

Autism and the Neurodiversity Movement: Self-Advocacy, Strengths, and Stimming

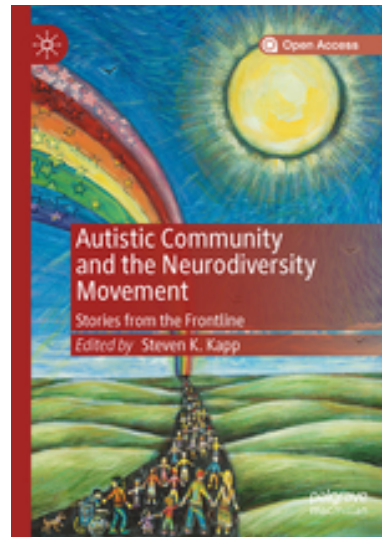
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EGENIS, THE CENTRE FOR THE STUDY OF LIFE SCIENCES



Autistic Community and the Neurodiversity Movement: Stories from the Frontline



Steven Kapp

Book's scope

- Overview of (autism rights branch of) the neurodiversity movement, with history and impact
- Accounts of actions by autistic advocates and allies in their own words
- Examines understandings of *neurodiversity*, offer critical analysis of the movement

Structure of book

- ‘Sandwich’: ‘meat’ by advocate contributors, ‘bread’ (largely) by editor
- Part I: Gaining Community
- Part II: Getting Heard
- Part III: Entering the Establishment?

Institute For the Study of the Neurologically Typical



"The common belief that (persons) with pervasive developmental disorders are humorless is frequently mistaken." - Stephen Bauer, M.D., M.P.H.

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders)

Disorders Usually First Evident in Infancy, Childhood, or Adolescence

666.00 Neurotypic Disorder

The essential features constitute a severe form of Invasive Developmental Disorder, with onset in infancy or childhood.

Diagnostic criteria for 666.00 Neurotypic Disorder



What is neurodiversity?

- A biological fact?
- A set of beliefs?
- A (political, autistic) movement?

Autism and Neurodiversity

If you have been told by a doctor, that you are on the autism spectrum, you might be interested in neurodiversity. This leaflet will tell you all about neurodiversity.



What is neurodiversity?

- The word neurodiversity has two parts- 'neuro' to do with the brain, and 'diversity' to do with differences.
- Neurodiversity is how differences in a person's brain can mean that they experience the world differently.



Diversity

- Differences in people's brains such as with autism are natural and useful parts of the way humans are different.
- There is no 'right' or 'wrong' way to grow. There is no such thing as a 'normal' brain.



Upset



Feeling better

Neurodiversity and the world

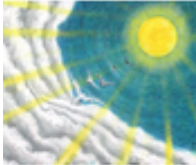
- Some people on the autism spectrum might get upset by lights or sounds that are common in everyday life.
- The neurodiversity movement thinks that people should make sensible changes to help people with autism feel better in everyday life.



Thanks to easy on the eye for the use of their image bank. © UPP1 www.easyontheeye.co.uk

Autism and Neurodiversity

If you or someone in your family has received a diagnosis, or identifies as on, the autism spectrum, you might be interested in knowing more about the *neurodiversity movement*. The neurodiversity movement can provide a source of support and information about living with autism.



WHAT IS NEURODIVERSITY?

Neurodiversity is the differences in people's brains that affect how we experience the world.

The neurodiversity movement (NDM) argues that forms of 'neurodivergence' such as autism, dyslexia, and ADHD are inherent and valuable parts of the spectrum of human variation. There is no 'right' or 'wrong' way to develop. There is no 'normal' brain.





THE SOCIAL MODEL OF DISABILITY

Ideas about Neurodiversity parallel the **social model of disability**, which recognises that the negative consequences of having an impairment – i.e., the disabling quality of a condition – are often caused by societal structures rather than the condition itself.

For example, some autistic persons may react badly to lights or sounds that are common in the social world as they may overstimulate their senses.

The social model of disability argues that barriers in society create disability, and require reasonable adjustments for those who need them.

There are parallels between the neurodiversity movement and other social justice movements like the broader disability rights movement and feminism.



