

Autism and Neurodiversity: Understanding and Supporting Autistic Patients

Steven Kapp



Learning outcome 😊

- Apply neurodiversity concept, movement and their impact to my research

Inclusion criteria 😊

- My peer-reviewed journal articles
- My academic book
- Any other publications as relevant



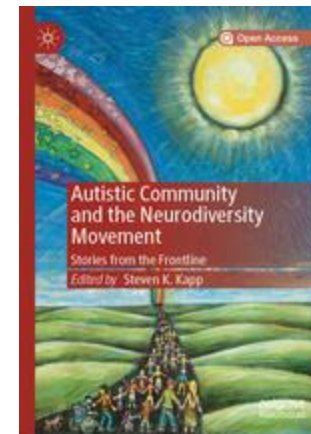
What is neurodiversity?

(data tied to Gillespie-Lynch, Kapp, Pickens, Brooks, & Schwartzman, 2017)

- The ‘fact’ of neurocognitive differences:
“variations in brain function that lead to differences in perception and bodily experience”
- A framework that values those differences:
“Acceptance of neuroatypical people, like people with autism or depression or schizophrenia”
- A movement advocating for the *neurodivergent*:
“An advocacy movement for people with neurological disabilities, based on acceptance and civil rights.”
- Autistic people are more likely than non-autistic people to define *neurodiversity* in terms of the movement (thriving, societal reform) than the framework (celebration) (Dwyer et al., 2024)



“Neurodiversity, to me, means both a fabulous celebration of all kinds of individual minds, and a serious, holistic acknowledgment of the necessity of diversity in order for society to survive, thrive, and innovate. It means identity, belonging, and community. It means I am not broken, not alone, and neither are my siblings standing with me beneath that huge, multi-colored neurodiversity umbrella: we the autistic, the mad, the weirdly-wired, the queer, the crippled, and the labeled with neurodivergent diagnoses like flowers that glorify our beautiful bodies and minds.” (Raymaker, p. 142, in Kapp, 2020)



History of neurodiversity movement

- The term *neurodiversity* emerged (first as *neurological diversity* by Tony Langdon in 1996) (Botha et al., 2024), as a rhetorical frame for autism rights movement
- Movement has since become part of cross-disability rights activism (Gillespie-Lynch et al., 2020)
- Book presents first history of movement from first-hand accounts (Kapp, 2019)
 - 19 core chapters by 21 advocates (2 non-autistic), with academic analysis
 - organisations, politics, protests, websites, book, conference, research, mailing list



Volume 1, No. 1

DON'T MOURN FOR US



Autism Network International

The *neuro-* in *neurodiversity*

- Neurodiversity framework positions autism as essentially biological
 - Feature of being autistic, not supporter of the movement (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013)
 - Autistics more likely to define autism internally (Gillespie-Lynch et al., 2017)
- Autism as ‘hard-wired’ part of the self
 - Autistic traits heavily overlap with personality traits (Schwartzman, Wood, & Kapp, 2016)
 - Not related to reduced prosocial behaviours (Riccio et al., 2020)
 - Adolescents associate *autism* label with uncontrollable brain (White et al., 2020)
- Yet autistic people often feature lived experience (e.g. autistic burnout [Raymaker et al., 2020], social trauma, discrimination) in core autistic traits (Ratto et al., 2023)

The Autistic Genocide Clock

Estimated time remaining before prenatal testing and routine abortion:

8 years, 6 months, 4 days, 16 hours, 19 minutes, and 20 seconds



The *diversity* in neurodiversity

- Autism viewed as a *complex* difference (Russell et al., 2019)
- Values experiential expertise and leadership of autistic people
 - Autistics had highest autism knowledge, related to lower stigma (Gillespie-Lynch et al., 2017)
- Quality of life (QoL), not 'cure', supported (Kapp, 2018; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013)
 - Responsive and accepting parenting, school inclusion help QoL (Kapp, 2018)
 - Against normalisation (Gillespie-Lynch et al., 2017)



Impact of Neurodiversity

- People aware of neurodiversity movement are more likely to have views aligned with it (Kapp et al., 2013)
- Neurodiversity support is largely robust to people close to autistic people with high support needs (Hersh et al., 2024)
- Becoming aware of autism through proactive, nuanced parental disclosure helps autistic adolescents have a more positive identity (Riccio et al., 2021)
 - Becoming aware of autism diagnosis early associated with more well-being (Oredipe et al., 2023)
- Autistic activists influenced revision of autism's diagnosis (Kapp & Ne'eman, 2020)
- Avoiding ableist language: suggestions for autism researchers (Bottema-Beutel et al., 2021), has had wide impact already
- The neurodiversity movement may fare best in helping people to cope with autism (Kapp, 2022)
 - Supported by a compensatory model in which responsibility for cause of problem (disability) is attributed mostly to society, but responsibility for solution to problem is attributed mostly personal (self-advocacy)

Figure 1: Word cloud of advantageous traits

(Russell et al., 2019)

