

Supporting the Individual Differences of Autism: Respecting Neurodiversity

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Preview of talk

- Introduction to social model, neurodiversity movement
- Individual differences – strengths, eye contact
- Helpful support vs. abuse marketed as treatment
- Social support's contribution to quality of life

Disability rights movement

- Social contribution to/construction of disability
- Civil rights model – not medical model
- Self-advocacy: “Nothing About Us Without Us”
- Focus on self-determination and quality of life: building independence, inclusion, productivity through rights and support
- For respect, against personal tragedy narrative

**NOT
BEING ABLE
TO SPEAK IS
NOT
THE SAME
AS NOT
HAVING
ANYTHING
TO SAY**



**DYSABLED
& PROUD!**

Neurodiversity movement

- Autism: complex, pervasive; part of personality
 - Often identity-first, non-medicalized language
- Autism: natural, on spectrum of human diversity
- Focus on rights, access, opportunities -> quality of life
- For acceptance; against prevention and normalization



What works for whom and why?

- Little knowledge about what “works” for whom and why
 - Common knowledge that no intervention works for all
- Little evidence treatment improves long-term “outcomes”
- Little ability to predict “outcomes” at individual level
- Little known for whom, how autism diagnoses tend to help

**ASAN Statement on Fein Study on
Autism and “Recovery”**

**Opportunities and Perils of Extremely Early
“Autism” Intervention**



Strengths of autism

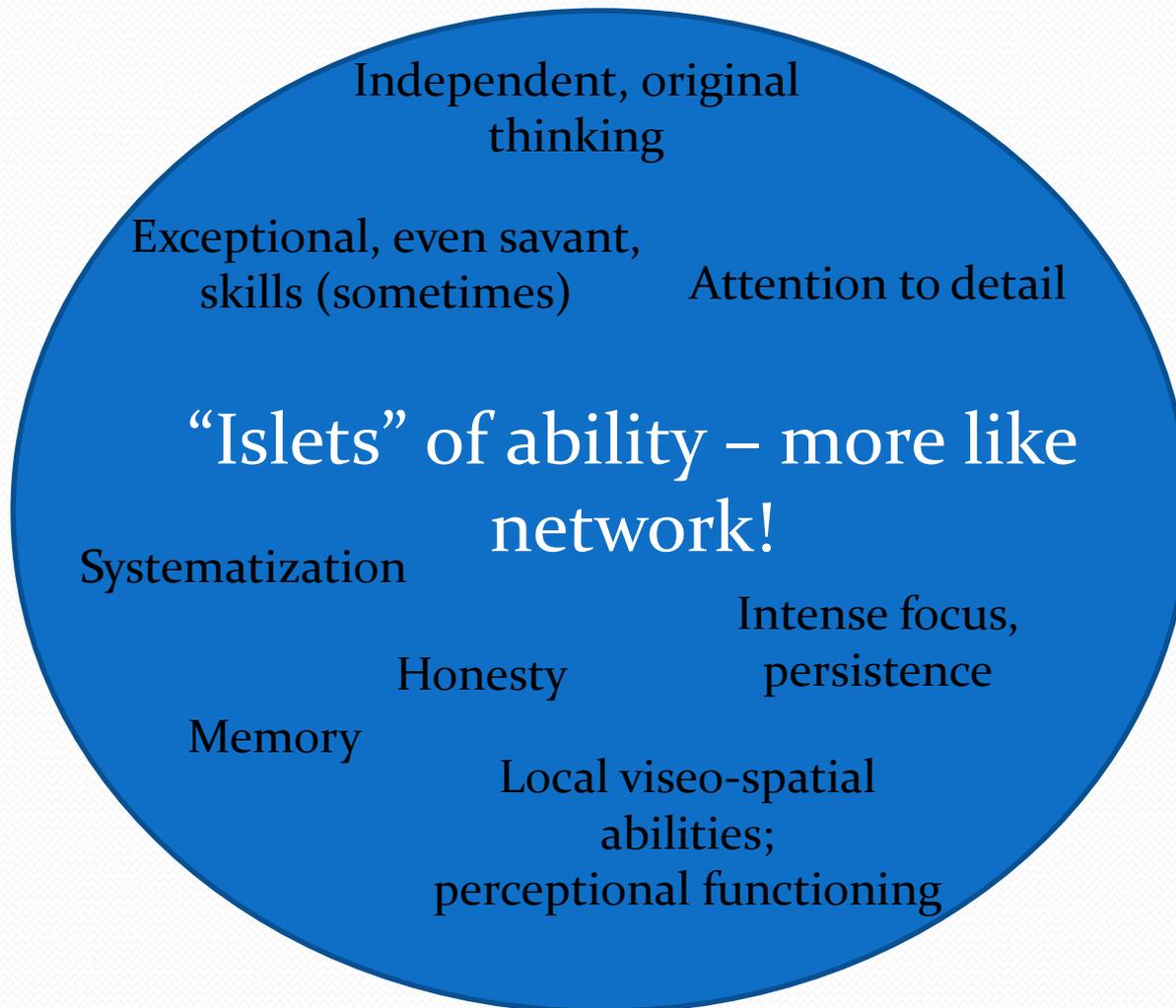


Figure 1: Word cloud of advantageous traits described by participants

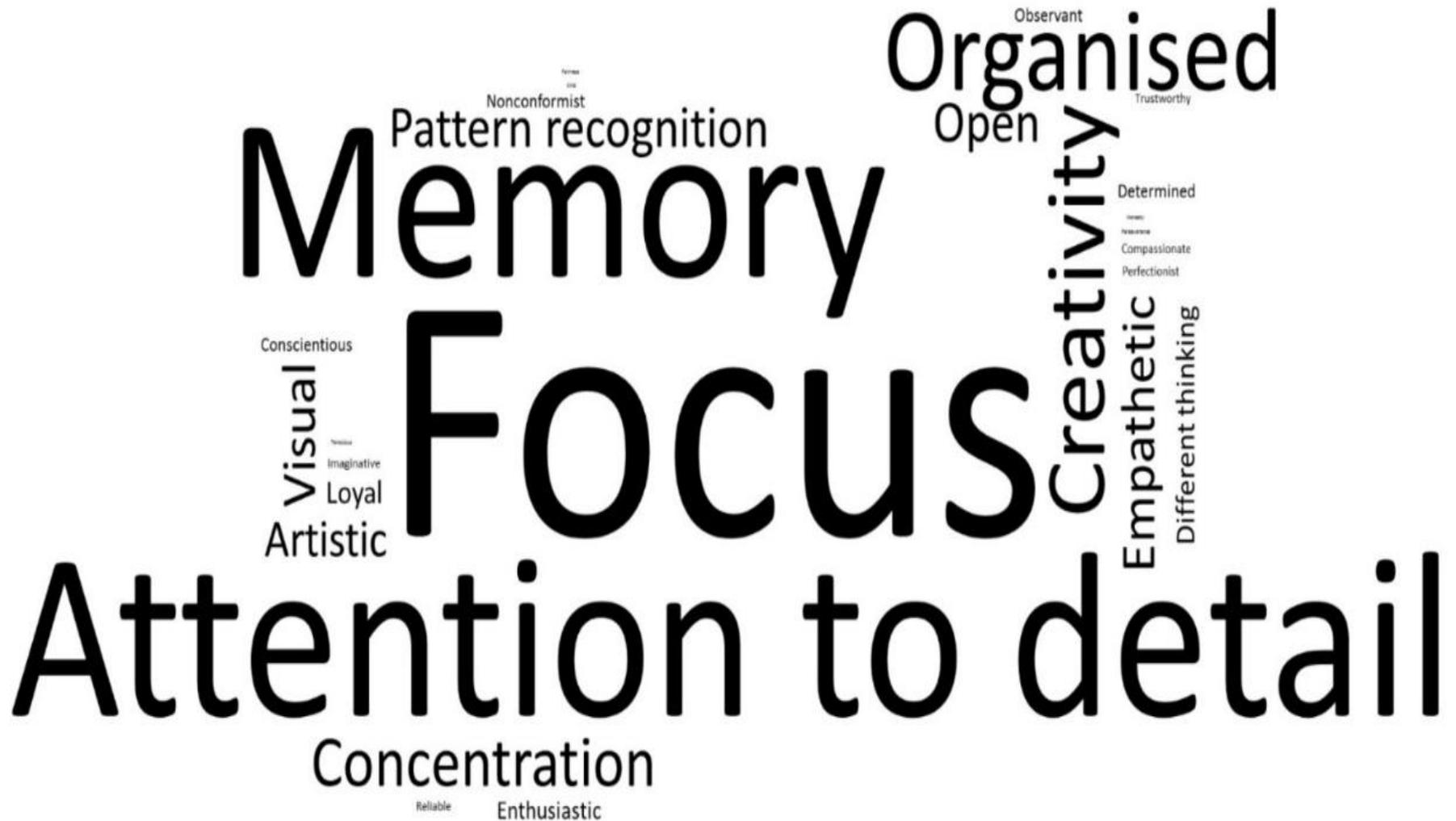
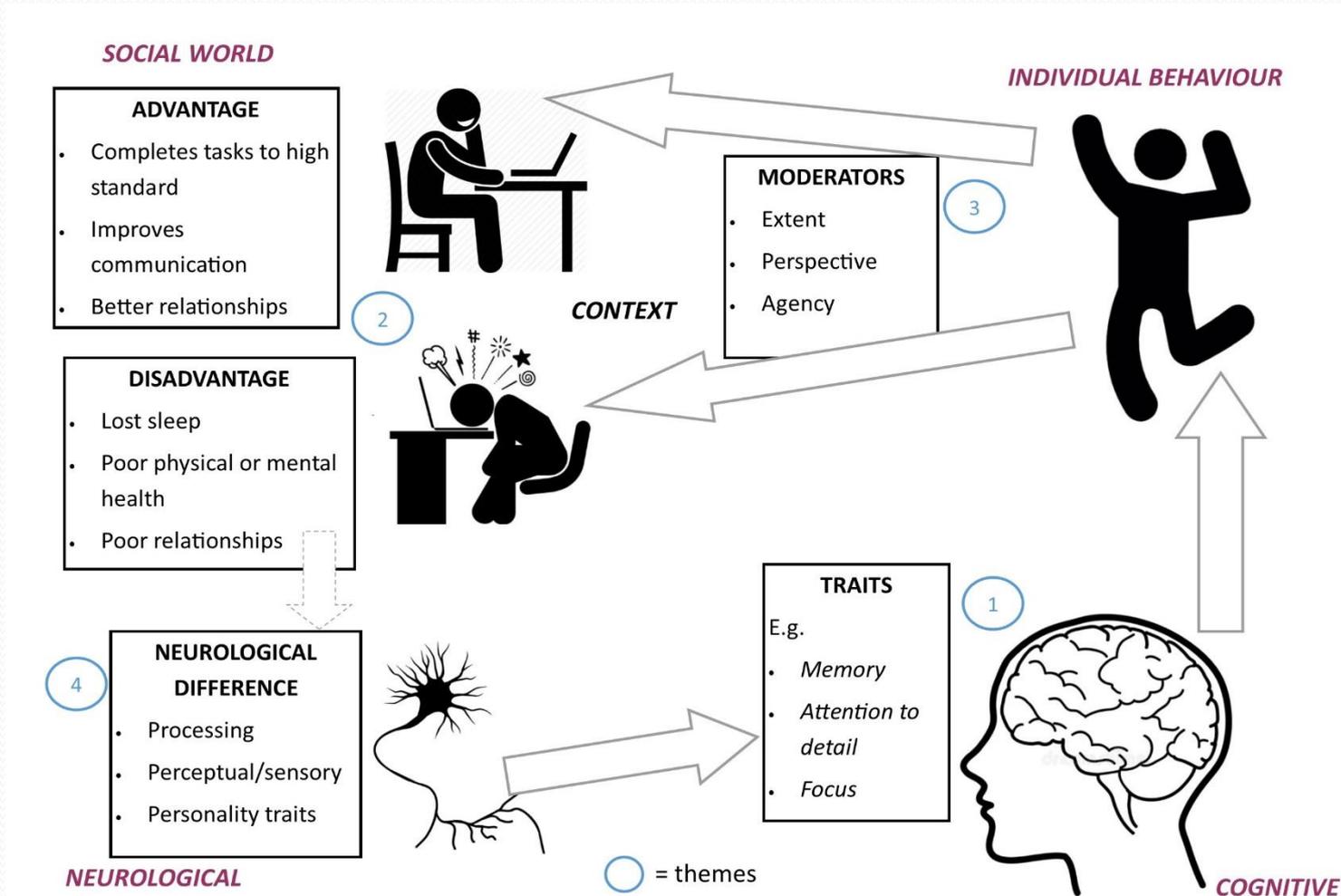