Intention of book

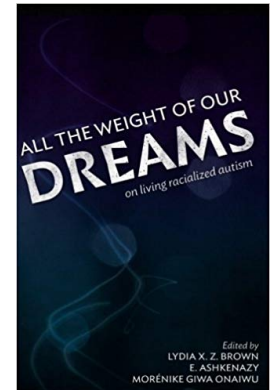
- Help to understand how the movement has shaped understanding of autism
- Document historical contributions for scholars and practitioners
- Offer opportunity for activists to engage with critiques of movement

Audiences

- Professionals, students, and researchers
 - Anthropology, bioethics, childhood studies, community development, disability studies, education, policy, psychiatry, psychology, paediatrics, social care, social work
- Autistic people, family members, allies

Contributors

- First-hand accounts from 21 advocates (19 autistic, 2 non-autistic parents) mostly from the US and UK
- 19 core chapters representing diverse areas of activism
 - Organisation, website, annual event, issue activism, protests, gathering spaces, research



Content of contributor chapters

- Why and how contributors became involved in the autism community
- The individuals or organisations critical to their involvement
- What their contribution intended to accomplish, whether it succeeded
- How they carried it out
- Whether and how they identify their action(s) with movements
- Their views on what *neurodiversity* means

Contributors' engagement with advocacy

- All accounts marked by *absence* of grief, shame
 - “When Oliver Sacks’s article ‘An Anthropologist on Mars’ appeared...my husband and I thought of our youngest child... ‘Sounds familiar!’ we said to each other, but saw no reason for special concern.” (non-autistic parent)
- Early writings and activism by autistic adults introduced them to neurodiversity movement
- All possessed sense of mission to challenge pathological narrative of autism while recognising disability

Emerging observations from submissions

3 middle-aged+ adults with children

- Knew little about autism until c. 2000's despite different pathways to diagnosis
 - One diagnosed as a child: "Although I had seen the word in reference to me as a child, I thought it simply had to do with early childhood language development." (Evans)
 - Another as adult following son's diagnosis
 - Another through son's diagnosis

Contributors' impact

- None anticipated the impact they would (not) make
 - “Then one day, my husband said, “Hey, [name], did you know that so many people have been deep-linking to your [web] page that we’re running out of bandwidth?” (Evans)
 - “[news website] covered the [issue] three times, nearly crashing the server with each flood of hits.” (non-autistic website creator)
 - “I felt a deep sadness, realizing my four years of advocacy work within the organization had not made one bit of difference to the leadership.” (autistic ex-advisor)

Difficulties in unearthing personal histories

- Limitations of access to
 - Historical actors
 - Source materials
 - Authors' 'truths'
- (Book will be published 'open access', however)



Jim Sinclair, Don't mourn for us

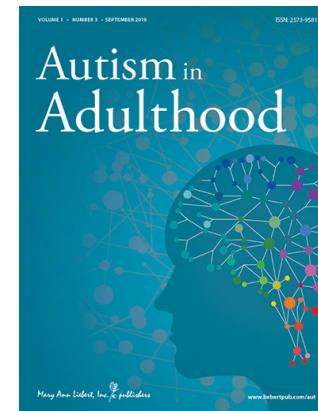
- Grieve if you must for your own lost dreams, but don't mourn for us. We are here and we're waiting for you
- The ways we relate are different.
- You're going to have to learn to back up to levels more basic than you've probably thought about before.
- You're going to have to give up the certainty that comes from being on your own familiar territory
- If that prospect excites you, then come join us, in strength and in determination, in hope and in joy. The adventure of a lifetime is ahead of you



Mapping the autistic advantage from the accounts of adults diagnosed with autism: a qualitative study.

