

The neurodiversity paradigm through the years

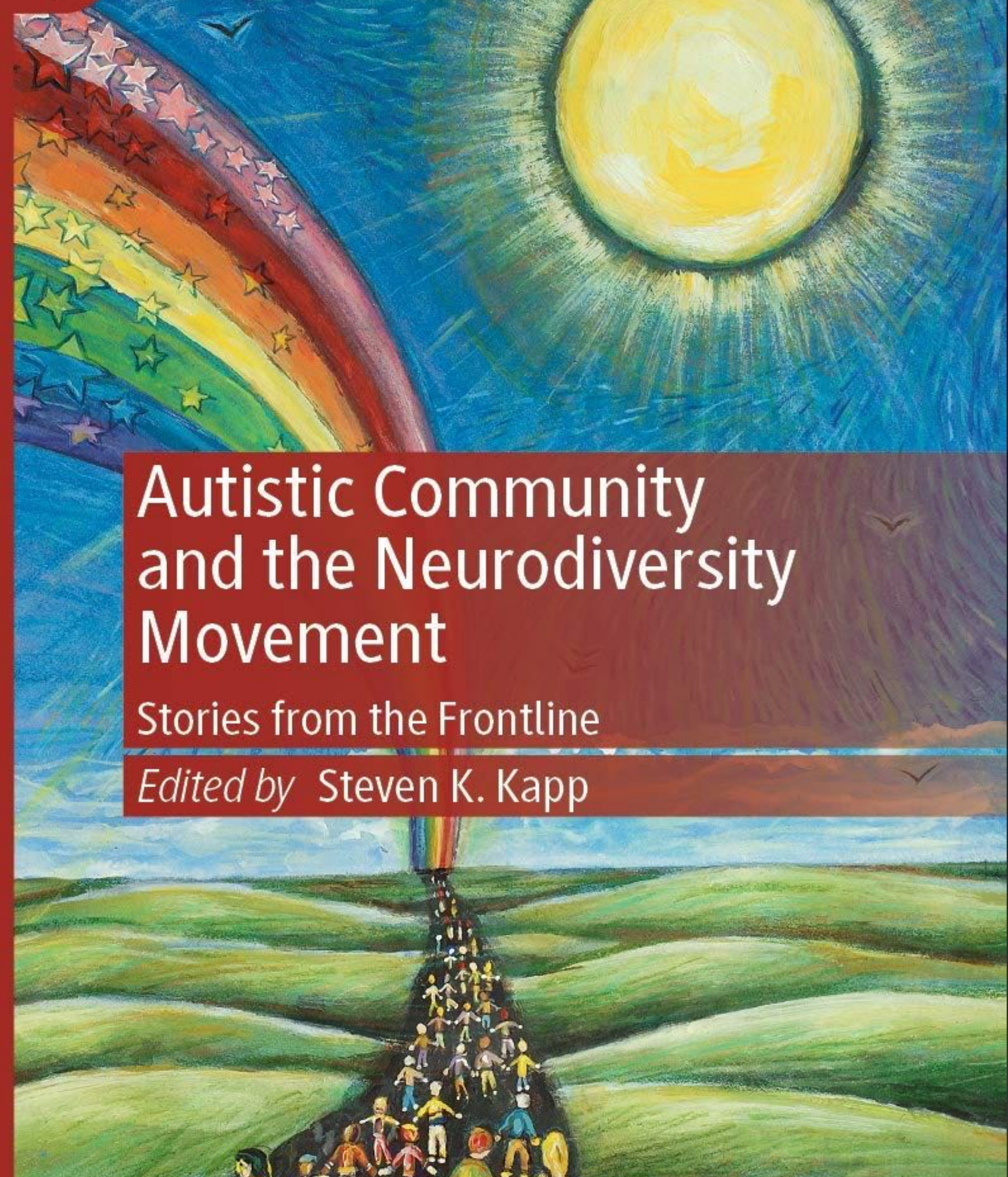
Autscape 2021: Growing, Developing & Learning

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History



Autistic Community and the Neurodiversity Movement

Stories from the Frontline

Edited by Steven K. Kapp



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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)

WE HAVE YOUR SON. WE ARE DESTROYING HIS ABILITY FOR SOCIAL INTERACTION AND DRIVING HIM INTO A LIFE OF COMPLETE ISOLATION.
IT'S UP TO YOU NOW.