Figure 2 Conceptual map of whether or not traits were experienced as advantageous



- Autistics may need support to use differences positively

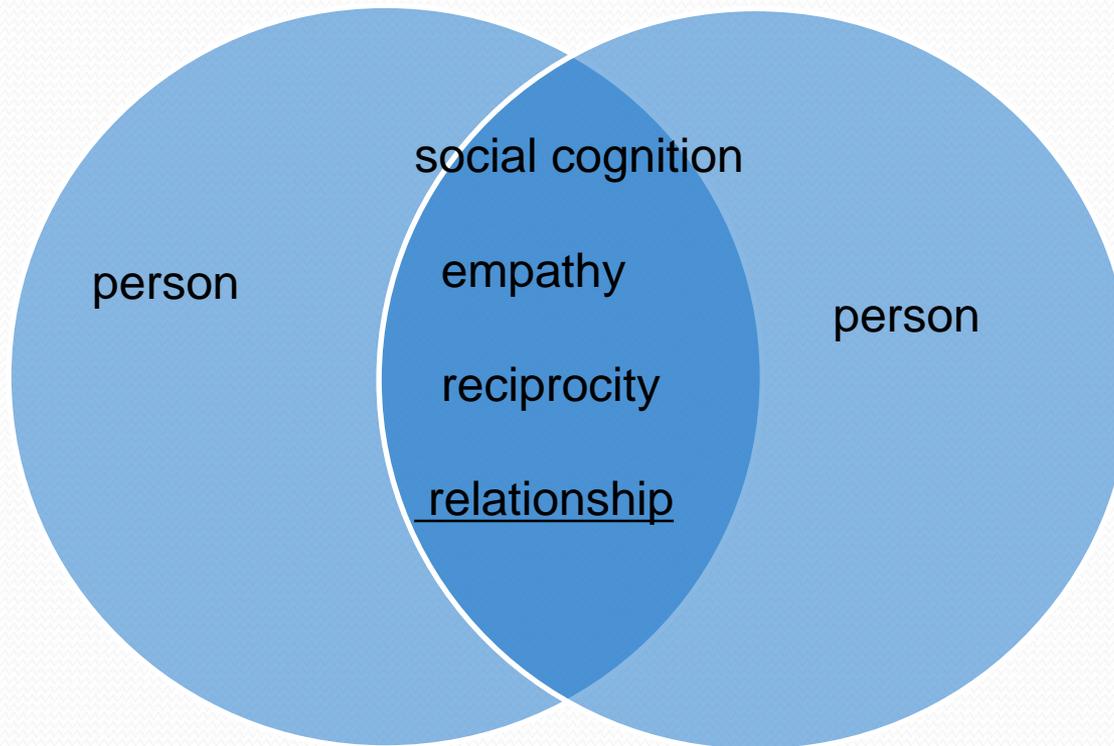
Reasons for atypical eye contact

- Enhanced perception
- Difficulty watching and listening at the same time
- Intense threat detection
- Reduced oculomotor (eye movement) control
- Sticky attention
- Prosopagnosia (faceblindness)
- Culture!

