



This presentation is in English.

Deze presentatie wordt in het Engels gegeven.

Voor vertolking naar het Nederlands: ga (in een ander scherm) naar  
[Discord/Presentaties/#2-LAVA-](#)

The logo for LAVA is contained within a black rectangular frame. The word "LAVA" is written in a bold, blue, sans-serif font. Below it, the full name "Lees- en Adviesgroep Volwassenen met Autisme" is written in a smaller, blue, sans-serif font. A solid black circle is positioned at the top right corner of the frame, with a vertical line extending downwards from its center to the bottom edge of the frame.

**LAVA**

Lees- en Adviesgroep Volwassenen met Autisme

# Reading & Advice Group Adults with Autism (Flanders)

- Lees & Advies groep Volwassenen met Autisme
- Who are we?
  - Adults with autism, mostly late diagnosis
  - Partner, parent, employee, business owner, ...
  - Academic education
  - Started 2017
- Our goals: Reading and Advice
  - Reading autism research papers
  - Giving input to autism researchers
  - Provide a direct, positive autistic voice



# our lift-off

- Reading group – spring 2017
  - Informal group of +/- 10 autistic adults coming together to discuss autism research papers
  - First paper discussed: “What should autism research focus upon?” (Pellicano et al. 2014)
- Bottom-up conclusion: add ‘Advice’ to our mission:
  - Agree on mission/vision statement (2018):
    - Dutch: <https://lavautisme.wordpress.com/>
    - English: <https://lavautisme.wordpress.com/english/>
  - Setting our priorities for autism research
  - Affiliation to Leuven Autism Research Group (LAuRes/KULeuven)



**KU LEUVEN**

## our mission

- Build a constructive dialogue with autism researchers
- We want to give another, additional, voice to autism.
- As adults with autism, we want to bring a positive message:
  - instead of merely focusing on the tip of the iceberg (the 'challenges' associated with autism)
  - we want to show there is a vast sea of opportunities and refreshing ideas beneath the surface
- Help change the public's perception of autism.

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## our vision

In order to achieve our mission we want to

- proceed to a critical reading of autism research;
- reflect and advise on priorities in autism research;
- adjust opinions and perceptions of autism in the media;
- participate as **one** of the voices of the autistic community.

In this way, we want to give autism a direct voice in both scientific and public debate and to show that our innate uniqueness is an enrichment.

# our autism research priorities

- Research on the longterm impacts on autistics
  - Pressure/suffering due to camouflaging and compensating,
  - shift focus from the 'causes' of autism to 'living with' autism.
- Longitudinal (socio-economic) research
  - Not only focusing on what goes wrong,
  - Also learning from where it went well.
- Inventory of relevant current autism research: Only if we now what gets funded, can we influence the priorities in funding

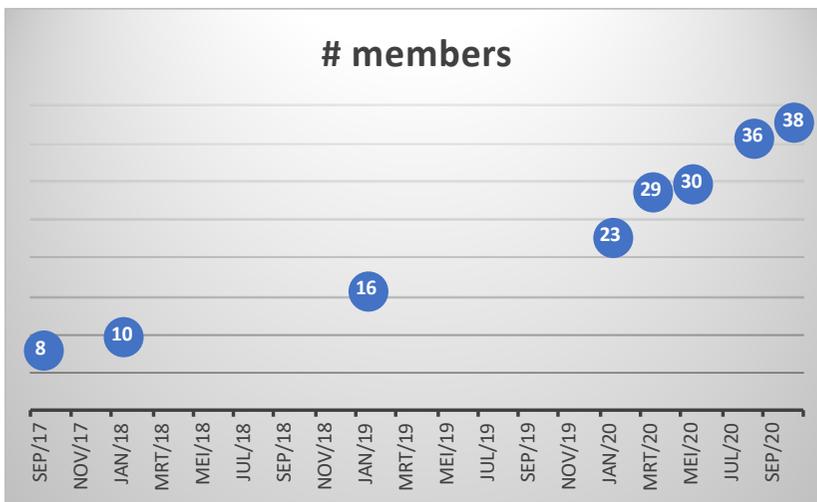
**Our method:** active contribution to participatory autism research (Fletcher-Watson et al. 2018).

