Thinking with Neurodiversity in philosophy & research

Kristien Hens

R2D2 Mental Health

Funded by the European Union

neuroEpigenEthics

University of Antwerp

erc European Research Council Established by the European Commission

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Introduction

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Neurodiversity in philosophy and science

NeuroEpigenEthics: developing a developmental perspective

Beyond NeuroEpigenEthics

Who am I?

PhD 2010: ‘Ethics of Pediatric Biobanks’

2011-2014: Postdoc on reproductive technologies

- -> interested in disability studies

2014-2018: different projects on autism and (epi)genetics

- 2014: ethics of autism genetics
- 2015-2017: qualitative study on experiences of autism

Interest:

- Concepts of biology
- Importance of experience
- Reflection on the task of bioethics

- 2019-2023: ERC-StG NeuroEpigenEthics

Neurodiversity?

- *“Neurodiversity is a term that describes the natural variation in brain function and behaviour among humans. It means that there is no one “right” way of thinking, learning, and behaving, and that differences are not viewed as deficits or disorders, but as part of normal human diversity “*

A divergence from normative functioning as expressed in phenomena such as perception, sociability, emotionality, learning, and attention (the list of phenomena is from Stenning & Rosqvist, 2021)

Neurodiversity!

- Not denying that specific neurotypes have specific needs.
  - But: needs defined on the basis of what people themselves think important
- A paradigm, a way of doing research
  - Not about ‘curing’ but about what makes people of different neurotypes flourish
  - Importance of lived experience! Active engagement of neurodivergent people!
- A political term,
  - Requesting inclusivity.

Neurodiversity in philosophy and science

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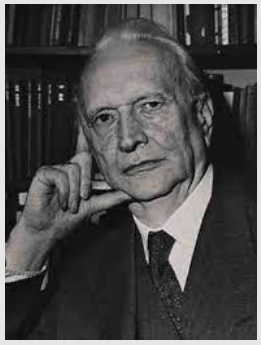
Philosophy: the good life

- Theories about the good life often start from a neurotypical view on functioning.
- Sometimes philosophers have even argued that this means neurodivergent ways of living have less value.
  - Need for philosophy to engage with lived experiences.

Science: explaining behaviour rather than understanding it

- For a long time, autism science has been about explaining the etiology of neurodevelopmental differences
  - The gene for
  - The brain region for
  - The cure for
- But it is equally important to understand what being autistic actually means.
  - Lived experience



Critique: The neuronormative ideal is not productive

- Science: the normal behaviour, the normal biology, the normal mind.
- Philosophy: the ‘default’ human being, and associated concepts of happiness and what it means to function well

- → Standpointepistemology: ‘strong’ objectivity should include viewpoints and perspectives of those who often are left out, but who have specific knowledge that default people don’t have.

Autism in philosophy and science today

Turning point:

In search of explanatory models that are closer to autistic experience (enhanced perceptual functioning, HIPPEA)

Explanatory models that come from autistic researchers themselves (eg Dinah Murray, monotropism)

Ethics that doesn't question the importance of different neurotypes anymore

Autism in philosophy and science today

Social difficulties not solely conceived as problems of the individual (double empathy problem (Damien Milton), participatory sense making (Hanne Dejaegher)

More attention towards what flourishing means for autistic people

→Neurodiverse science as paradigm shift

→Not only about being 'ethical' but yields better science!

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NeuroEpigenEthics

& Philosophies of Staying With The Trouble

NeuroEpigenEthics 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. NeuroEpigenEthics is funded by an ERC Starting Grant (grant agreement No 804881) and is hosted at the University of Antwerp and KU Leuven.

The NeuroEpigenEthics family includes those working on the ERC-project, but also extends beyond it. Researchers working on similar topics, with backgrounds in a range of disciplines, all come together at our biweekly team meetings to inspire each other.

We believe that complex questions require an interdisciplinary approach. We use different empirical approaches: experimental philosophy, interviews and other types of qualitative research. We believe in the value of experience stories (all voices matter). We engage with ideas from different disciplines and theoretical approaches, such as analytic philosophy and philosophy of biology, new materialism, bioethics...