Note: eye contact is not necessarily atypical



Social interaction



Inclusion and support

- Aides focus on whole class
- Preparation for work in and through school
- Communication technology such as iPad and its apps
- Positive parenting
- Intervention programs that value autistic culture

Helpful support

- Positively seek useful skills/development but
 - Not normalization, compliance
- Ways to build communication
 - Understand and accept the person; become in sync
 - Speak in the person's language, follow person's lead, imitate
 - Do not talk, touch too much, but do gesture
 - Consider incorporating the arts (music, drama)
 - Augmentative and alternative communication

I ♥ AAC

Augmentative and Alternative Communication

other ways to communicate besides speech

Sensory-sensitive support

- Lipreading to interact
- Slowing down the presentation of facial expressions
- Colour filters for communication
- Looking at own body to learn movements
- Responsive rather than directive caregiving
- Song, music
- Others' imitation of autistic people
- Augmentative & alternative communication (e.g. iPad)

Figure 1: Stimming is a self-managing process

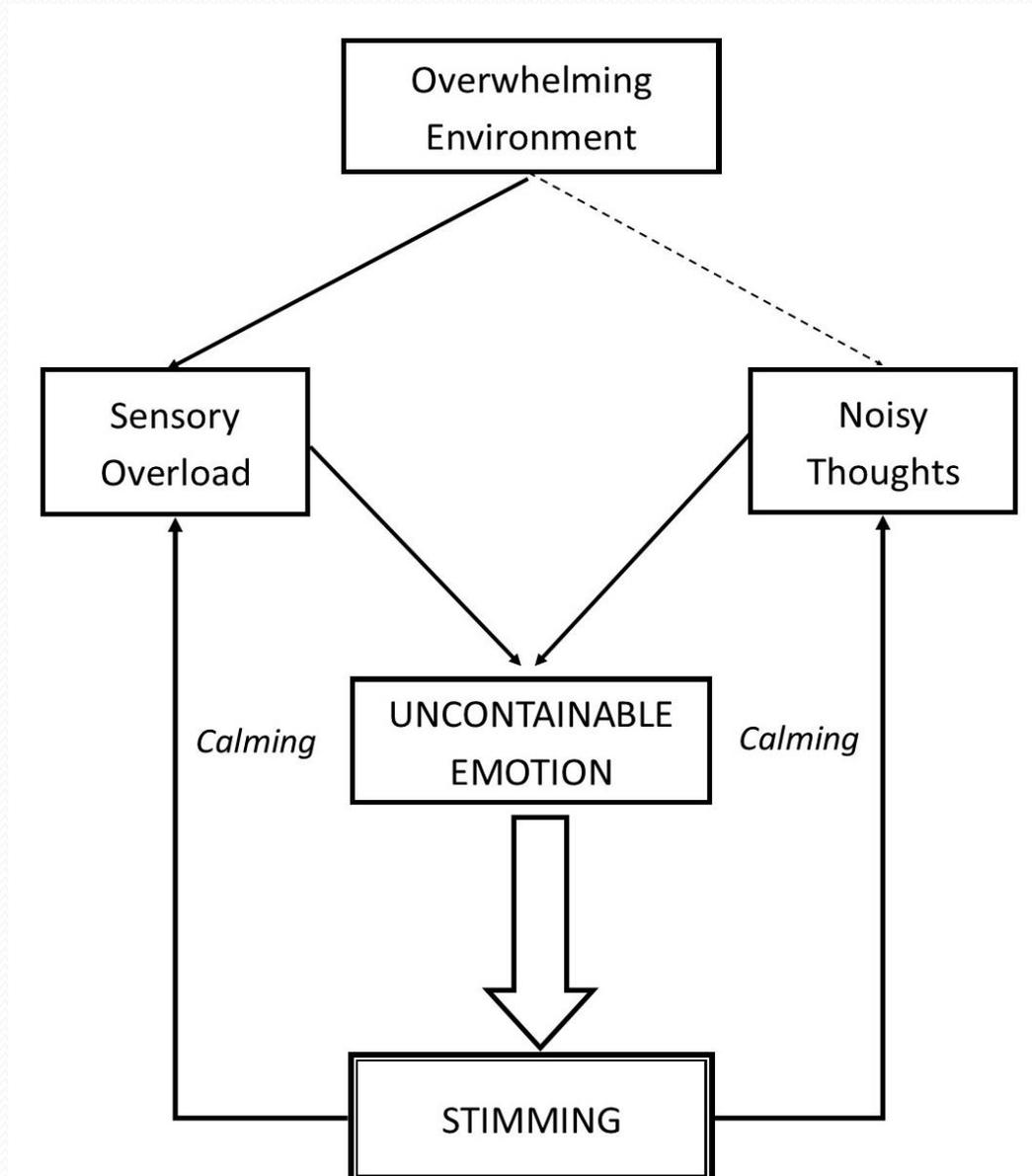
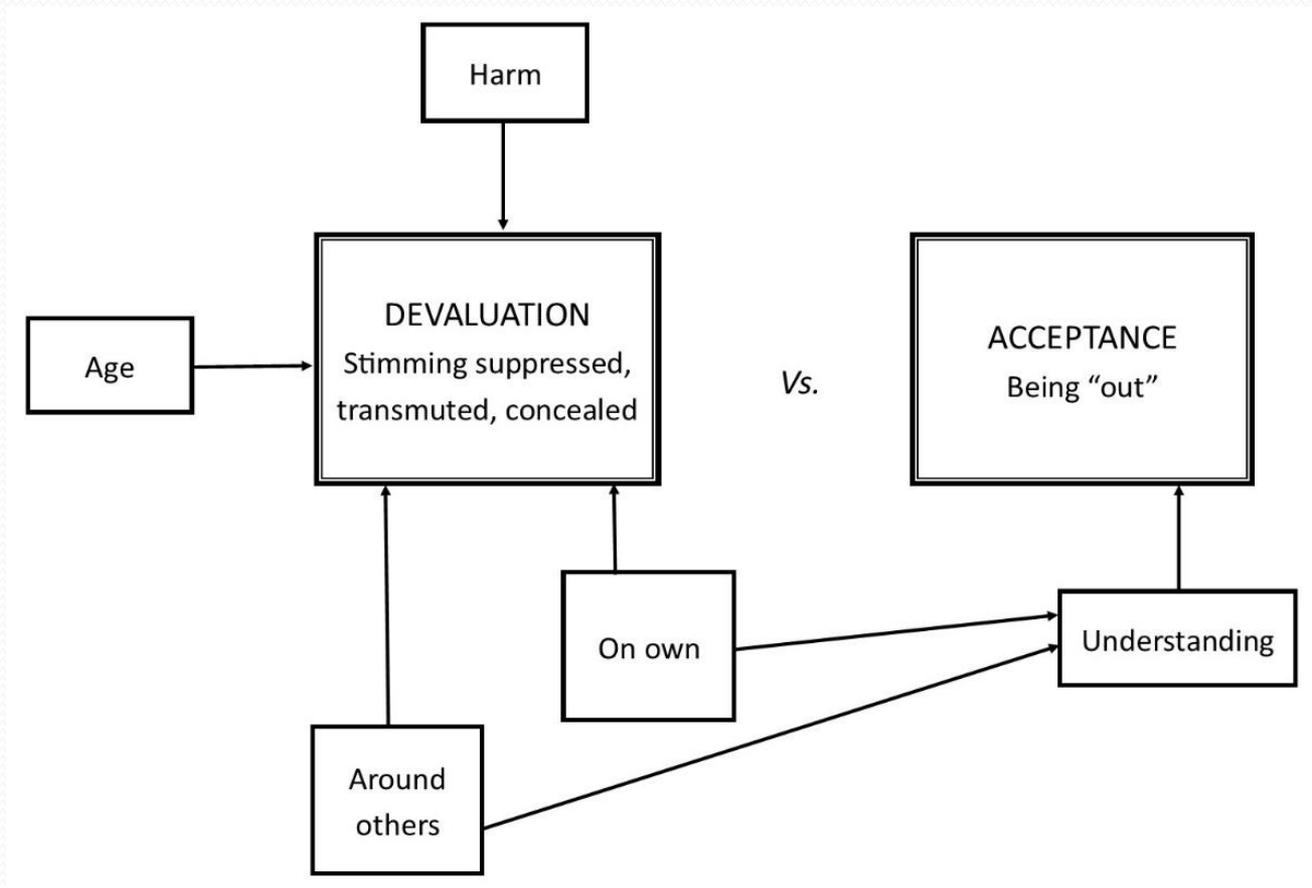
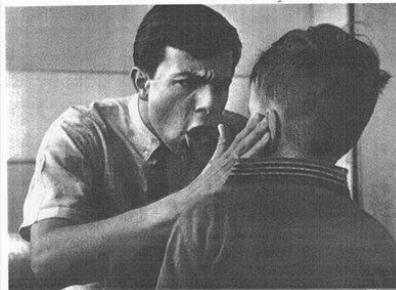