Ginny Russell, Steven K. Kapp, Daisy Elliott, Chris Elphick, Ruth Gwernan-Jones, and Christabel Owens

Published in



Autism and Neurodiversity
Exploring Diagnosis



Strengths of autism

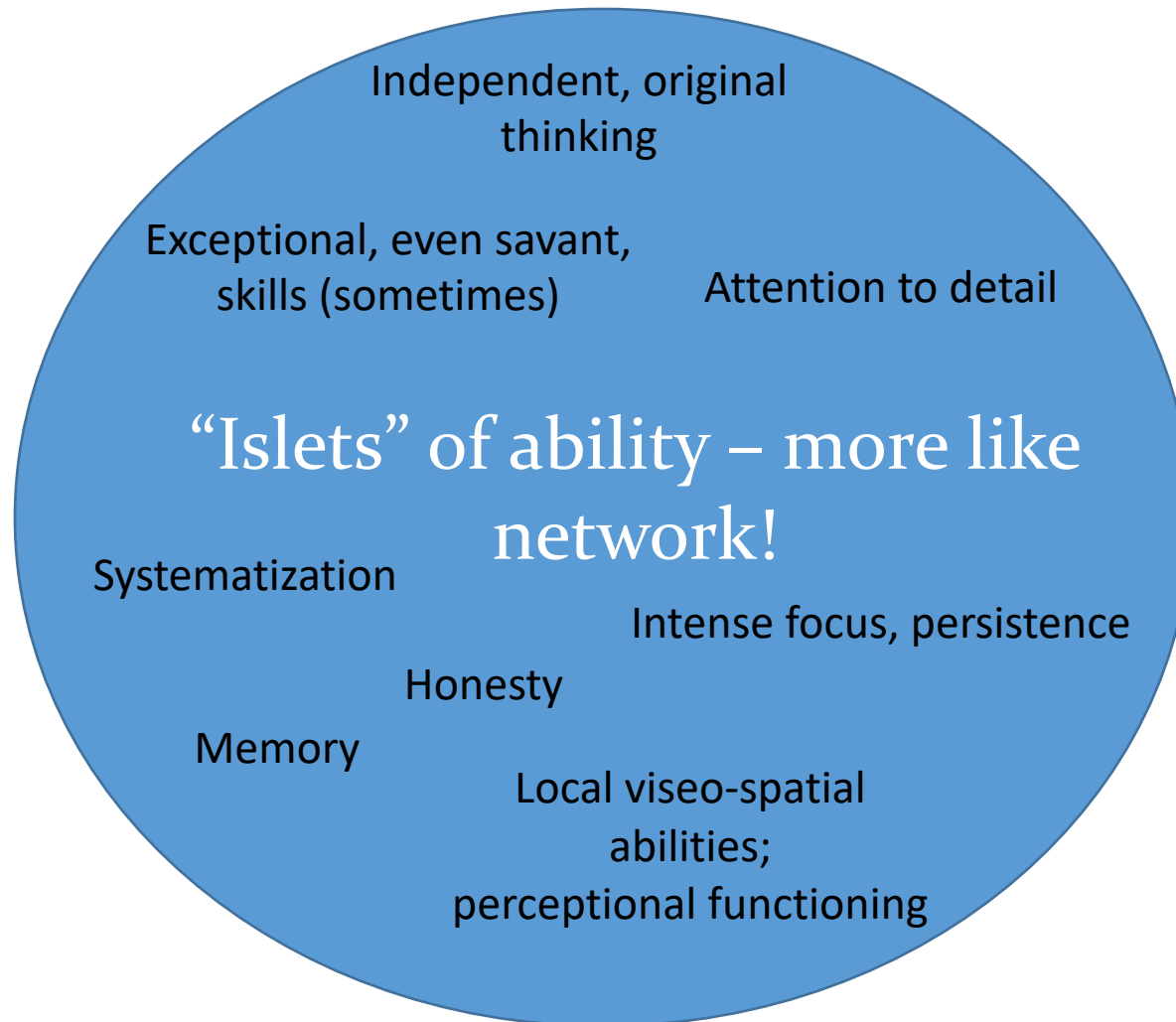


Figure 1: Word cloud of