1943, Kanner suggested that autism was primarily an innate and biological disorder, although he later seemed to temporarily adopt psychoanalytic views as well.<sup>30</sup> In the 1960s and 1970s, after the wane of the popularity of psychoanalytic explanations in many countries (see Rutter,<sup>31</sup> for example), autism became firmly entrenched in the minds of professionals, parents, and lay people alike as a biological disorder, one that is considered innate and quite probably lifelong. This conception has led to a proliferation of research into the genetic etiology of autism.<sup>24,32</sup> The idea of autism as a disorder firmly

located in a person's genetic biology has also served to take away the blame from parents for the behaviour of the child, a blame that was often present in psychoanalytic approaches. Today, a diagnosis of autism may have the function of deculpabilizing the parents of the child, or the diagnosed adult; the fact that autism is seen as originating from a difference 'in the brain' or 'in the genes', is often taken to imply that people should not be blamed for their behaviour. This insight can serve an important therapeutic function.<sup>33</sup> In the context of psychiatric disorders in general, certain findings suggest that people with a diagnosis that is considered innate, genetic, and biological are considered less responsible for their actions than those with a personality disorder.<sup>34,35</sup> For example, in a vignette study by Lebowitz et al. it was found that lay people's conceptions of attention-deficit/hyperactivity disorder as caused by either biological or psychosocial factors influenced stigmatizing attitudes and prognostic beliefs. When attention-deficit/hyperactivity disorder was attributed to a biological cause, the condition was thought of as less treatable. But a biological conception also led to less stigmatization, as the person with attention-deficit/hyperactivity disorder with a presumed biological cause was considered less to blame for his or her actions.<sup>36</sup> Also, such beliefs about mental disorders influence how normative responsibility towards these individuals is conceived. For example, beliefs influence how clinicians assess the usefulness of medication for certain disorders. In a study investigating mental health clinicians' beliefs about biological, psychological, and environmental bases, Ahn et al.<sup>29</sup> found medication to be more effective for what they thought of as biologically based cognitive disorders and psychotherapy to be more effective for what they thought of as psychosocially based cognitive disorders. Hence, the conceptualization of a psychiatric disorder, including autism, has profound implications for clinical practice.

In the first part of this paper I argued autism is, besides a heterogeneous concept, also a polysemous concept. Disability scholars have demonstrated that this polysemy need not be problematic, as it opens up possibilities for different possible narratives about the autistic person. The biological explanation helps exculpating autistic people and their parents, as they are now considered less responsible for, and thus less to blame for, their or their child's behaviour, an insight that may be helpful in a therapeutic context. A biological explanation also serves to underscore the realness of the autistic experience; it is not merely a quirk in one's personality that one can overcome. However, an emphasis on biological–etiological explanations in research can actually have the opposite effect: mechanistic–biological explanations of autism may redirect resources from research into what it is like to be autistic, and what purpose certain autistic behaviours serve, to the investigation of autistic mice and fruit flies, whose behaviour is explained solely through the genes that were knocked out. In the next part, I suggest a way to conceptualize autism that does not deny its biological basis, but does so in a non-reductionist way,

and that sees experiences as necessary ingredients for understanding behaviour.

## DYNAMIC CONCEPTIONS AND THEIR ETHICAL IMPLICATIONS

In the second half of the 20th century, there was a prevailing hope that the increasing knowledge of genomics would lead to major breakthroughs in drug development and personalized medicine. Since the beginning of the 21st century, however, it has become apparent that many of these expectations were based on a naïve view of what genes actually do. Discoveries in the field of epigenetics, which studies gene expression, suggest a more dynamic concept of human nature and human diseases and disorders. Indeed, the 'central dogma of genetics' assumes a unidirectional way in which genes define a phenotype (an organism's observable characteristics). However, geneticists and biologists have always been aware that this unidirectional model cannot explain certain phenomena. Philosophers of biology have already reflected extensively on how plasticity, the ability of organisms to adapt flexibly to environmental change, affects the nature–nurture distinction.<sup>37</sup> Observations in biology seem to challenge the idea that human norms can be understood apart from an individual's environmental context. For example, it is suggested that human organisms are the result of the whole organism–environment system that supports human development.<sup>38</sup> As such, the assumption that human nature is something 'from within' (as in a genetic blueprint), or that human nature is universal, is challenged.<sup>39</sup> The effect of such dynamic conceptions of human nature on normative reflection can be interpreted in at least two different ways.

