

The Neurodiversity Paradigm: what's in it for researchers and practitioners?

Researchers' meeting, Parenting and Special Education Research Unit
November 16, 2022

Who am I?



- Gert-Jan Vanaken
- PhD research: “**Ethics of early autism care**”
- Ilse Noens, Kristien Hens, Jean Steyaert

KU LEUVEN



Universiteit
Antwerpen



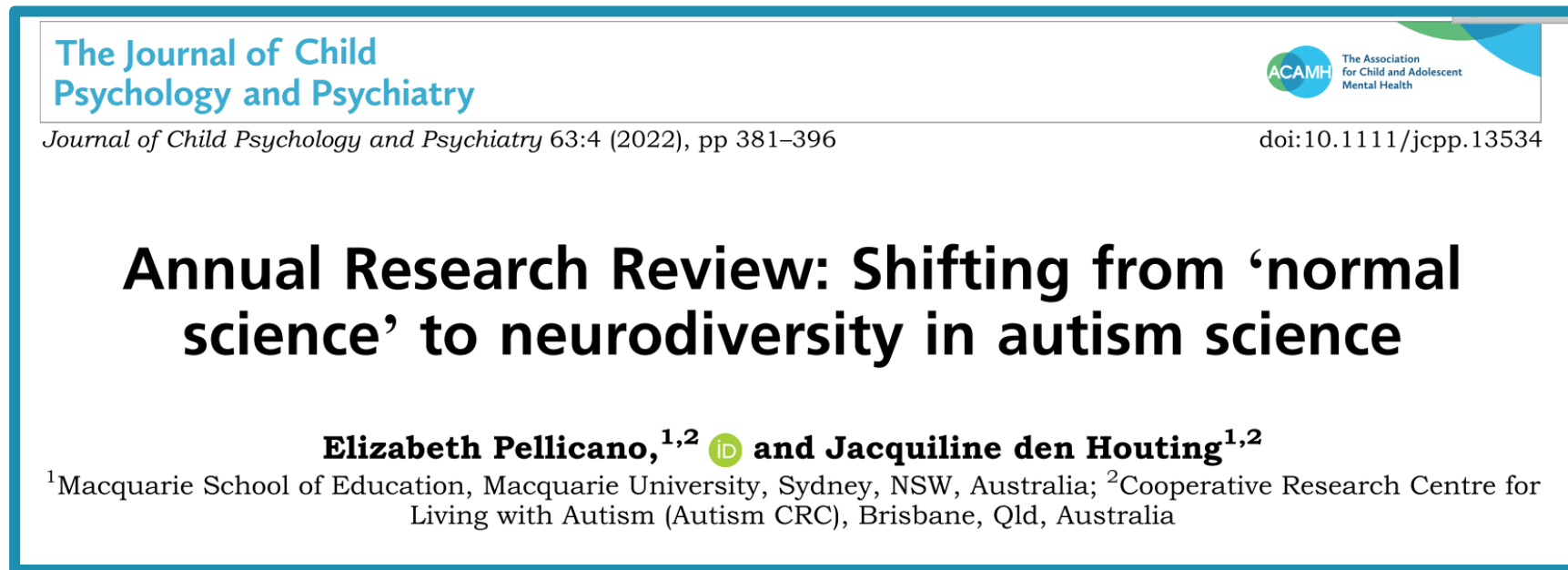
- Interdisciplinary work

Ethics of early autism care?



Ethics of early autism detection and intervention?

- Autism field is structurally changing



Structural changes in the autism field



autism as set of deficits to be remedied



autism as expression of
neurodiversity to be accommodated



individual symptoms



problems arising in interaction with
social and societal context



professional expertise



including voices of autistic people
and autistic-led organisations

Ethics of early autism care?

- Autism field is structurally changing



What could *good and just* early autism care look like in the age of neurodiversity?

Overview

- Introduction
- Neurodiversity and the Neurodiversity Paradigm: what is it? what isn't it?
- Some implications for research and clinical practice
- Discussion