advantageous traits described by participants

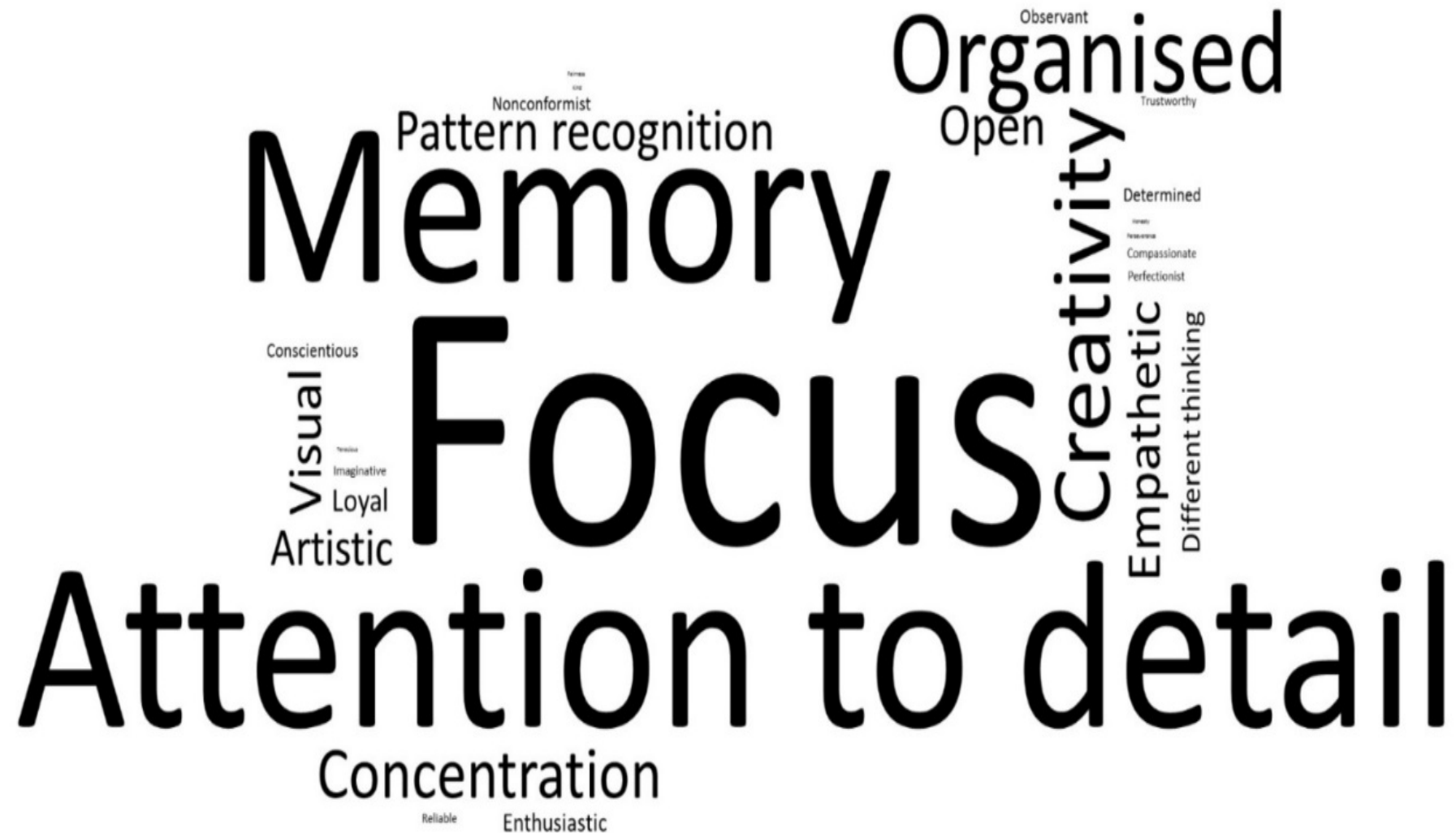
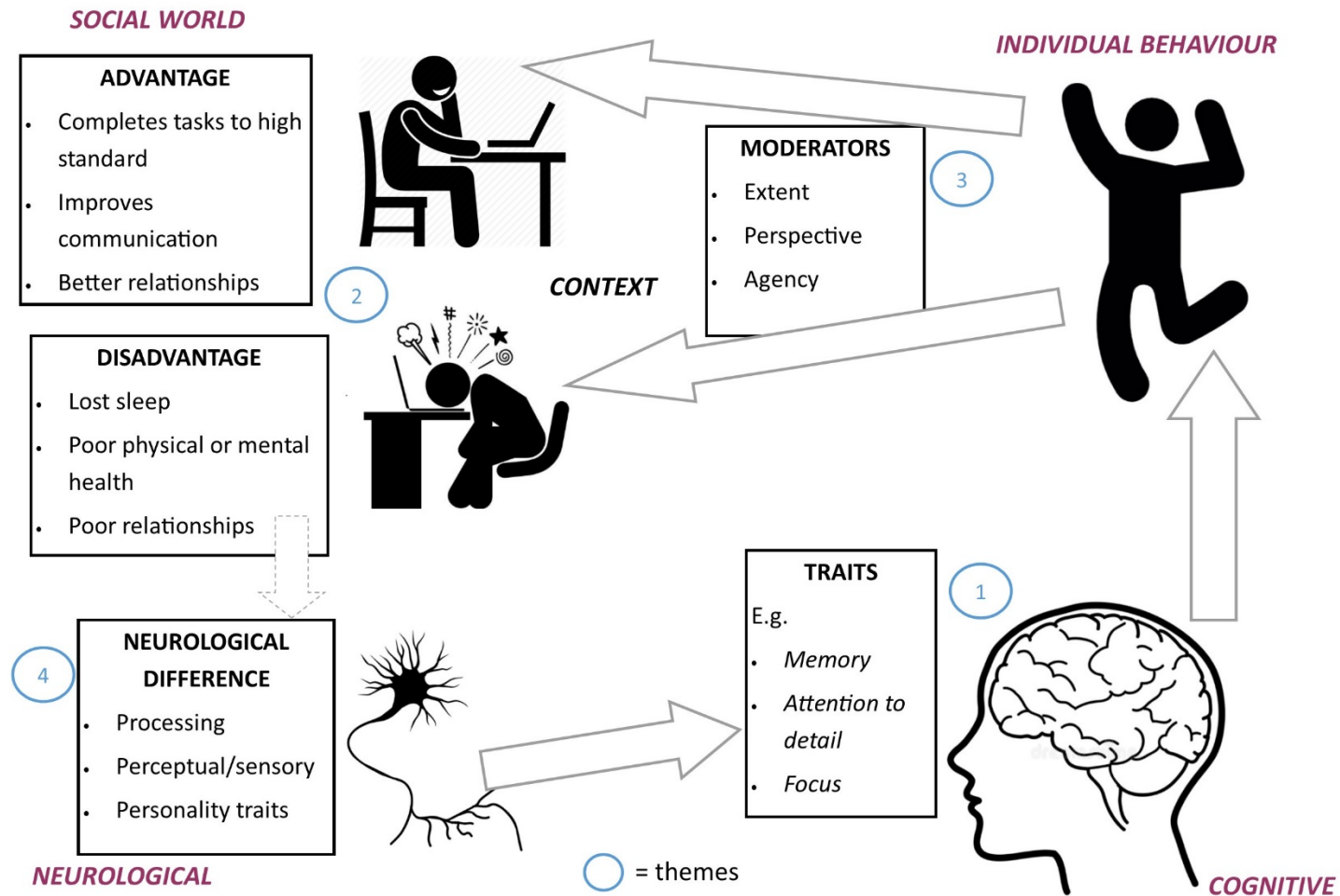