Figure 2: (De)stigmatisation of stimming (rejection and acceptance)



Attempts to end stimming

- 1965: “Screams, Slaps, and Love”, *LIFE Magazine*
- 1987: 47% of autistics “indistinguishable from peers”
- Present: Judge Rotenberg Center in U.S. still shocks



Trying to end stimming is “abuse”

- “...but 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”



Social Support, Well-Being, and Quality of Life Among Individuals on the Autism Spectrum



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Introduction

- Autism mainly diagnosed by social communication
- Social interaction occurs *between* people
- Dynamics with others hugely affect autistics' lives
- Talk highlights roles of social support and subjective well-being for autistics' quality of life (QoL)
 - Objective QoL: adaptive functioning in major domains
 - Subjective QoL: personal judgment, feelings about life

Parental support:

Language acquisition

- Responsive parenting especially helps autistic children performing at lower levels to develop language¹⁻¹¹

Autism acceptance

- Parental autism acceptance¹²⁻¹⁵ and positive emotions toward child¹⁶ are *not* associated with child symptoms, disability
- Parental autism acceptance *is* associated with better parent-child reciprocity^{17,18} and relationship^{19,20}

School support:

Educational inclusion

- Inclusive learning settings are associated with better functioning for autistics²¹⁻²³, especially those with delays²²

Social (peer) inclusion

- Autistic youth with *more* social attempts and skills tend to suffer more victimization, stigma, distress²⁴⁻²⁷

Systemic support in adulthood

- Among autistic young adults transition from secondary school tends to produce relatively more struggle for those *without* intellectual disability²⁸⁻³⁰
 - More often lose services³¹
- Services³² and employment³³ tend to improve functioning

Subjective well-being

- Children and adults who perform or are perceived as higher skilled or functioning tend to judge their autism as more severe and endorse more anxiety and depression³⁴⁻³⁹
- Pattern may relate to victimization and mistreatment
 - Autistic adults report quality of life may relate to social support, not autistic traits⁴⁰
 - Similarly, social support tends to weigh more heavily in self- than parent report of autistic adults' quality of life⁴¹

Implications

- No direct relationship between autism symptoms and functioning
 - Importance of social context
 - (Some) autism symptoms can have neutral or positive effects on well-being
- Importance of understanding and sensitive responding to autistic people, acceptance, inclusion

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Q & A

- Questions?
- Comments?
- Suggestions?



Thank You!

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