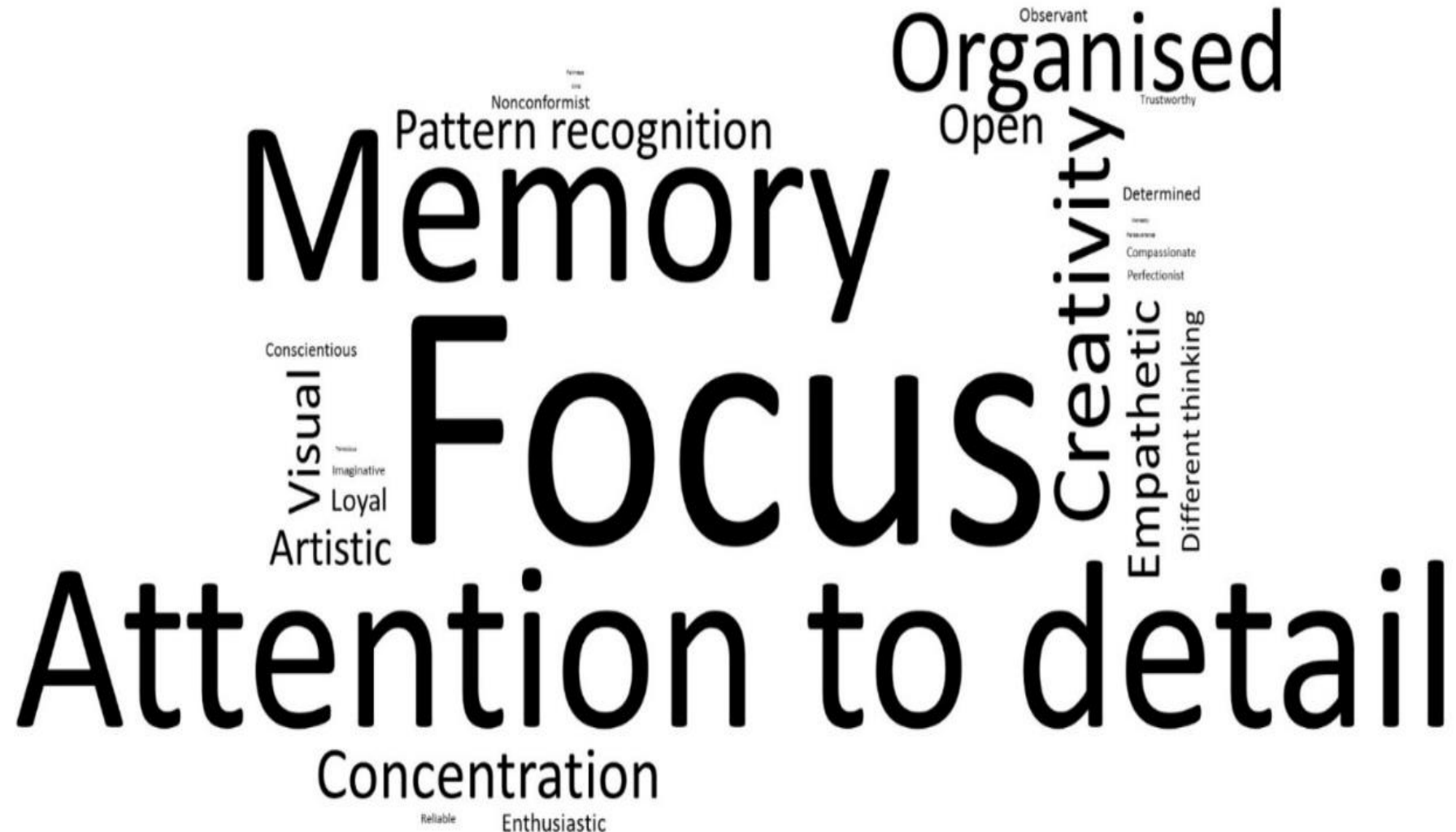