Figure 2 Conceptual map of whether or not traits were experienced as advantageous



- Autistics may need support to use differences positively

“People should be allowed to do what they like”: Autistic adults’ views and experiences of stimming.

Steven Kapp, Robyn Steward, Laura Crane, Daisy Elliott, Chris Elphick, Elizabeth Pellicano, and Ginny Russell

Published in



Background

- Critical language and treatments for stims remain popular
 - Despite weak grounds scientifically and ethically
- Autistic people and neurodiversity activists say stims are useful
- Pilot study: autistic adults usually value, enjoy stimming (Steward, 2015)
- No in-depth study on autistic people's perspective on stimming



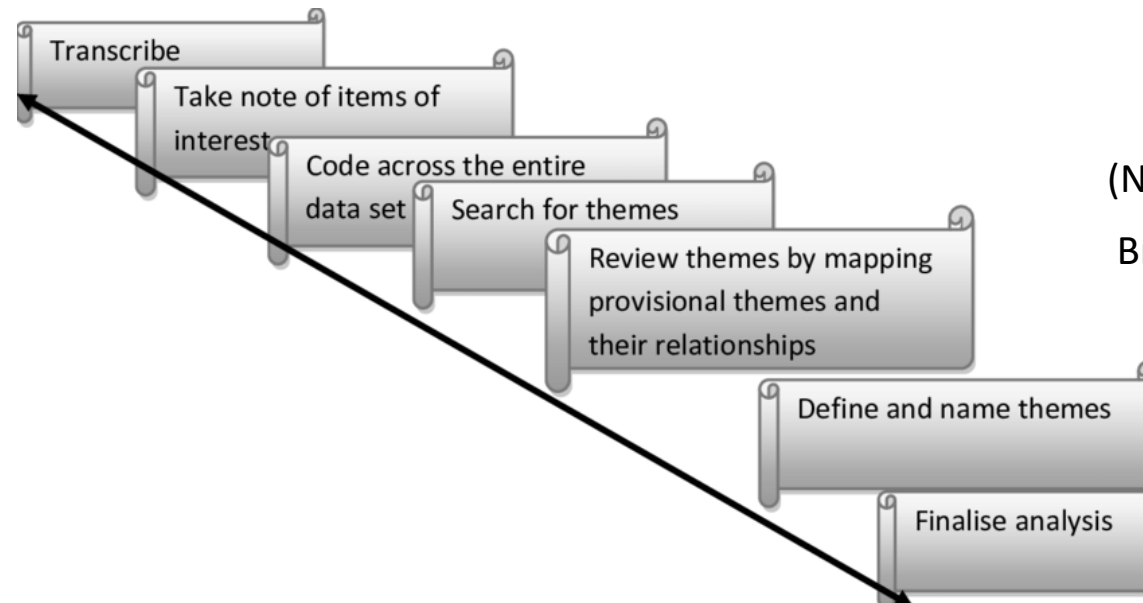
Study Aims

To examine autistic adults'

- 1) Understanding of repetitive 'stimming' behaviours
- 2) Perceptions of why they stim
- 3) Views on the value, if any, of such behaviours

Method

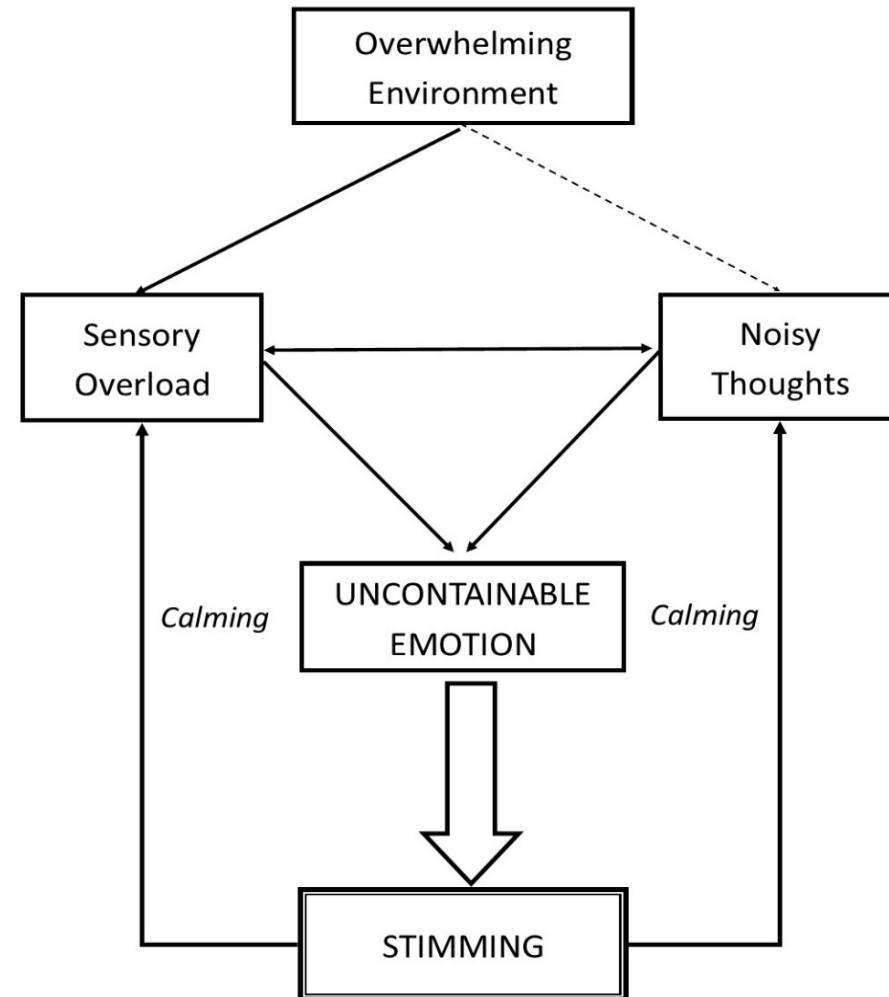
- 31 autistic adults were recruited in Southwest England and London
- Participants took part in interviews ($n = 19$) or focus groups ($n = 12$)
- Data were combined in thematic analysis



