

# The neurodiversity paradigm through the years

Autscape 2021: Growing, Developing & Learning

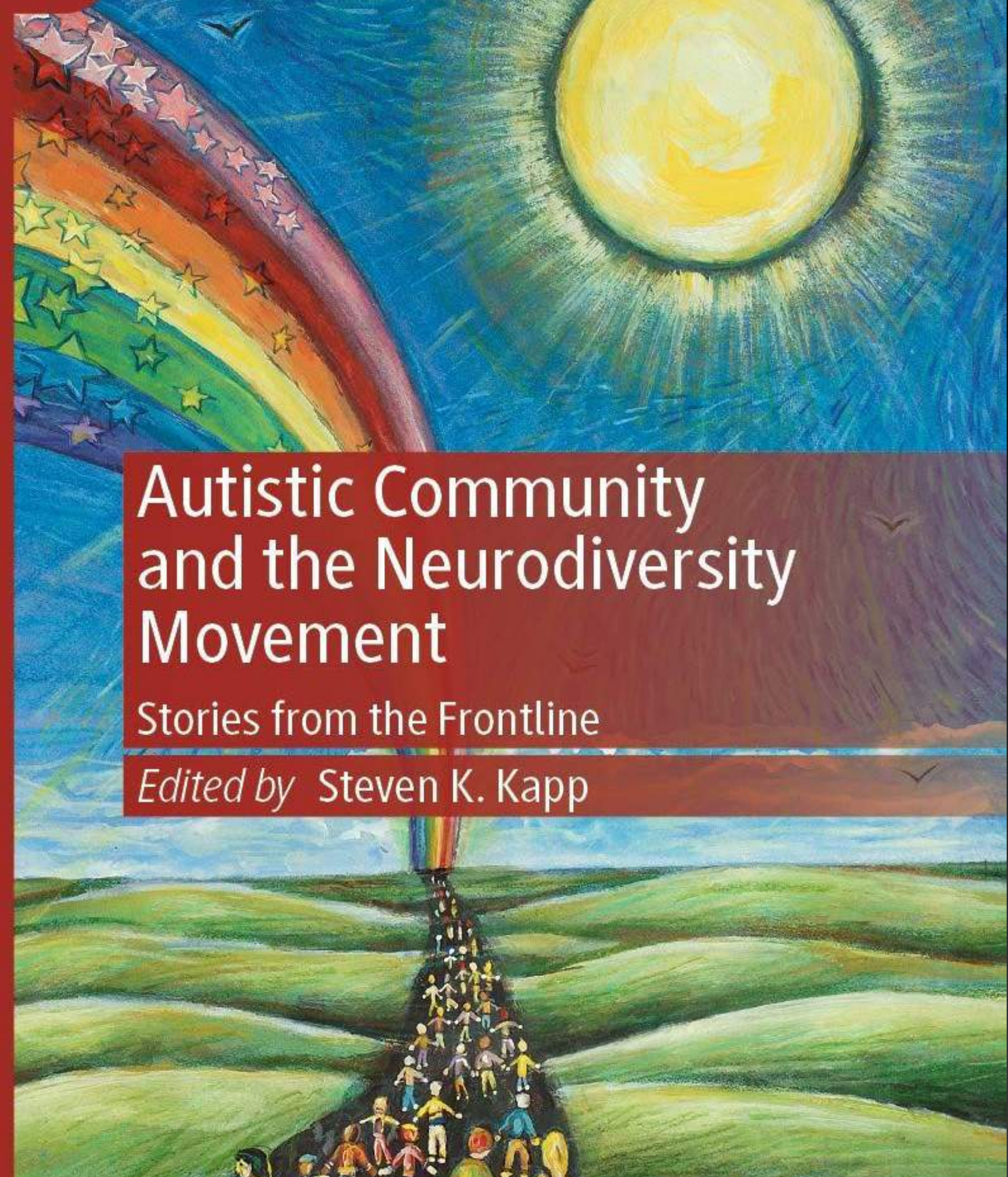
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# History



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# Rise of parent narratives

## 1960/70s

- 1940s: original autism narratives (Kanner, Asperger)  
Autistic perspective completely absent from narrative
- Parents demonised: refrigerator mother theory
- Reaction: parents start organising (NAS, 1962)
- Parental trauma and desperation begat notion of 'early intervention'



# Where is the autistic narrative?

- 1992: SJU AUTISM mailing list: parent- and treatment-oriented
- Autistic people start meeting parents, and each other
- Autistics: “fix our problems, not us”  
Parents: “you are not like my child”
- Two opposing groups, both traumatised: perfect conditions for enduring conflict