# gaining cruising altitude

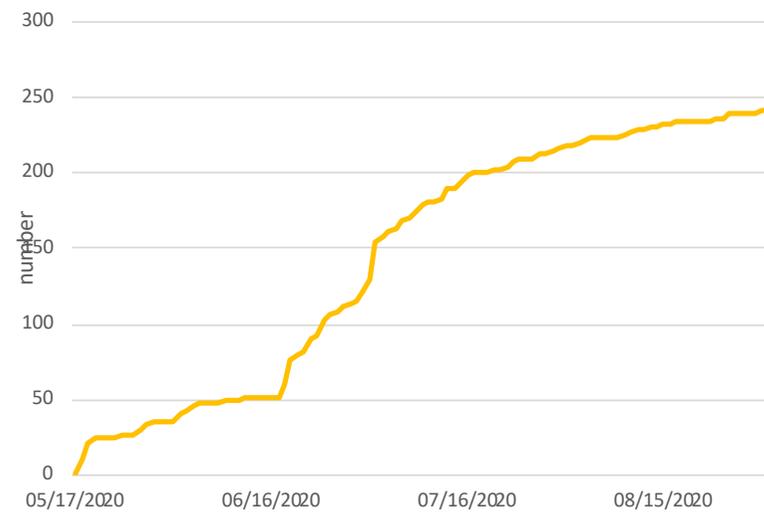
- Establishing a website, admitting new members, core organizing group
- Organization of 'member days' – from spring 2019
  - Invited speaker: autism researcher
  - 10-15 members discussion
  - Conclusion/actions for outreach
- Corona-proof on-line reading sessions from spring 2020
  - Paper on a specific topic, introduced by autism researcher
  - 12 member discussion via Zoom
  - Circulating conclusions
- Participation in research activities & selected speaking opportunities

# our growth

## # members



## LAVA - LinkedIn-connections



our achievements



## participation in Flanders 'academic workplace autism'

- What: practice-oriented research aiming to ensure better participation of autistic people in society.
  - Flemish government (funding)
  - Flemish researchers - universities Leuven and Ghent
  - LAVA - autism community representatives
- How: LAVA is represented in the Steering Committee and in an Expertpanel.
- Timing:
  - 2018 call for proposals and selection of project (6 selected projects)
    - 4 domains: image/representation, early intervention, transitions and mental health
  - 2019 – 2020: elaboration, research, evaluation
  - By June 2021: implementation
    - > second round?
- Link: <https://academischewerkplaatsautisme.be>



# member day on Autism Ethics (with dr. Gert-Jan Vanaken)

- What: Ethical reflection on 'Tracking Infants At-Risk for Autism' project
  - Flemish government funded cross-university project
  - Focused on early detection/intervention autism (2-3 yr old)
- How:
  - Introduction Autism Ethics by TIARA ethics researcher (dr. GJ Vanaken)
  - Member discussion: questioning the 'At-Risk' terminology
    - Autism is not something to be 'avoided' or 'fought against'
    - Early detection is helpful to prevent problems **not** to 'battle' autism
    - Early interventions can be independent of 'labeling' (respect for 'open future')
- Timing:
  - May 18th 2019: member day
  - November 8th 2019: LAVA feedback to TIARA group
- Link: <https://www.tiara-onderzoek.be>