(Ngulube, 2015, adapted from Braun and Clarke, 2013; 2006)

Results: Stimming as a Self-Regulatory Mechanism

- Stimming: a repetitive behaviour (body movements or vocalisations)
- Soothed excessive emotions caused by intense sensations or thoughts

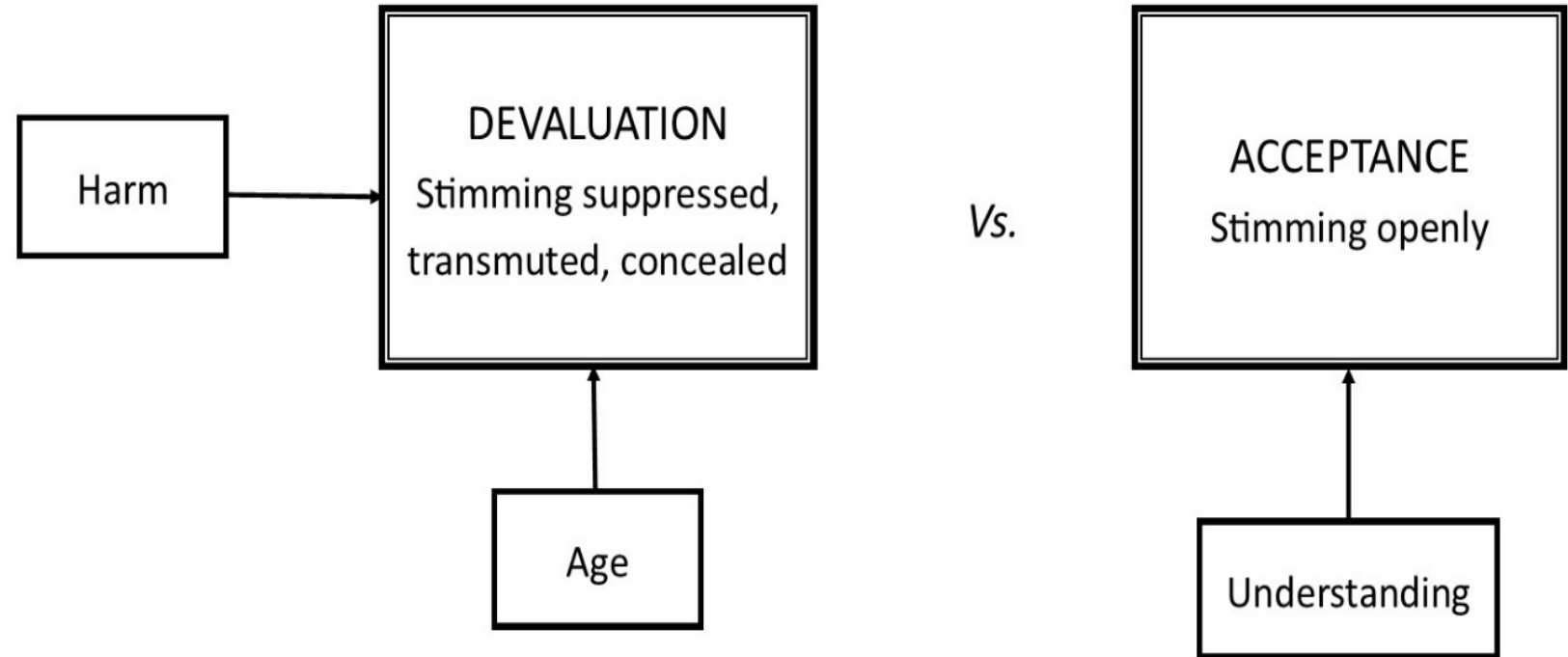


Stimming in participants' own words

- “Stimming is just the release of any high emotion, so really anxious, really agitated, really happy...” *‘Rebecca’*
 - Emotions can affect the form the stims take:
“Flapping happens when I'm unsure or stressed and also when I'm very happy - happy flapping tends to be much more active with arms raised - very obvious, I may jump up and down too. Stressed or upset flapping is usually with my hands by my side just flapping my hands” *‘Chris’*
- Stimming as a soothing feedback loop: “So it just sort of helps quell everything, because you're at the same rhythm with everything” *‘Luke’*

Results: (De)stigmatisation of stimming

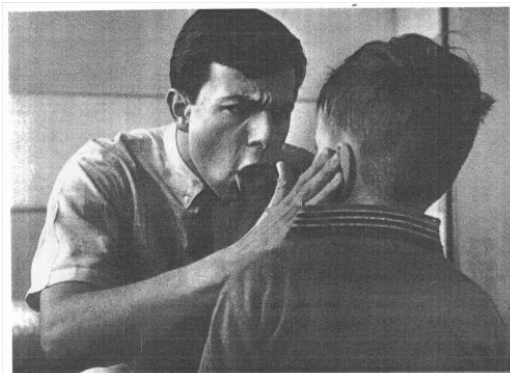
- Participants resented being told or made to stop stimming
- Many tried to suppress their stims, transmute them into different forms, and conceal them from view
- They wished to avoid harmful stims
- Stimming became less acceptable with age