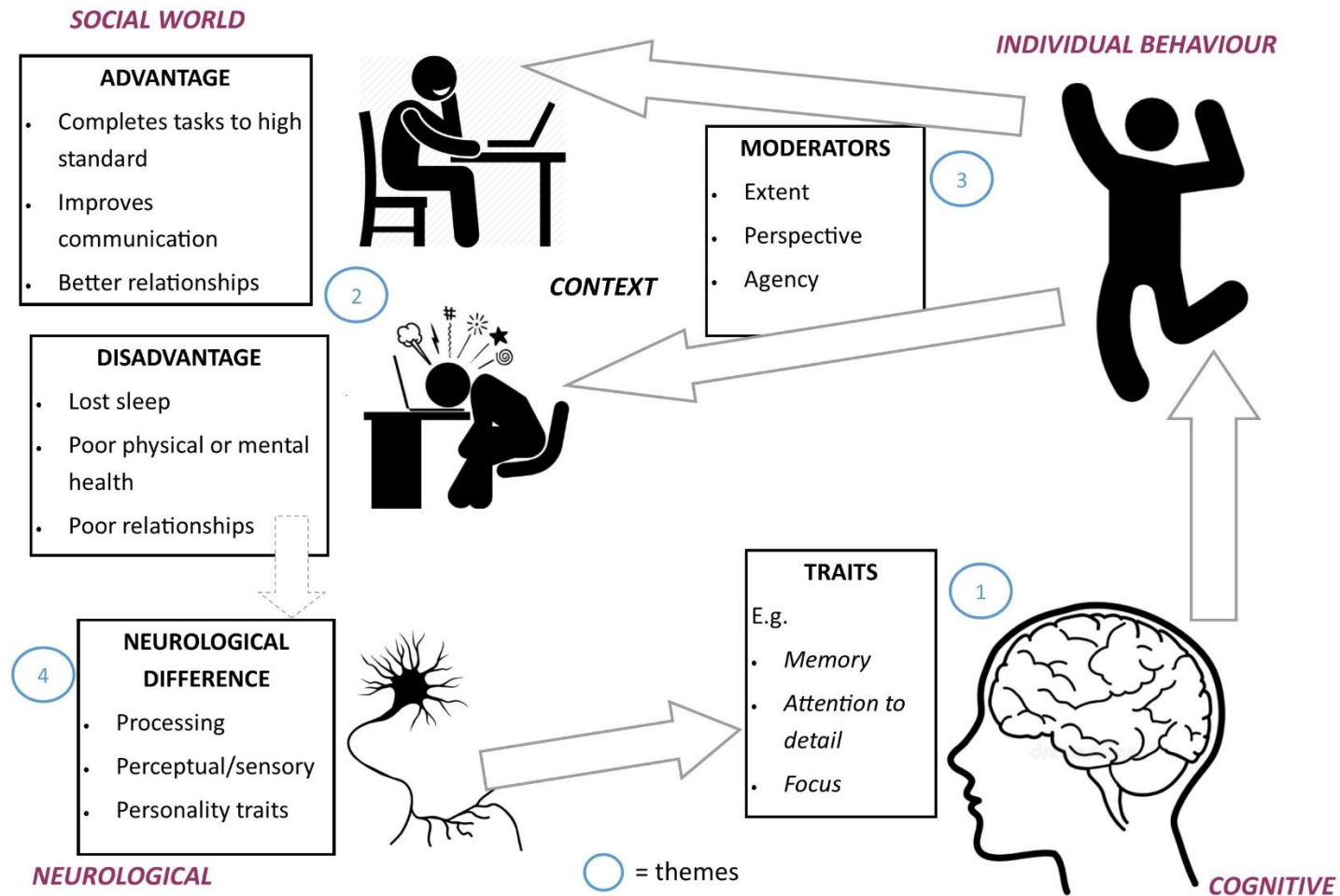