# Reaction: Autistic space

- 1994: Autism Network International, ANI-L
- Central idea: *autistic people are in charge*
- Inclusive notion, *autistics and cousins* (ACs), foreshadowing neurodiversity.
- 1996: *Autreat*, the first conference for and by autistic people
- First autistic community! But: not everyone's cup of tea



# Neurodiversity

- 1996: I self-host my own group, InLv ('Independent Living on the autistic spectrum') on dialup, 'uphill both ways', etc.
  - Invited participation not just by autistics but any marginalised neurominority
  - Independence → Autonomy: being in control over your own life choices
  - 'Neurodiversity' (Singer, 1998; Blume, 1998)
  - Thoughts On Finding Myself Differently Brained (Meyerding, 1998)
  - 'Face blindness' (Choisser, 1998)
  - 'Inertia' (Buckle et al, 2021)



# Neurodiversity

## Growth

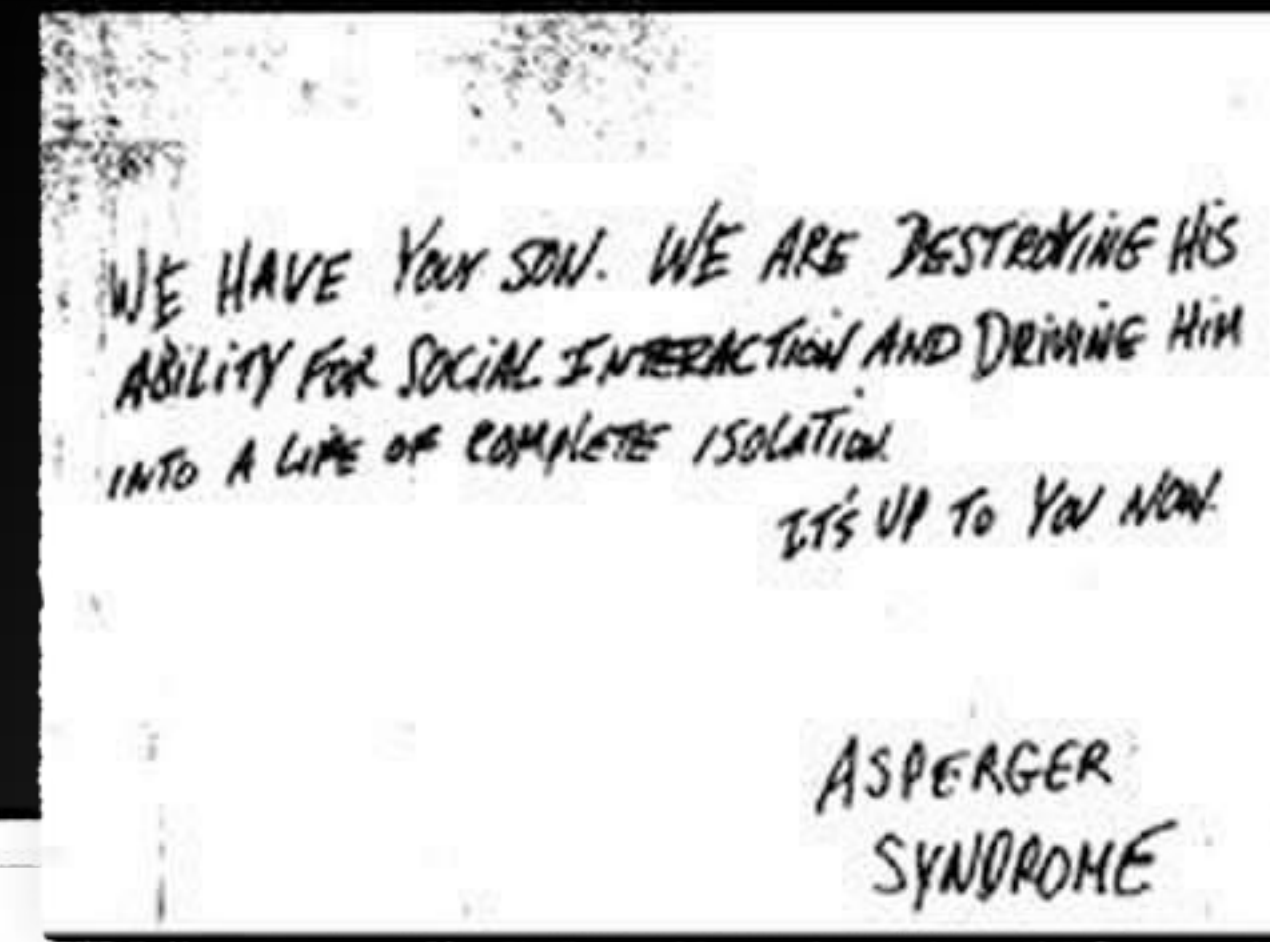
- Explosion in autistic-run groups enabled by:
  - Public list servers
  - Web sites with forums
  - Social media
- The neurodiversity paradigm spread to other neuro-minorities: ADHD, Tourette's, dyslexia, stuttering, ...