Language matters

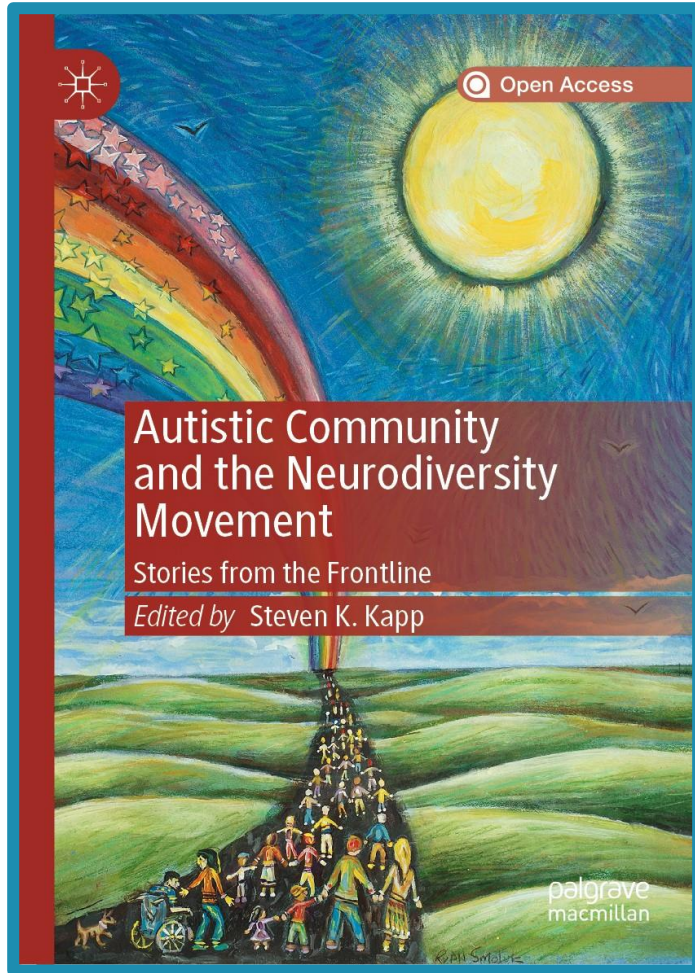
“autistic people”, “people on the autism spectrum”
and “people with autism”

(Bottema-Beutel et al., 2021; Buijsman et al. 2022)

Disclaimers

Neurodiversity >> autism
Not all entirely new proposals
Work in progress

Origins of ‘neurodiversity’



- Term coined in 1998 by autistic sociologist **Judy Singer**
*“The neurologically different represent a new addition to the familiar **political categories** of class/gender/race and will augment the insights of the **social model of disability**.”*
- Evolved from autism rights’ movement and **online communities**
- Originated from
dissatisfaction with medical, deficit model of autism,
marginalisation of autistic voices,
need for **belonging** in affirmative sense
- Adopted and applied **beyond autistic communities**

(Dekker, 2020)

Neurodiversity



= recognition of significant human **diversity** regarding cognitive, sensorial, behavioral, emotional, communicative ways of experiencing and engaging with the world (**neurotypes**)

comparable with concepts of gender and ethnic-cultural diversity



no consensus definition of neurodiversity

Neurodiversity movement

= a **social movement** of neurodivergent self-advocates, organisers and allies

= an **academic, research paradigm**

comparable with
disability, feminist and post-colonial movements

assumptions



- intrinsic **equality** among neurotypes
- structural **discrimination and exclusion** (i.e. **ableism**) are important contributors to experienced problems of neurodivergent people

political demands



- **acceptation** of diversity
(‘anti-cure’, ‘anti-normalisation’, inclusive language)
- **emancipation** of neurodivergent minorities, striving for just, inclusive society for all neurotypes

Neurodiversity as social movement

assumptions



what is autism?
how to understand autism as phenomenon?
(ontology)



how to gather relevant and reliable
knowledge on autism?
(epistemology)



what are good and just ways of engaging
between autistic and non-autistic people?
(ethics)

Neurodiversity as academic paradigm

assumptions



- Autism is an expression of **neurodiversity**
- Autistic people are a **neurominority** facing structural injustices (ableism)
- Autism-related problems arise in the context of these **ableist injustices**



- Knowledge is **socially situated**
- **Lived experiences** give autistic people unique access to autism-related knowledge



- (non-autistic) researchers and practitioners ought to be **allies**
- Allies ought to promote **acceptance** of diversity and **empowerment** of neurominorities

Neurodiversity as academic paradigm

Neurodiversity : what it is not



- Not merely a strengths-based approach
- Not “everyone has strengths and weaknesses”



- Value is in diversity of population or group
- Experienced problems (“weaknesses”) can be contextualised and politicised



- Not anti-labelling per se
- Not a mere shift from a categorical towards a dimensional approach



- Recognition of difference is valuable and needed,
- Pathologisation of mere difference is opposed

Neurodiversity : what it is not



No return to biological reductionism or essentialism ('differently wired brains')



Neurodiversity understood as diverging experiences from the norm (cf. 'gender' and 'race' constructs)



Not value-free



Explicitly committed to emancipation, justice, inclusivity



Can the neurodiversity paradigm be compatible with autism research and clinical practice?