Figure 2: Conceptual map of whether or not traits were experienced as advantageous

(Russell et al., 2019)



Traits as coping mechanisms: stimming (Figure 1)

(Kapp et al., 2019)

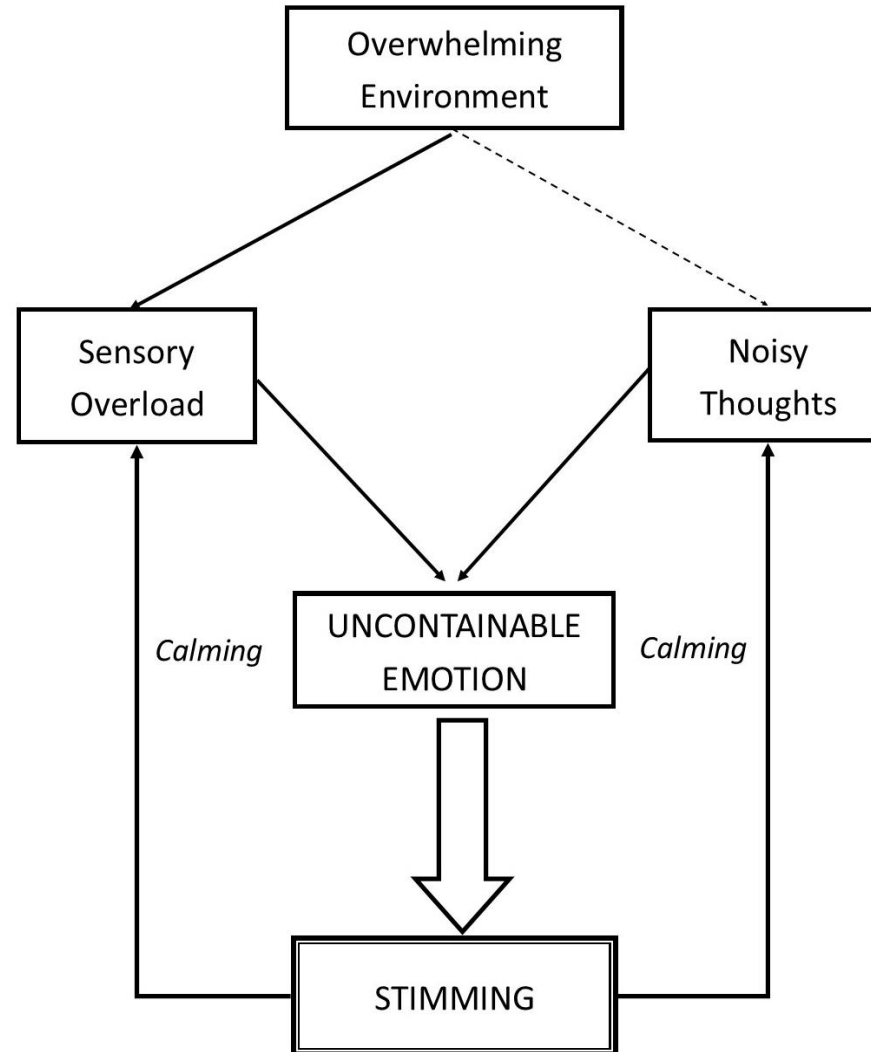
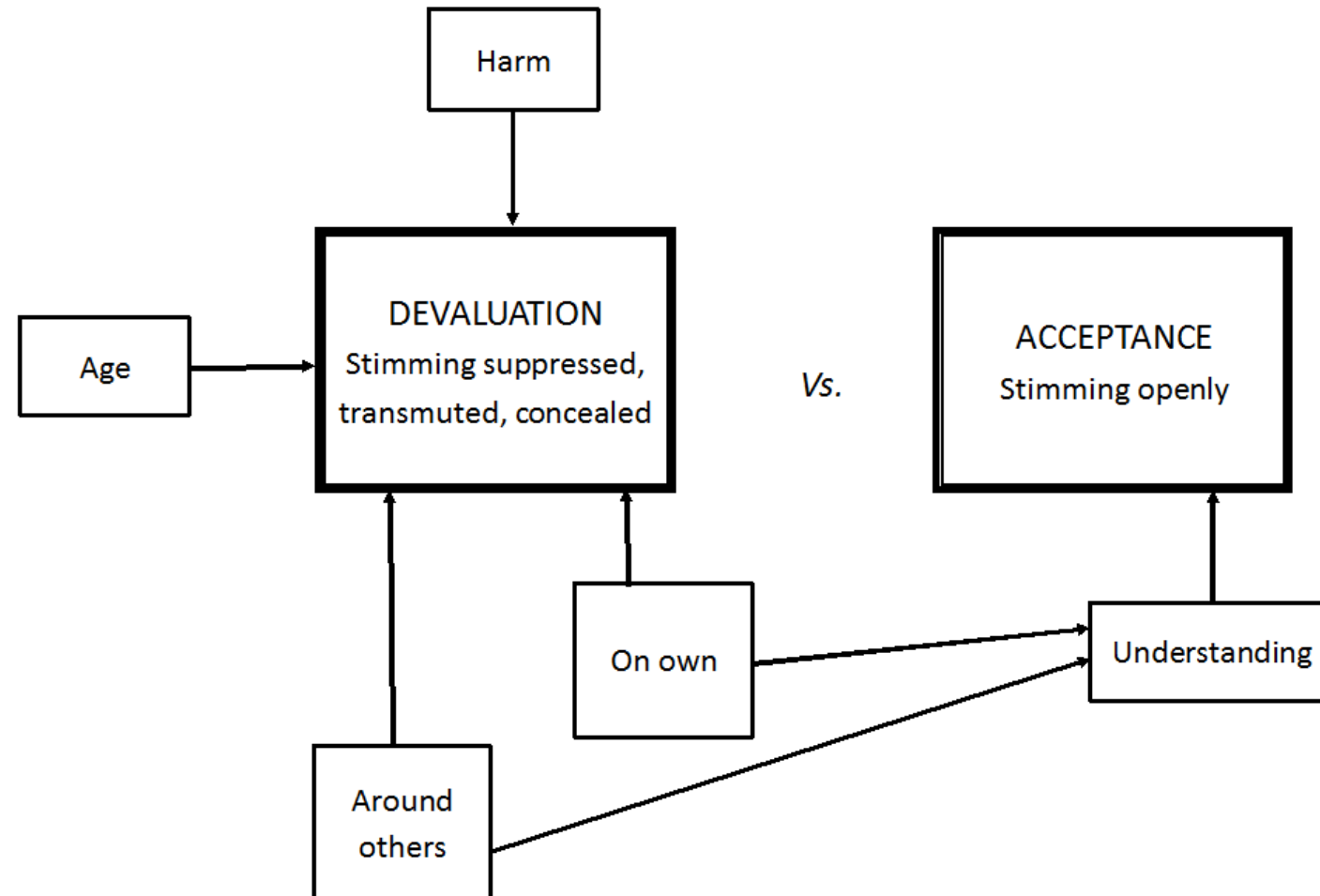