**KU LEUVEN**

# member day on 'the autistic brain' (with dr. Sander Van de Cruys)

- What: Reflection on recent 'brain theories' of autism
  - HIPPEA: "High & Inflexible Precision of Prediction Error in Autism"
  - Capturing autistic atypicality as an atypical way of perception
- How:
  - Introduction HIPPEA by its originator (dr. S. Van de Cruys)
  - Member discussion: does this theory capture our common experience?
    - Yes, causality is from different perception to possible social issues (not vice versa)
    - Yes, autistic perception tends to more 'precision', hence to higher sensitivity
    - Potential to capture why autistic diversity contributes to a better society
- Timing:
  - October 12th 2019: member day
  - September 2020: published in Wetenschappelijk Tijdschrift Autisme
- Free download of article (in Dutch), pre-type-setting version:  
[https://www.academia.edu/44245053/Autistic\\_brains\\_talk\\_about\\_the\\_autistic\\_brain](https://www.academia.edu/44245053/Autistic_brains_talk_about_the_autistic_brain)

WTA

WETENSCHAPPELIJK TIJDSCHRIFT AUTISME

Autistische breinen praten over het autistische brein

Jo Bervoets, Sander Van De Cruys

# co-organization “Autism Ethics Network” study days

- What: study days for autistics, academics & professionals
- How:
  - 2019: physical workshop at University of Antwerp
  - 2020: virtual workshop recorded & available via [NeuroEpigenEthics](#)
- Timing:
  - April 4th 2019: [Looking at Autism Dynamically](#) (dr. Sanneke De Haan, dr. Kris Evers, dr. Leni Van Goidsenhoven)
  - September 28th 2020: [Philosophical Perspectives on Neurodiversity](#)
- Links: recordings of last study day
  - Introduction: [to AEN, LAVA, NeuroEpigenethics](#)
  - dr. Janna Van Grunsven : [Re-thinking deficiency with 4<sup>E</sup> cognition](#)
  - dr. Robert Chapman: [Neurodiversity, Objectivism, Realism](#)
  - Jo Bervoets: [Neurogradualism: neurodiversity without categorical difference](#)



Autism Ethics Network



# on-line reading session on 'autistic burn-out' (with Prof. Ilse Noens)

- What: on-line reading session on lived experiences of autistic burn-out
- How:
  - Reading article “Having all your internal resources exhausted ...”
  - Introduction Prof. Ilse Noens
  - Member discussion on LAVA experiences on autistic burn-out:
    - Autistic burn-out is specific & needs specific care
    - Background is one of being exhausted in ‘keeping up appearances’
    - Recognition autistic specificity by clinical professionals critical for good outcome
- Timing:
  - 26th May 2020: reading session
  - 2nd June: [Call to action published on LinkedIn LAVA group](#)
  - 22nd June: [In depth analysis published on LAVA website](#)
- Links: see above (both in Dutch!)



**AUTISM IN ADULTHOOD**

*Many Areas Left, too, published*

Journals Search Alerts

Autism Adulthood, June 2020; 2(2): 132–143.

Published online 2020 Jun 10. doi: [10.1089/aut.2019.0079](https://doi.org/10.1089/aut.2019.0079)

PMCID: PMC7313636

PMID: [32851204](https://pubmed.ncbi.nlm.nih.gov/32851204/)

“Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew”: Defining Autistic Burnout

[Dora M. Raymaker](#), PhD,<sup>1,2</sup> [Alan R. Teo](#), MD, MS,<sup>3,4,5</sup> [Nicole A. Steckler](#), PhD,<sup>6</sup> [Brandy Lentz](#),<sup>1</sup> [Mirah Scharer](#), BS,<sup>1</sup> [Austin Delos Santos](#),<sup>1</sup> [Steven K. Kapp](#), PhD,<sup>2,7</sup> [Morrigan Hunter](#), MA,<sup>2</sup> [Andee Joyce](#), BA,<sup>2</sup> and [Christina Nicolaidis](#), MD, MPH<sup>1,2,5,8</sup>

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# on-line reading session on 'autism as a dynamic phenomenon' (with Prof. Kristien Hens)