Acknowledging and supporting autistic people in their struggles, **without pathologising** autism as such?

Fostering **social change**, in individual encounters?

Mobilising professional expertise, while opening up for **expertise by experience**?



Neurodiversity-affirmative research and clinical practice




INVITED REVIEW

Neurodivergence-informed therapy

Robert Chapman✉, Monique Botha

First published: 09 September 2022 | <https://doi.org/10.1111/dmcn.15384>

Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice

 Kathy Leadbitter^{1*},  Karen Leneh Buckle^{1,2},  Ceri Ellis¹ and  Martijn Dekker^{2,3}

Commentary | [Open Access](#) | [Published: 13 October 2021](#)

Neurodiversity and Autism Intervention: Reconciling Perspectives Through a Naturalistic Developmental Behavioral Intervention Framework

Rachel K. Schuck✉, Daina M. Tagavi, Kaitlynn M. P. Baiden, Patrick Dwyer, Zachary J. Williams, Anthony Osuna, Emily F. Ferguson, Maria Jimenez Muñoz, Samantha K. Poyser, Joy F. Johnson & Ty W. Vernon

Implications for research and clinical practice



‘Autistic people are a neurominority facing ableist injustices’



‘Lived experiences provide unique insights’



‘Researchers and practitioners ought to be allies’

Implications for research and clinical practice



‘Autistic people are a neurominority facing ableist injustices’

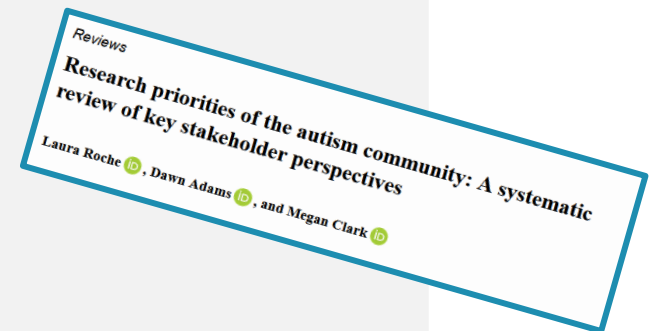
- Reframe research questions and support objectives around **autistics-endorsed priorities** to address experienced problems
For example: improving accessibility of physical and mental health care, disseminating accurate knowledge on autism to third parties, identifying early environmental factors impacting development

- Adapt **language use and discourse**

For example: “autism symptoms” > “autism characteristics”
“normal controls” > “non-autistic” or “neurotypical” (...)



“at-risk-for-autism” > “at an increased likelihood for autism”
“economic burden of autism” > “solidarity to meet needs”



Implications for research and clinical practice



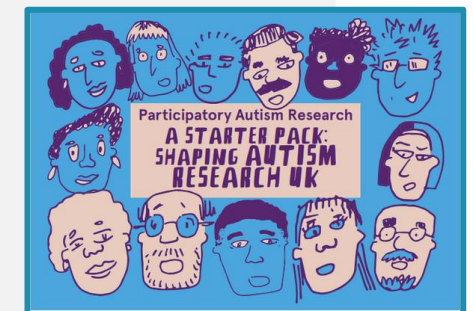
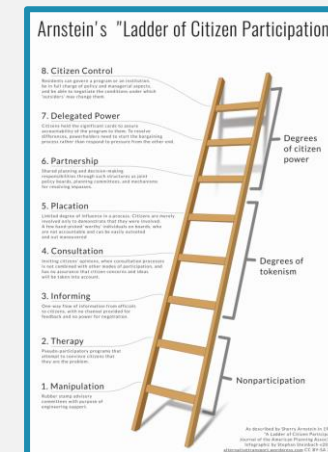
‘Lived experiences provide unique insights’

- **Qualitative** research and creative methods
(capturing experiences across the entire spectrum)
- **Participatory** research
- **(Neuro)diversifying** research teams and consortia

For ex.



For ex.