Figure 2: (De)stigmatisation of stimming

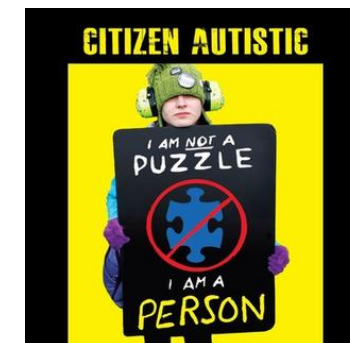
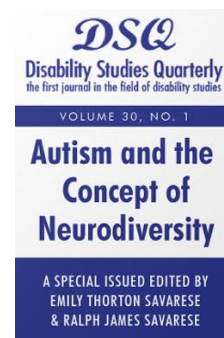
(Kapp et al., 2019)



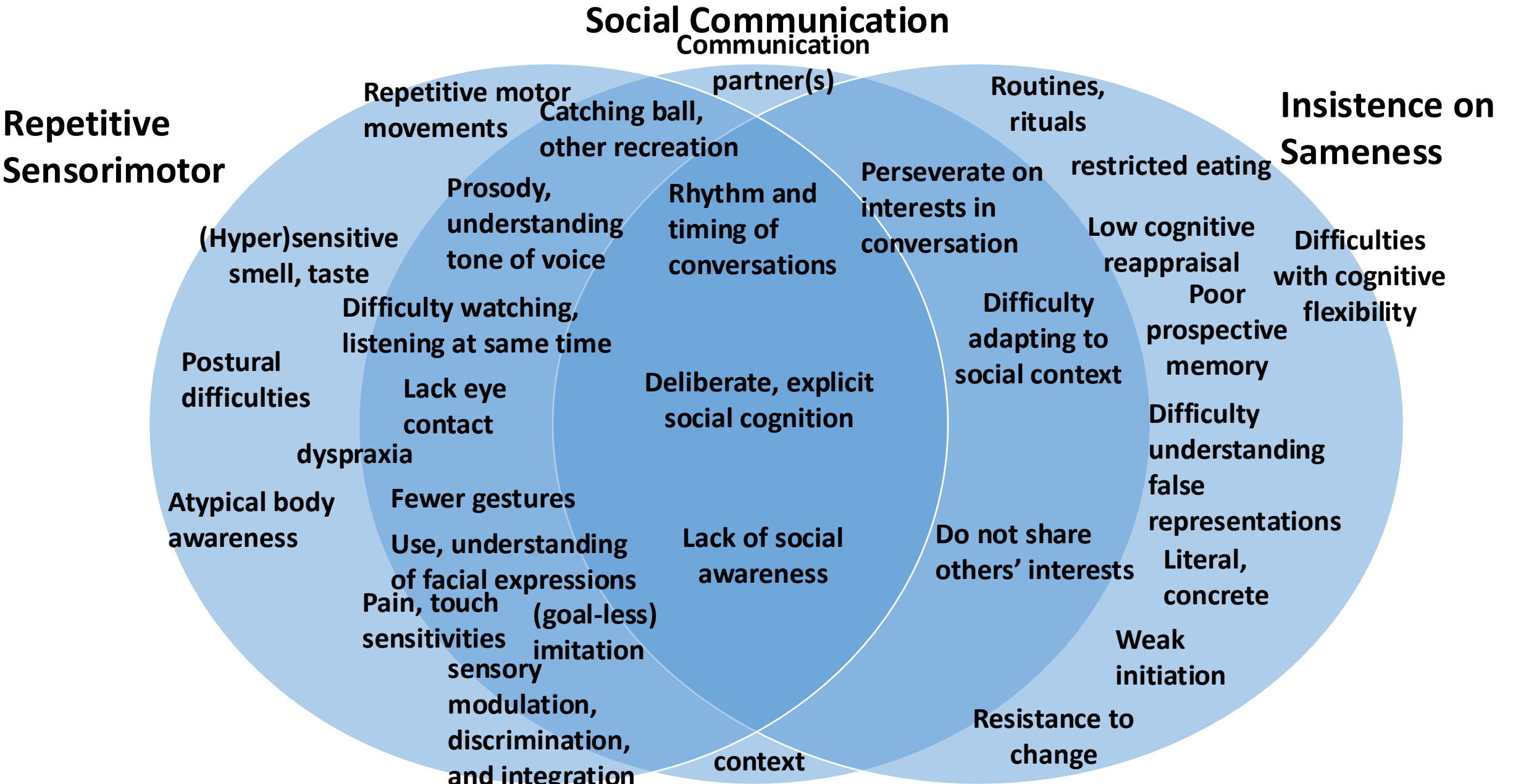
Neurodiversity as an integrative disability model

(Kapp, 2013b; see also Kapp, 2019)