ASPERGER SYNDROME



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

ATTENTION!

PEOPLE WITH
DISABILITIES
ARE **STILL** BEING
TORTURED
AT THE JRC



#StopTheShock



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 muddied, 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 making, 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
- ...



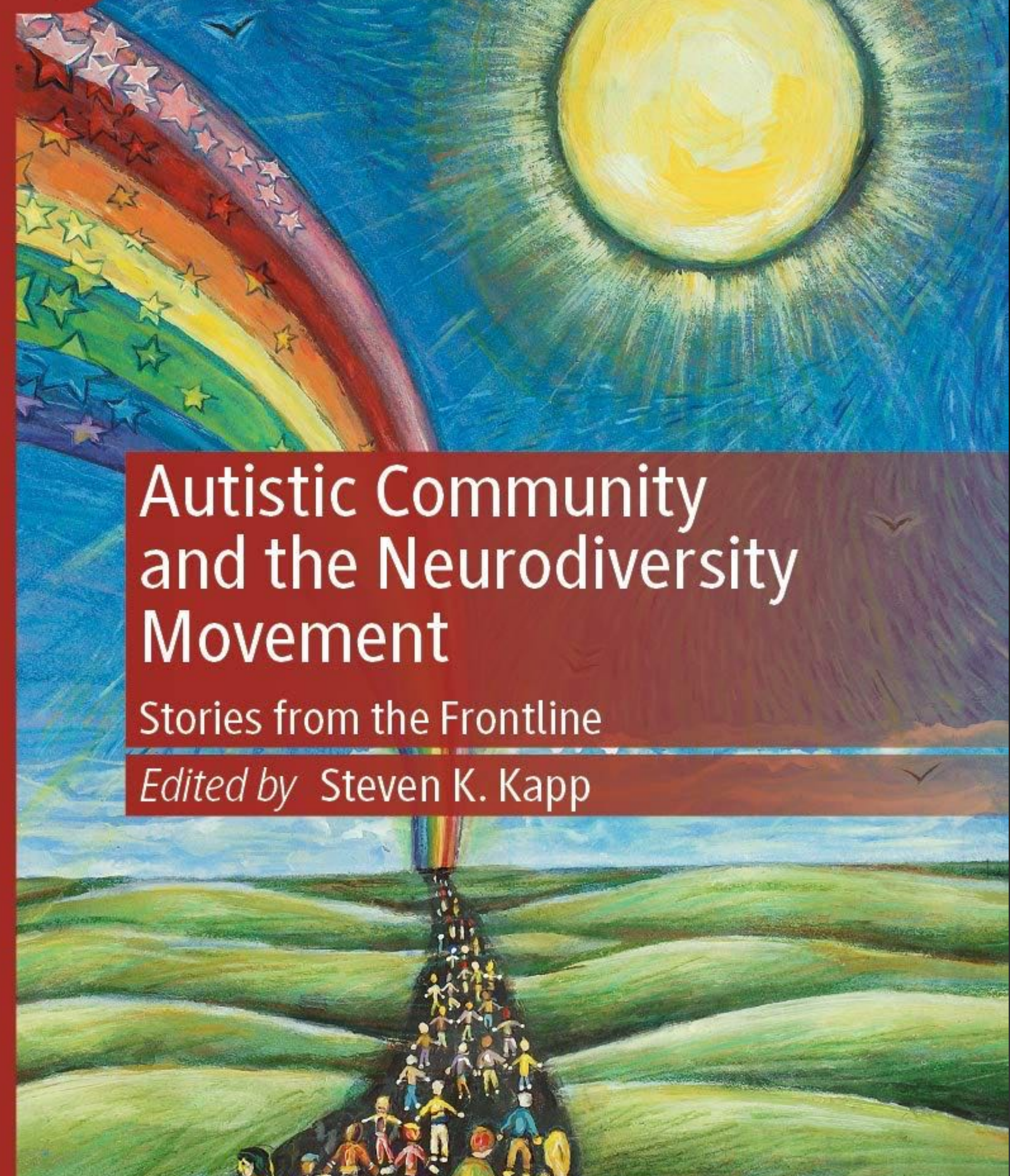
Conclusions

- 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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