Implications for research and clinical practice



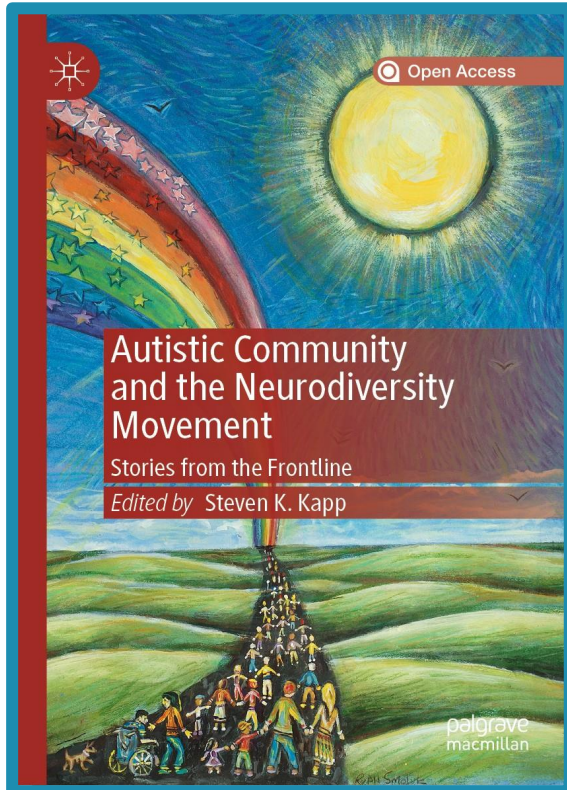
'Researchers and practitioners ought to be allies'

- Reflexivity on one's own position and potential biases
 - Authentic relationships with neurodivergent communities
 - Epistemic humility
-
- Research and clinical practice guided by solidarity to help meet needs, irrespective of neurotype empowerment of neurodivergent minorities

Letter to the Editor
Reflections on my experiences as a non-autistic autism researcher
Sandy Thompson-Hodgetts ^{ip}

Crippling vulnerability: A disability bioethics approach to the case of early autism interventions
Gert-Jan Vanaken

Where to start reading?



The Journal of Child
Psychology and Psychiatry

Journal of Child Psychology and Psychiatry 63:4 (2022), pp 381–396



doi:10.1111/jcpp.13534

Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science

Elizabeth Pellicano,^{1,2} and Jacqueline den Houting^{1,2}

¹Macquarie School of Education, Macquarie University, Sydney, NSW, Australia; ²Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Qld, Australia

[Hum Dev](#). 2022 May; 66(2): 73–92.

PMCID: PMC9261839

Published online 2022 Feb 22. doi: [10.1159/000523723](#)

PMID: [36158596](#)

The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers?

[Patrick Dwyer](#) a, b, *

Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice

Kathy Leadbitter^{1*}, Karen Leneh Buckle^{1,2}, Ceri Ellis¹ and Martijn

Dekker^{2,3}

References

- **Bottema-Beutel**, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, 3(1), 18–29. <https://doi.org/10.1089/aut.2020.0014>
- **Chapman**, R., & Botha, M. (2022). Neurodivergence-informed therapy. *Developmental Medicine & Child Neurology*. <https://doi.org/10.1111/dmcn.15384>
- **Dwyer**, P. (2022). The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers? *Human Development*, 66(2), 73–92. <https://doi.org/10.1159/000523723>
- **Kapp**, S. K. (2020). Introduction. In *Autistic Community and the Neurodiversity Movement* (pp. 1–19). Springer Singapore. https://doi.org/10.1007/978-981-13-8437-0_1
- **Leadbitter**, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic Self-Advocacy and the Neurodiversity Movement : Implications for Autism Early Intervention Research and Practice. *Frontiers in Psychology*, 12(April), 1–7. <https://doi.org/10.3389/fpsyg.2021.635690>
- **Pellicano**, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. <https://doi.org/10.1111/jcpp.13534>
- **Roche**, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism : The International Journal of Research and Practice*, 25(2), 336–348. <https://doi.org/10.1177/1362361320967790>
- **Schuck**, R. K., Tagavi, D. M., Baiden, K. M. P., Dwyer, P., Williams, Z. J., Osuna, A., ... Vernon, T. W. (2021). Neurodiversity and Autism Intervention: Reconciling Perspectives Through a Naturalistic Developmental Behavioral Intervention Framework. *Journal of Autism and Developmental Disorders*, 1–21. <https://doi.org/10.1007/s10803-021-05316-x>
- **Thompson-Hodgetts**, S. (2022). Reflections on my experiences as a non-autistic autism researcher. In *Autism*. SAGE Publications Ltd. <https://doi.org/10.1177/13623613221121432>
- **van Goidsenhoven**, L., & de Schauwer, E. (2020). Listening beyond words: Swinging together. *Scandinavian Journal of Disability Research*.
- **Vanaken**, G.-J. (2022). Crippling vulnerability: A disability bioethics approach to the case of early autism interventions. *Tijdschrift Voor Genderstudies*, 25(1), 19–40. <https://doi.org/10.5117/TVGN2022.1.002.VANA>
- **Walker**, N. (2014). Neurodiversity: some basic terms and definitions. Retrieved November 30, 2021, from <https://neuroqueer.com/neurodiversity-terms-and-definitions/>

My door is (sometimes) open for discussion



room 03.04
gertjan.vanaken@kuleuven.be