- Advocates support celebrating *and* ameliorating autism (Kapp et al., 2013)
 - Autistic people often define *autism* in nuanced ways (Kapp et al., 2017)
- Neurodiversity scholars critique social-first views of autism
 - Critique social motivation (Kapp, Goldknopf, Brooks, Kofner, & Hossain, 2019) and social cognition theories of autism (Kapp, 2013a; Kapp, 2019)
 - Support for dynamic brain-body, person-environment interactions
- Activists worked with authorities for autism in DSM-5 (Kapp & Ne'eman, 2020)
 - E.g., recognised structured assessments improve reliability (Kapp & Ne'eman, 2020; see also Milton, Bovell, Timimi, Kapp, & Russell, 2019)

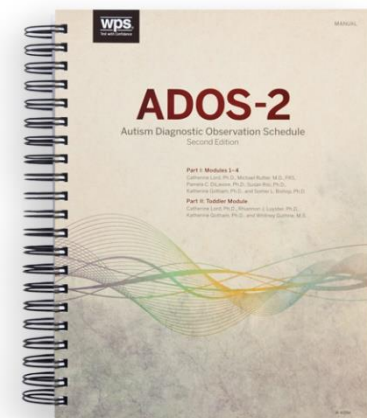
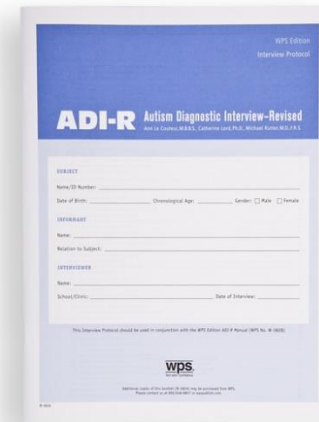


Clinical View of Autism

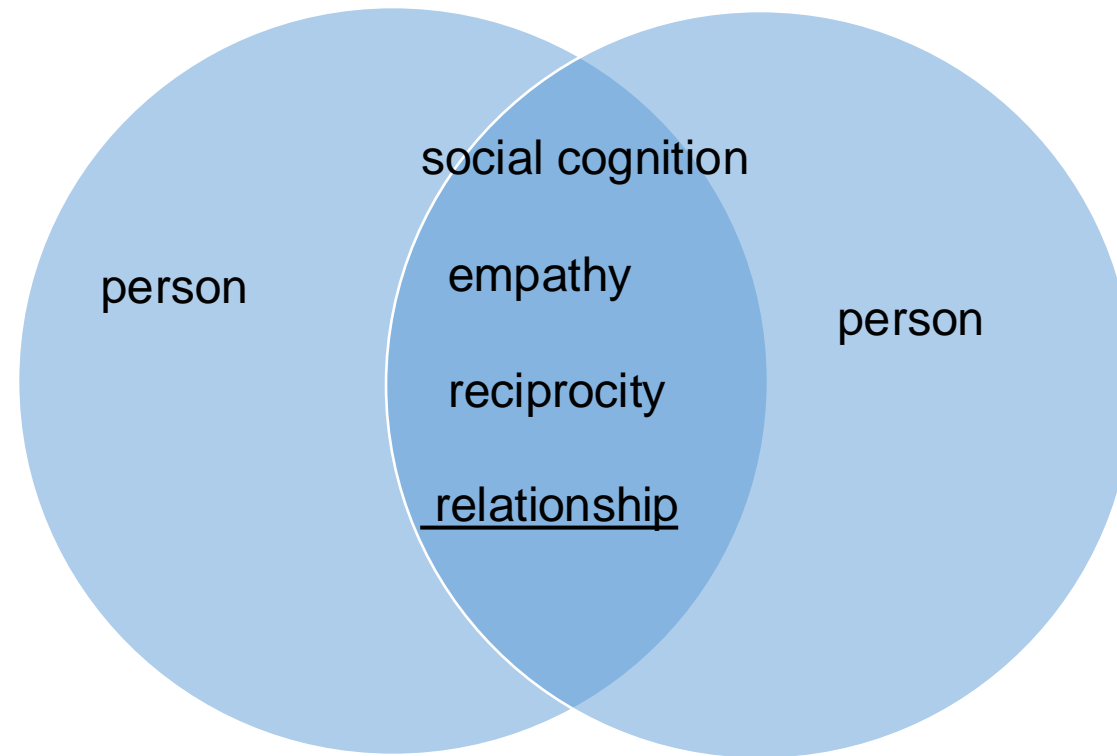


Do social disorders really exist?