Kristien Hens

I am investigating concepts of biology and their relevance for bioethics. More specifically, I try to investigate how posthumanist and ecofeminist ideas can inspire more traditional bioethical approaches. ***Kristien Hens is the PI and Grant Holder of NeuroEpigenEthics.***

Jo Bervoets

My research is on **neurodiversity, specifically autism and Tourette's**. I investigate how our current view of neurodivergence contributes to the problems of the atypical. I try to elaborate a more nuanced view that alleviates stigma and spurs new scientific inquiry.

Lisanne Meinen

I explore the possibilities of using **videogames to convey lived experiences of psychological vulnerability**. In doing so, I critically engage with concepts such as empathy and care and reflect on cultural approaches to disability.

Joke Struyf

I examine **feminist conceptions on motherhood/mothering** and the underlying assumptions about agency. Furthermore, I want to phenomenologically explore mothers' sense of agency in their mothering practice. I am influenced by queer and crip theory and intersectional feminism.

Daan Kenis

I investigate the **ethics and epistemology of precision medicine**, a novel data-driven approach to medical research and healthcare practice through a feminist lens. I tackle questions such as: how do conceptions of medical knowledge affect care and caring relationships?

Ina Devos

I investigate the **ethical issues in large-scale biomedical proteomics research**. Through collaboration with proteomics researchers and integration of participant experiences, I aim to develop guidance on the scientifically and ethically sustainable implementation of such research.

Nele Buyst

I am interested in how creating stories with and for a community of multi-species can help us to (re)define our responsibility towards our surroundings: how it may help us to restore our relationship with our environment and ourselves. I am inspired by ecofeminism, new materialism, care ethics, the works of poets, artists, gardens, things.

Leni Van Goidsenhoven

I focus on **disability studies and crip theory**.

Gert-Jan Vanaken

I am currently wrapping up my doctoral research project on the ethics of early clinical autism care. My work combines empirical qualitative methodologies with ethical reflection at the intersections of disability and neurodiversity studies, clinical autism research and bioethics. In future research I will focus on exploring neurodiversity-affirmative approaches to clinical autism care.

Emma Moormann

My PhD thesis is a philosophical exploration of epigenetics and moral responsibilities for health. In particular, I employ various methods to reflect on what is owed, by whom, towards future generations with regards to their epigenetic health.

Varsha Aravind Paleri

My research focuses on the **ethical aspects of Synthetic** ology (SynBio). More specifically, my interest is in the human and environmental justice aspects of SynBio. I aim to create an ethics-by-design toolkit that would act as a guiding tool to adopt an ethically oriented approach in SynBio

François-Lucien Vulliermet

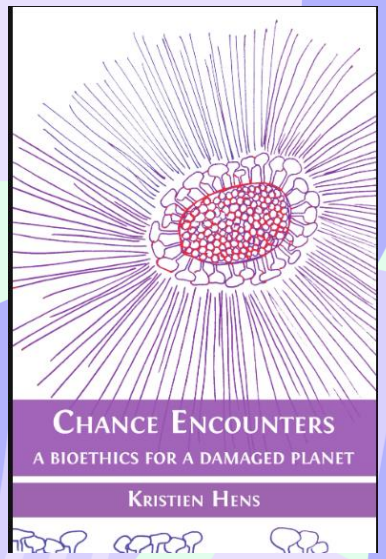
I investigate how epigenetics redefine the relationship we have with nature and places to question the moral responsibility we have towards environmental pollution. I draw inspiration from non-western theories focusing especially on indigenous populations in Ecuador.

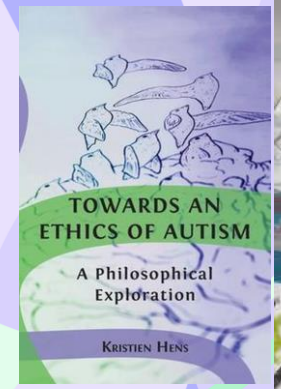
Lies Van Den Plas

With a background in psychology, I work on the interdisciplinary ERASMUS project: empower parents of autistic children through neurodiversity-affirmative psycho-education.