On the one hand, epigenetic explanations can be interpreted in a similar way to genetic explanations; instead of looking for a single causal explanation for a behaviour in genes, we look at a causal explanation in the environment, hence embracing what Lock<sup>40</sup> has called 'a new form of somatic determinism'. For example, it has been demonstrated that air pollution can cause epigenetic changes resulting in adverse health outcomes.<sup>41</sup> Rather than a genetic culprit, we find an environmental culprit, pollution, which is more easily traced down to a single (or multiple) human who is (or are) responsible. Indeed, the language about the science of epigenetics is already imbued with suggestions of responsibility and blame; Pembrey et al.<sup>42</sup> found that when males started smoking at a young age, this had an effect on the body mass index of their future sons. A response to these findings mentions 'the sins of the fathers and their fathers'.<sup>43,44</sup> Further, Richardson et al.<sup>45</sup> warned that careless reporting of epigenetic influences may lead to harm to women, as they would be blamed for epigenetic effects that occur in utero.

On the other hand, epigenetics may suggest that the search for etiological causes of behaviours can always only be part of the story. Epigenetics ties organisms tightly with their context and environment, and may demonstrate, on a molecular level, that behaviours of people are always also a reaction to the context, rather than merely upstream effects of genetic differences. Hence, Lock<sup>40</sup> states nature and nurture are to be

conceived of as thoroughly entangled, an idea that moves us beyond mere gene–environment interactions. Dupras and Ravitsky call for an approach that gives closer attention to the difficulty of defining what constitutes epigenetic normality and plasticity, and how the idea that certain epigenetic modifications leading to disorders may suggest a mismatch between individual and a specific environment, rather than an abnormality per se.<sup>46</sup> As such, epigenetics seems to be a vindication of the thoughts of French medical doctor and philosopher Canguilhem, who considered organisms to be in constant dynamic interaction with the environment. A pathology is a state that is experienced by the organism as negative biological experiences; it is not solely located in the individual, but arises through the mismatch between individual and environment. Hence, according to Canguilhem,<sup>47,48</sup> medicine is not purely ‘hard science’; it may be possible to pinpoint the mismatch between individual and the environment, but whether something is considered normal or pathological is located in the experiences of the individual. Such a systemic approach to health and disease, which seems to be corroborated by epigenetics, poses new challenges for bioethicists, who up until recently have often favoured questions about what we can know about our genes and whether we should take control of our genes to improve children or mankind as a whole. But epigenetics, and the challenges it poses to traditional concepts of genetics and human nature, may force us to rethink our ethical considerations. We may have to move from questions concerning the possible dangers of too much knowledge and control, for example in debates about prenatal screening, to fundamental questions on how we should deal with complexity, risk, and dynamically adapting systems that are intricately intertwined with their physical and psychosocial environment.

What implications does such a dynamic view on human nature have for autism and autism ethics? It has been acknowledged that autism can probably not be explained by a simple genetic cause. In most cases, genes that are associated with an autistic phenotype are risk factors. It has been suggested that environmental influences, such as particulate matter due to pollution, may affect the development of autism spectrum disorder.<sup>49</sup> The current understanding that there probably are epigenetic components in its development challenges the predominant view on autism as a neurodevelopmental disorder with a purely genetic basis.<sup>50</sup> Environmental factors, as well as psychosocial factors, directly influence gene expression, and hence resonate on a molecular level, as is shown by recent studies on epigenetics and early childhood trauma.<sup>51</sup> Such acknowledgment of environmental factors in