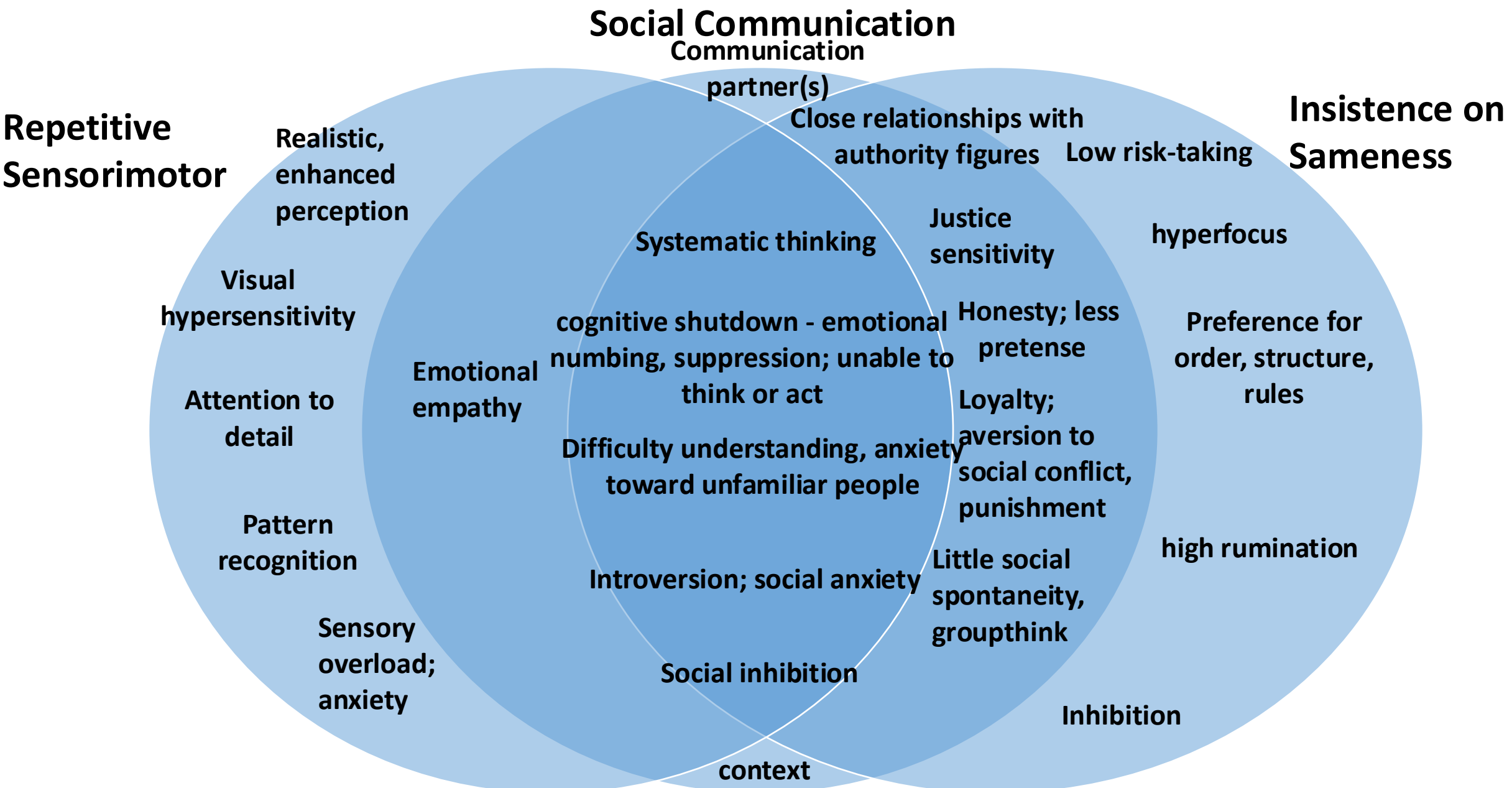
- "...as somebody who's been trying to measure social behavior for a long time, I don't think there's even one thing that is social behavior. I think social behavior is actually many different things. We do much less well quantifying social behavior than we do lots of other things, even repetitive behavior."
- The new social communication (pragmatic) disorder was created for “political and health reasons...DSM-5 was not a scientific process...the empirical evidence is NOT in support of social pragmatic disorder”.
- *Catherine Lord* (Simons Live DSM-5 Discussion)



Social interaction



Social Justice View of Autism (*Opposite* Psychopathy)



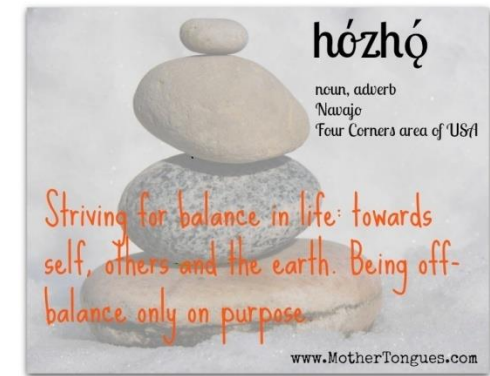
Why autistics are misunderstood

At an interpersonal level, how differences manifest in interaction is of course more apparent to others, but their underlying reasons are more meaningful

- Lack of eye contact: emotionally threatening, cognitively taxing
- Social withdrawal: sensory overload, anxiety, rigidity
- May not be cuddly: sensitivity to touch, not lack of affection
- Atypical social approach: lack of awareness of personal space
- Poor impressions: less willing, able to wear “social masks”
- Repetitive body movements: help with self-regulation but stigmatized
- Seem like in own world: often need to focus on own body to move
- Seem monotone: more tonal variability but it defies listeners’ expectations
- Many other reasons