Anna Smajdor (University of Oslo)
Andreas De Block (KU Leuven)
Daniel Jones (Newcastle University)
Daniela Cutas (Lund University)

www.neuroepigenethics.com | YouTube NeuroEpigenEthics





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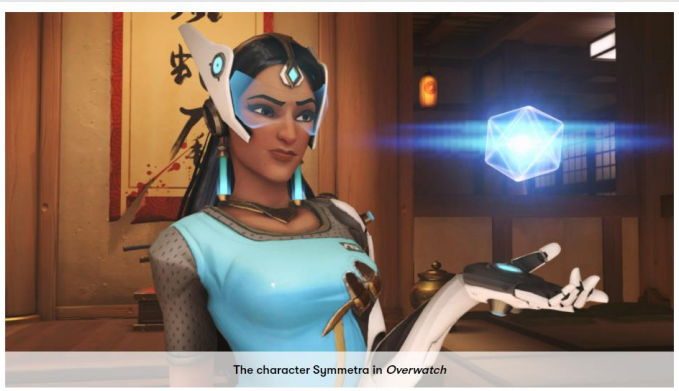

The character Symmetra in *Overwatch*

SJDR Scandinavian Journal of Disability Research

Reading: Listening Beyond Words: Swinging Together Share:

Article

Listening Beyond Words: Swinging Together

Authors: Leni Van Goidsenhoven, Elisabeth De Schauwer

News & views

Genetics

https://doi.org/10.1038/s41591-023-02403-7

How to talk about autism: reconciling genomics and neurodiversity

Luca Chiapperino & Kristien Hens

A new study showing that genetic and non-genetic factors contribute to autistic traits calls for a fundamental realignment of the concepts and methods of genomics, with a critical understanding of the biosocial complexity of autism.

Social understandings of autism have gone hand in hand with scientific ones since Leo Kanner characterized early infantile autism as a neurodevelopmental disorder in the mid-twentieth century. Historically, this relationship has been adversarial, to put it mildly. Even recently, the Spectrum 10K project — which examined the DNA of a large sample of autistic people — was heavily criticized by the autism community for the lack of clarity on the handling of genetic samples, uncertainty about the potential benefits of the study and fears that the results could lead to harm[1]. Into this turbulent context comes a paper in this issue

people themselves. A qualitative study found that many adults, after receiving a diagnosis of autism, feel a sense of relief[2]. The diagnosis is

Bioethics and development

CONCEPTUAL ANALYSIS article

Front. Psychiatry, 06 January 2023
Sec. Autism
Volume 13 - 2022 | https://doi.org/10.3389/fpsyt.2022.986732

This article is part of the Research Topic
Is Autism a Biological Entity?
View all 12 Articles >

Developmental diversity: Putting the development back into research about developmental conditions

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The dominant discourse surrounding neurodevelopmental conditions such as autism and ADHD emphasizes biological explanations. Neurodevelopmental conditions are conceived as different types of brains, the result of different types of genes. This way of thinking is present both in medical research and in clinical practice. Indeed, it is widely acknowledged that the idea of having a biological diagnosis helps people see beyond blame and guilt. It aids acceptance. However, simplistic approaches to biology risks neglecting the experiences and stories of autistic people in favor of finding etiological causes. At the same time, there is growing awareness that risks, functioning, and resilience are not solely defined by genes and brains but have a cultural and experiential component as well. Furthermore, atypical cognitive trajectories are not straightforwardly associated with poor outcomes. In this paper we describe the concept of developmental diversity as an

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R2D2-MH: cocreation

Participatory research: Nothing about us without us

Focus on resilience. What makes neurodivergent people flourish?

Aims and concepts are cocreated

- What do neurodivergent people find importance?
- How to integrate this also in science that talks about brains and genes?