- What: on-line reading session 'autism as a dynamic phenomenon'
- How:
  - Reading article "Autism as a multi-layered & dynamical phenomenon" by Kristien Hens & Leni Van Goidsenhoven
  - Introduction by one of the co-authors
  - Member discussion LAVA on 'dynamics' of autism:
    - Seeing autism through 'static characteristics' is stereotyping
    - Our experiences/personalities cannot be reduced to being autistic
    - Challenge: how to see the underlying commonality in our differences?
- Timing:
  - 30th of June 2020: reading session
  - Conclusion/Analysis: to be worked out
- Link (Dutch!): [Recording of introduction by Prof. Kristien Hens](#)



## **Autisme als meerduidig en dynamisch fenomeen**

Kristien Hens & Leni Van Goidsenhoven

*Algemeen Nederlands Tijdschrift voor Wijsbegeerte* 110 (4):421-451 (2018)

# contribution to panel discussions

- Docville International Documentary Film Festival
  - 2019 – Mind my Mind
  - 2020 – The reason I Jump



## what's next

- October – reading session
  - ‘autism and (paid) work’ with dr. Jeroen Dewinter
- November – reading session
  - ‘autism and multicultural diversity’ with dr. Gert-Jan Vanaken
- Advice participatory research funding request ‘Autism & Sexuality’
- Themes to be worked out in 2021:
  - Accessibility; broadly seen, how can accessibility for autistics improve accessibility for everybody else?
  - What can LAVA learn from non-speaking or intellectually disabled autistic people and vice versa?
  - Dialogue LAVA & autism seen from/experienced in diverse multicultural backgrounds?

# challenge: maintain cruising altitude

- Proud of what we achieved!
- But also: a bit stressed about what comes next.
- Where to go next?
  - How to cope with increasing members/questions?
  - How to become a recognized voice in research & policy making?
  - Need to formalize/obtain funding to remain sustainable in the long run
  - Need to find more core members to share the workload
- Challenge: keep small 'family' scale whilst also allowing expansion

# our critical success factors

- First & foremost: **our members**
  - Good mix of profiles/always engaged in discussion
  - Active 'core team'/willing to contribute actively based on own strengths
- A foot in the door in academia:
  - Initial link with research group LAuRes
  - Many academic sponsors seeing LAVA's benefit
  - Active involvement of autism researchers (inside & outside LAVA)
- Co-operative spirit with VVA (hats off to: Cis Schiltmans)
- Always starting from our own **independence** in autism debates
- Positioning as **a** voice in autism debates
- Keep the **focus** on what makes us **unique**: academic/advice angle

# why are we unique?

- One of a kind:
  - Not a purely academic group: the 'autistics next door' ;-)
  - Certainly not a peer support group: always research focused
- A ***positive*** approach
  - Not blind to our problems & challenges
  - Always confident of our value & contributions
- An ***independent*** group
- Remaining humble: ***a*** voice in autism discussions

## in a nutshell: our call to action

- Nothing about us without us: also applicable autism research
- Break ‘the double barrier’:
  - Be directly heard in setting research priorities like cancer patient organizations
  - But being able to contribute without being necessarily viewed as ‘patients’
- Who wants to take similar initiatives in other regions/countries?
  - To a network of research-focused autism organizations?
  - Involving the autism research-interested ‘autistic next door’
  - Weighing on international research priorities & public debates

questions? Ideas?



# useful articles

## What should autism research focus upon? Community views and priorities from the United Kingdom

Elizabeth Pellicano, Adam Dinsmore, Tony Charman

First Published April 30, 2014 | Research Article | [Find in PubMed](#) |  Check for updates

<https://doi.org/10.1177/1362361314529627>

## Making the future together: Shaping autism research through meaningful participation

Sue Fletcher-Watson , Jon Adams, Kabie Brook, more...

[Show all authors](#) ▾

First Published August 10, 2018 | Research Article | [Find in PubMed](#) |  Check for updates

<https://doi.org/10.1177/1362361318786721>



Thank you for your attention