autism also has certain challenges. As I have argued above, if epigenetics is viewed as another (single) causal explanation for autistic behaviour, the search for one specific genetic factor may be substituted by the search for one environmental factor. This may lead to a simplistic attribution of responsibility for autism to a specific individual or to a collective (such as an institution) responsible for a specific environment. Taking epigenetics to be an illustration of a more dynamic and systemic approach to health and pathology would allow us to step away from trying to explain autism by one specific factor to an assessment of the behaviour of an individual with a genetic vulnerability as a meaningful reaction within a given physical and psychosocial context. This may allow for a view on autism that acknowledges the biological realness of the condition. But at the same time such an approach acknowledges that certain genetic atypicalities need not lead to dysfunctioning in every situation or to a ‘disordered’ phenotype. As a dynamic approach to organisms considers behaviours as meaningful reactions to the environment, this conception also paves the way for an acknowledgment of the importance of autistic experiences, as these can yield important information, both in a clinical context and in research. For example, questions regarding the desirability of early detection and intervention of autism do not need to focus on the early detection of a condition, or a biomarker for a condition, that is solely located in the individual, but can take the approach of looking at the attunement of the individual and context, in constant dialogue with what is meaningful for the individual and their surroundings.<sup>52</sup> For autism research, this approach suggests that in order to understand why certain persons exhibit behaviour that is considered autistic, it may no longer be sufficient to map the behaviour one-on-one to a genetic or neurological problem. Rather than seeing behaviours as the upstream results of underlying genes or malfunctioning brains, autism’s etiology cannot be properly understood without a reference to what a certain behaviour actually means for an individual in a given context. Hence, this approach may also yield new insights in ethical questions regarding treatment or diagnosis, as it allows for a non-reductionist interpretation of autism.

## ACKNOWLEDGEMENTS

I would like to thank the three anonymous reviewers for their extremely useful comments and Leni Van Goidsenhoven for useful brainstorm sessions on disability studies and the philosophy of Georges Canguilhem. I have received funding from the European Research Council (ERC) under the European Union’s Horizon 2020 research and innovation programme (grant agreement No 804881).

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## RESUMEN

**LOS MUCHOS SIGNIFICADOS DEL AUTISMO: REFLEXIONES CONCEPTUALES Y ÉTICAS** El autismo es un concepto polisémico. Se define como un trastorno del desarrollo neurológico que se diagnostica basándose en una evaluación y la disfunción del comportamiento. El autismo también se refiere a una forma específica de información o procesamiento sensorial. Para aquellos diagnosticados con autismo, es una experiencia real y compartida. En este artículo, bosquejo el trabajo moral que realizan las concepciones biológicas del autismo. Ayudan a conceptualizar el diagnóstico y los desafíos asociados como reales y eliminan parte de la culpa de la persona diagnosticada y / o de sus padres. Pero tales enfoques también corren el riesgo de descuidar el papel del comportamiento como una reacción significativa a las experiencias. Al pensar en la ética de la investigación del autismo, el diagnóstico del autismo y el cuidado del autismo, los hallazgos recientes de la epigenética y la biología de sistemas pueden ayudarnos a superar la dicotomía entre biología y psique, y señalar el camino hacia una visión más matizada y ética.

## RESUMO

**OS MUITOS SIGNIFICADOS DE AUTISMO: REFLEXÕES CONCEITUAIS E ÉTICAS** Autismo é um conceito polissêmico. É definido como um transtorno neurodesenvolvimental diagnosticado com base em uma avaliação do comportamento e disfunção. O autismo também se refere a uma forma específica de processamento sensorial ou de informação. Para aqueles diagnosticados com autismo, é uma experiência real e compartilhada. Neste artigo, eu delinheiro o trabalho moral que as concepções biológicas do autismo desempenham. Elas ajudam a conceitualizar o diagnóstico e os reais desafios associados, e removem parte da culpa da pessoa com o diagnóstico e/ou seus pais. Porém, tais abordagens também correm o risco de negligenciar o papel do comportamento como uma reação significativa às experiências. Pensando sobre a ética em pesquisas, diagnóstico e tratamento do autismo, os achados recentes sobre epigenética e biologia dos sistemas podem nos ajudar a superar a dicotomia entre biologia e psique, e apontar o caminho para uma visão mais apurada e ética.