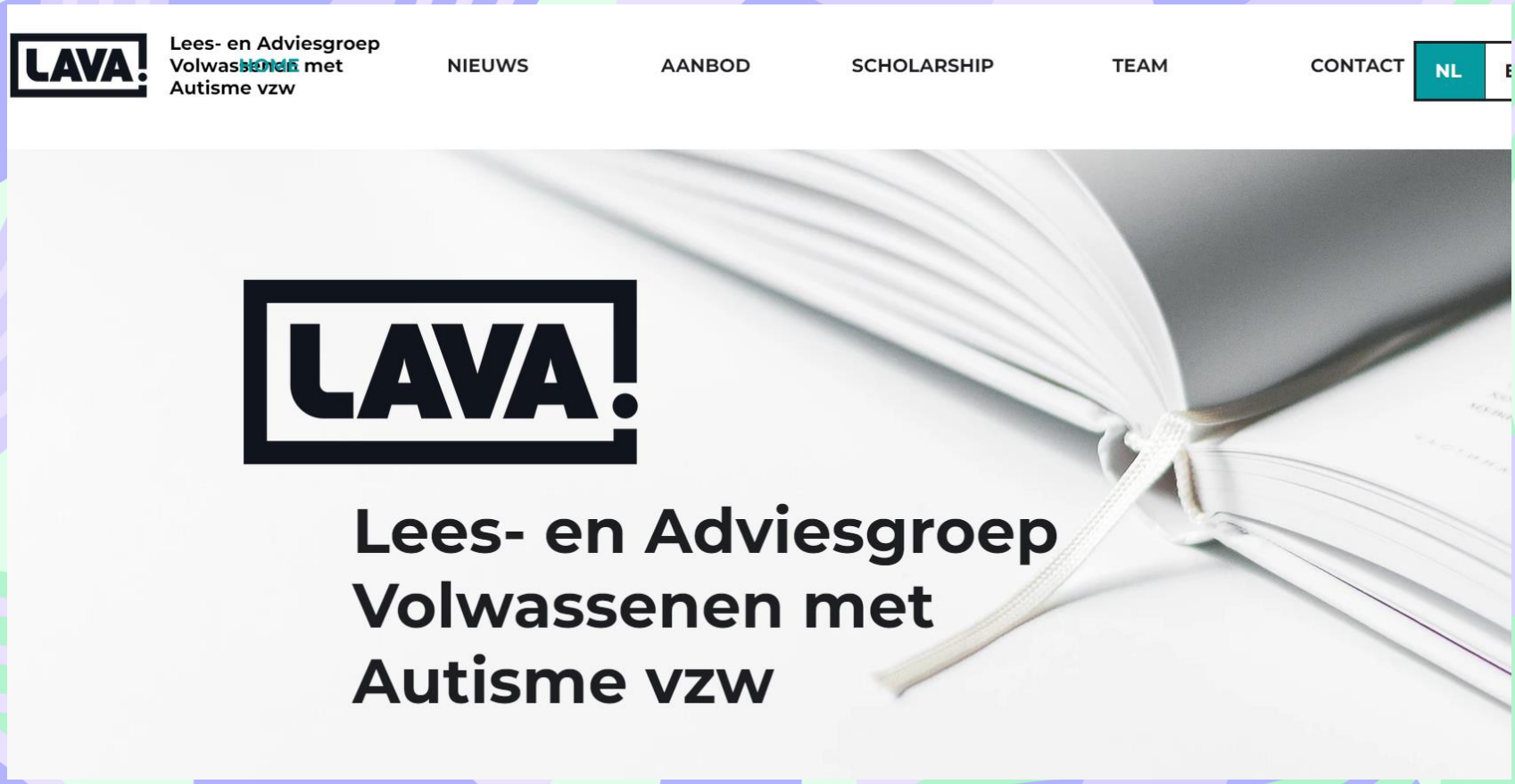
Challenges and opportunities:

- How to engage people with intellectual disabilities
- How to cocreate from the start (agenda setting, grant writing)
- How to make sure that autistic people feel heard and at ease in a big consortium

EPANEMA

- Empowering Parents of Autistic children through. Neurodiversity-Affirmative Psychoeducation
- Through:
  - Interviews with autistic researchers, neurodiversity scholars, autistic parents and autistic doctors.

Research Foundation Flanders
Opening new horizons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