- Others' understanding paved the way to acceptance



Results/Discussion: Depression from Repression

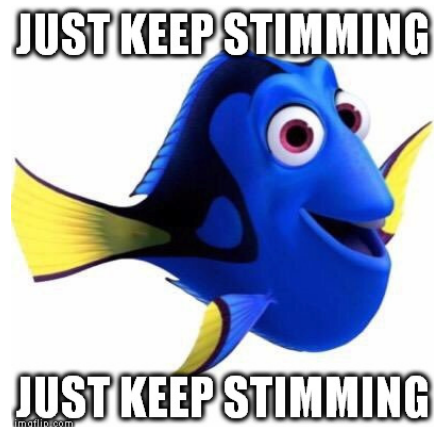
- On “ABA” in which “they basically condition them like Pavlov’s dogs to stop stimming”: “to me it was abuse, because stopping those children stimming when they’re trying to calm themselves down or cope with a situation, because even if they manage all the environment around them, there might be situations that they find stressful, and if they haven’t got the ability to calm them down, then they could be relying on other people for the rest of their lives or have a breakdown...”

‘Rose’



Discussion

- Stimming is a helpful coping mechanism for many autistic people
 - Can calm and communicate emotions, aide concentration and learning
- Social (understanding and) acceptance of non-harmful stims is key
- Ethical treatment of self-injurious, dangerous stims may be warranted



...as long as it's not harmful

Future directions

- Research autistic people's views on (treating) *causes* of stims
 - (Hyper)sensitivities, cognitive inflexibility, and emotional dysregulation?
- Compare stimming with non-autistic 'fidgeting': does everyone stim?



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