# Neurodiversity Galvanisation

- Anti-ND campaigns: “Ransom Notes” (2007), “I Am Autism” (2009)
- Institutional mistreatment and torture, e.g. use of electric shock torture devices at the Judge Rotenberg Center (USA)



AUTISM SPEAKS™

"I will fight to take away your hope. I will plot to rob you and your children of their dreams. I will make sure that every day you wake up you will cry, wondering who will take care of my child after I die."

Autism Speaks "I am Autism" video



www.the-art-of-autism.com





# Present state

Discussion



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# Tenets of neurodiversity

- Aspect of biodiversity
- Natural and valuable:
  - Not *necessarily* pathological
  - 'Good' and 'bad' often inseparable
  - Neurodivergence is part of who we are
  - Source of potential if embraced
- Recognition and acceptance of disability
- Rights and power inequalities
- *Humans who are different are human!*





# Validity of diagnosis

- Is self-diagnosis valid?
- Is official diagnosis valid?
- Should we care?
- More useful questions:
  - What are your concrete needs?
  - Is the diagnosis a key that can open the door to meeting these needs?



# Neurodiversity within autism

a.k.a. “Autism is not one thing”

- There is no one thing called autism  
“The ASD diagnosis lacks biological and construct validity” (Waterhouse, London & Gillberg, 2016)
- Most autistic people do seem to have something important and fundamental in common; there is a clear need for the label
- Autistic culture (akin to Deaf culture), based on shared communication characteristics (Dekker, 1999)
  - But does this include all autistic people?





# Inclusion

## in the neurodiversity movement

- Mostly fails to include non-speaking autistic people or those seen as severely disabled
- Mostly refuses to include autistic people who want to be cured
- Is mostly isolated from other disability rights movements
- Is mostly English speaking
  - ...promotes anglocentric notions such as identity-first language
- Is quite white
- The movement is in part based on notions designed for and by neurotypical activist communities: →



# Social justice notions

- **Identity:** self-understanding and acceptance
- **Allies:** neurotypical people fighting on our side
- **Intersectionality:** recognition of multiple ways of being disadvantaged (e.g. being both autistic and black, trans, mentally ill, etc.)
- **Pride:** it is great to be yourself
- **Safe space:** a space where:
  - it is safe to be yourself
  - your trauma triggers are respected





# Social justice notions

Do these need de-neurotypicalising to include all autistics?

- **Identity:** “I identify as ...” appears to be sacred; never getting honest feedback may limit self-understanding. Everyone needs a reality check sometimes
- **Allies:** can be condescending: allies not allowed to have viewpoints or opinions. Allyship may attract white knight saviours and virtue signallers
- **Intersectionality:** does not always recognise that different needs can conflict
- **Pride:** can be patronising: everything that an autistic person (especially a child) does is *super wonderful and fantastic* because they’re autistic
- **Safe space:** is often unsafe. The distinction between ‘triggered’ and ‘offended’ is muddled, creating a new social minefield: not safe to be yourself



# Identity

- I lived without an autistic identity, yet was still autistic
- “Autism” became my key to belonging somewhere  
The fact of *being* autistic became embedded in my sense of identity  
Yet, I still wouldn’t say that I “identify as” autistic
- Identity politics: we should have certain rights based on what we identify as
  - How about those who won’t identify, or can’t?
  - Neurodiversity is based on biological essentialism: we are different because our brains are. Does that not make identity irrelevant to the question of rights?
  - Shouldn’t our rights be derived from our needs instead?





# Disability

## Competing models

- Social model vs medical model
- By definition, all models have limited validity. Risk of overapplication. “All models are wrong, but some are useful” (Box, 1976)
- The social model is usually taken to an extreme (Dunn, 2005), but the medical model has a much longer history of that
- Is it possible to be autistic without being disabled?
- The need to mask is an oppression, but the ability to mask is a privilege



# At Autscope

## How we implement neurodiversity

- Designed for autistic needs. Autistic people are in charge.
- We welcome everyone regardless of identity or (self-)diagnosis
  - We do not ask who is autistic and who isn't
  - No special rules for carers or allies; *our friends* are included equally
- **Not** a 'safe space'. When autistic people stop masking, you encounter not only recognition but also disagreement and different viewpoints
- Intersectionality is necessary, but not at the expense of autistic needs



# The ND movement's achievements so far

- Societal awareness
- Widening of diagnostic criteria
- Participatory autism research
- Campaigns against institutionalisation and maltreatment, but no great progress
- Small islands of accessibility
- ...