Autism across cultures



- Navajo (Kapp, 2011)
 - Matrilineal society
 - People with disabilities can stay with mother without stigma
 - Caregiving by multiple “mothers”; natural support and relief
 - Value of harmony (hózhó wellness philosophy)
 - Also value individuality; people have unique social roles
 - Autistic people viewed as children on the brink of adulthood
 - Responsible, celebrated for what can do, accommodated and supported for what cannot
- Cross-cultural predictors of low autism stigma: autism knowledge, high-quality contact with autistics, openness, low acceptance of inequality (Gillespie-Lynch et al., 2019)

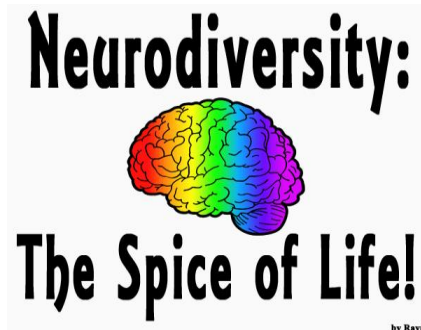


Training People about Autism

- Training increased knowledge, decreased stigma of autism (Gillespie-Lynch et al., 2015)
 - Replicated in many countries (e.g. Japan (Someki et al., 2018), Lebanon (Gillespie-Lynch et al., 2019))
 - Works best when co-designed by participatory research team (Gillespie-Lynch et al., 2022)

Does everyone wish autism could be cured?

- No: The neurodiversity movement views ASD as a minority identity that is an important part of human diversity like race or sexuality



Accessibility: autism and the internet

- Autistics often learn about the neurodiversity movement online (Kapp et al., 2013)
- Autistics more likely to use internet to meet others, report social benefits
 - Communication comprehension, control; access to similar others; true self-expression (Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014)
- Participatory web accessibility guidelines for autistic users (Raymaker et al., 2019)
 - Physical accessibility: e.g. [provide low-contrast neutral, various, no-style colour options](#)
 - Intellectual accessibility: e.g. use simple interface, images; concise language; little scrolling
 - Social accessibility: e.g. use precise language, define context-dependent terms

The New York Times

Autistics, freed from face-to-face encounters, are communicating in cyberspace.

By Harvey Blume

June 30, 1997

From university to employment

- Autistic university students' main goal in attending university was to improve career, but few learned career-specific skills at university (Cheriyān et al., 2021)
 - More likely to seek academic career, less likely healthcare, than non-autistics
 - More often than non-autistic students, writing skills and attention to detail expected to help with dream job
 - Yet more likely to expect discrimination and social and psychological difficulties to present barriers
- High-skilled autistic employees identified strengths and barriers
 - Autistic advantages and unconventional pathways to career
 - High stakes in disclosing autism; disconnects with services and supports; and impacts of discrimination, trauma, and burnout (Raymaker et al., 2021)

Healthcare

- Autistic people suffer health disparities, but they're mostly a matter of poor person-environment fit rather than due directly to autism (Nicolaidis et al., 2015)
 - Provider factors (e.g. autism knowledge, willingness to allow adjustments)
 - Systemic factors (e.g. healthcare system complexity, inaccessible healthcare facilities)
- Participatory AASPIRE Healthcare Accommodation Toolkit helped to improve patient self-efficacy, patient-provider communication (Nicolaidis et al., 2016)

AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This web site has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

Guidelines to include autistic adults as co-researchers

(Nicolaidis et al., 2019)

- Clearly communicate partnership goals; choose approach to match them
 - Equal partnership, authentic engagement or collaboration, consultation
- Clearly define community partner roles and pick people likely to help success
- Co-create process for communication and power-sharing; re-assess as needed
- Focus on building and maintain trust (e.g. visioning exercise, active listening)
- Collaboratively disseminate findings (co-author, co-create lay language briefs)
- Encourage capacity-building (professional development, yet keep lay partners)
- Fairly compensate community partners for their work





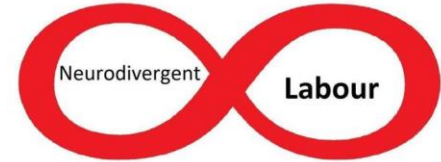
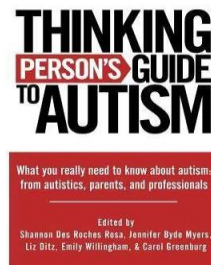
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The work continues...

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Listening to autistic people's loud hands

- Many autistics, e.g. in neurodiversity (ND) movement, push for social equality
- ND: autism complex, pervasive part of personality to accept, support
- [Loud hands](#): self-advocacy for autism acceptance (e.g. hand-flapping can be a form a communication), against normalization (e.g. “quiet hands”)
- Might “noncompliance” or “problem behaviors” often be acts of self-advocacy?



“When I was a little girl, I was autistic. And when you’re autistic, it’s not abuse. It’s therapy” – Julia Bascom, “Quiet Hands”