# Conclusions

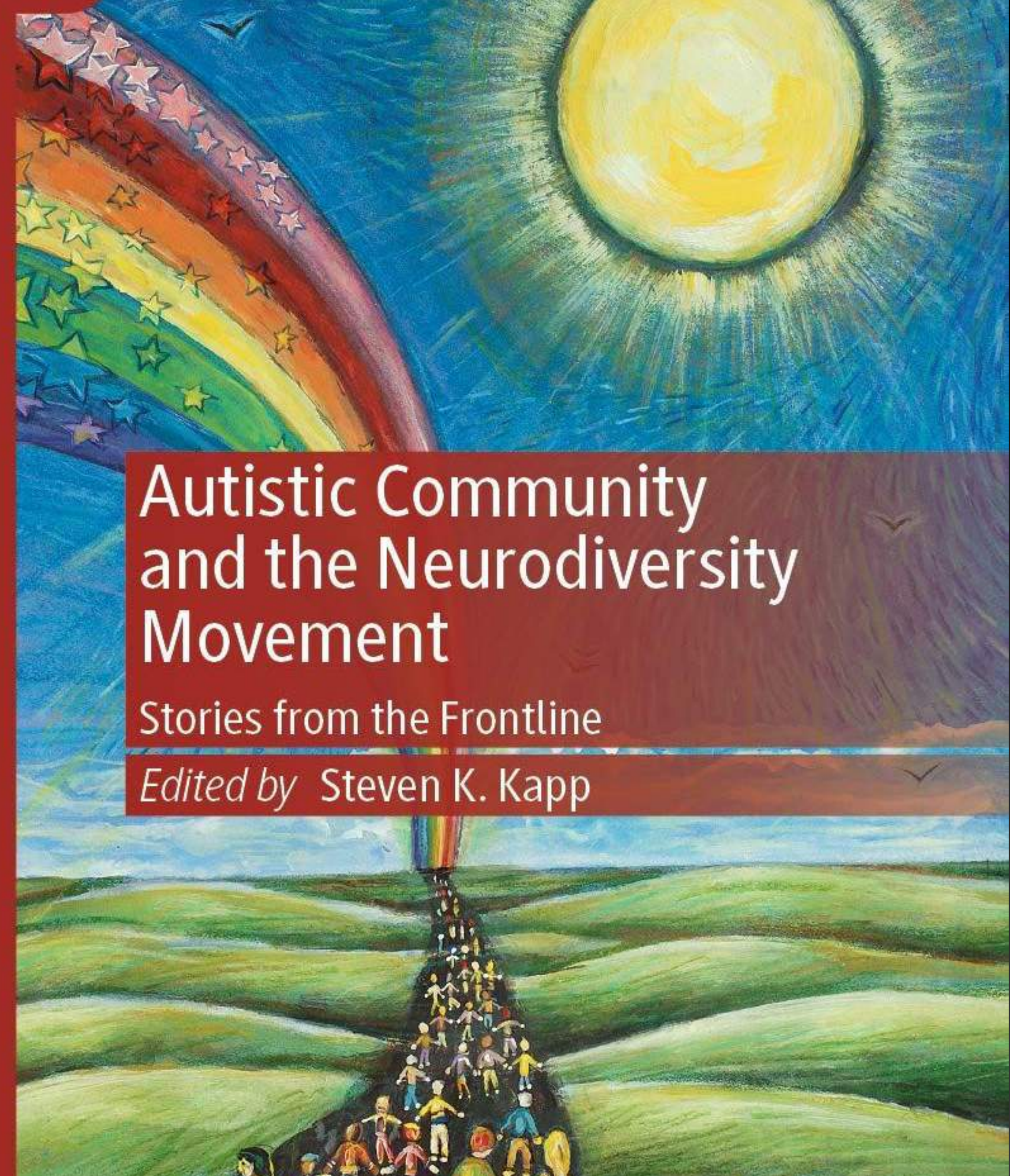
- We need to include a greater diversity of disability/functioning levels and viewpoints on autism
- We need to be better about including racial and ethnic minorities
- We need to cultivate healthy boundaries and productive ways to deal with disagreement
- We need more empathy with parents and carers, even NT ones
- Unifying goals:
  - Full representation and participation
  - Support and accessibility
  - Human rights





# Further reading

- 19 chapters by 21 authors about the forming of the autistic community and neurodiversity movement
- Published in 2020
- Hardcover and paperback available
- Read it online for free:
  - Kindle
  - <https://doi.org/10.1007/978-981-13-8437-0>





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