

Exploring Diagnosis: Autism and Neurodiversity

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Autism and Neurodiversity

Exploring Diagnosis

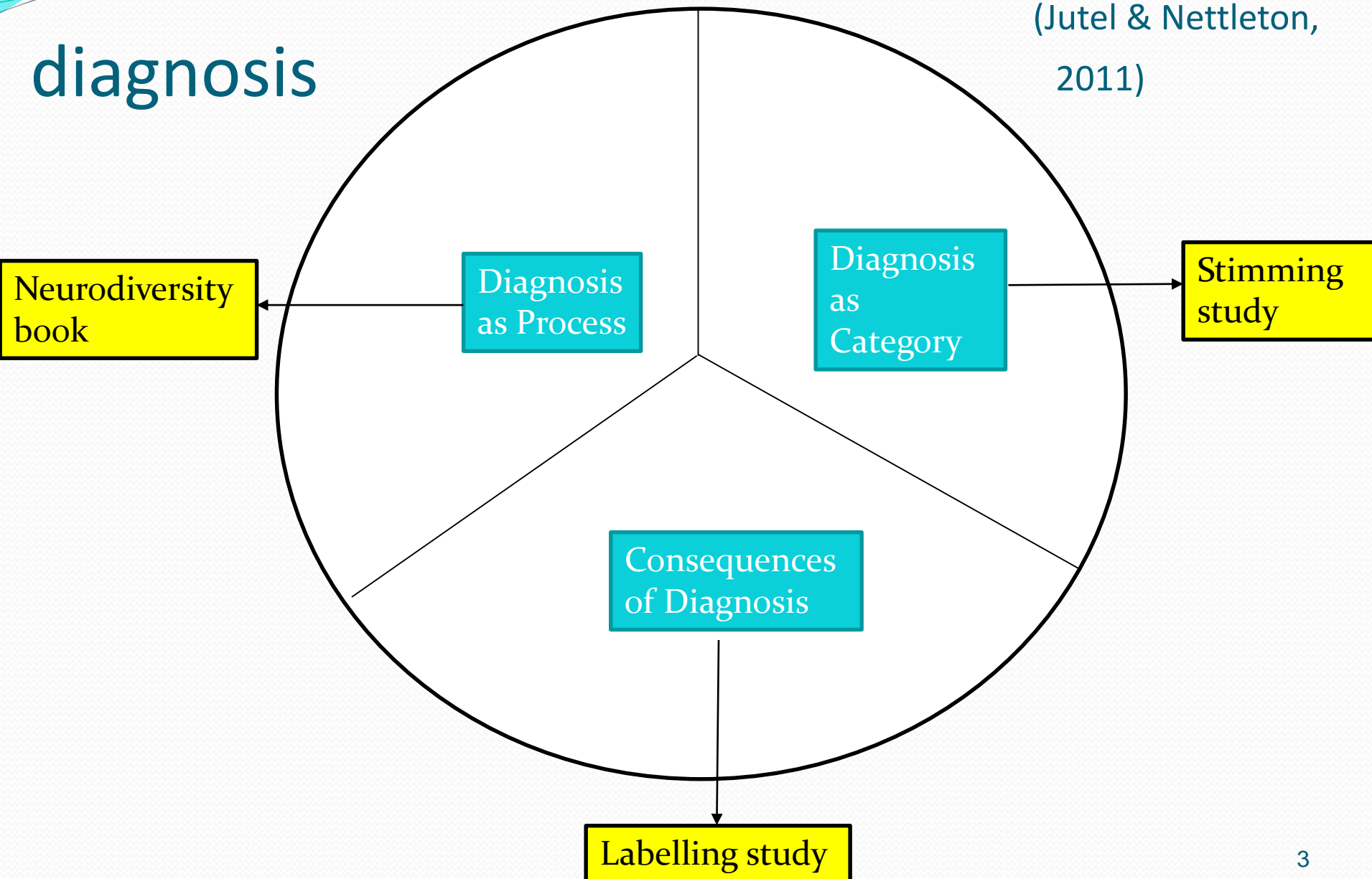


Preview of lecture

- Introduction to disability, neurodiversity movements
- Stimming study
- Labelling study
- Book on autistic community, neurodiversity movement

Sociology of diagnosis

(Jutel & Nettleton, 2011)



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

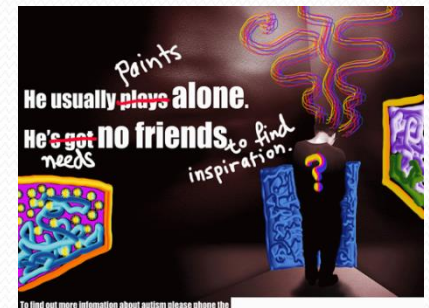
**NOT
BEING ABLE
TO SPEAK IS
NOT
THE SAME
AS NOT
HAVING
ANYTHING
TO SAY**



**D^YSABLED
& 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



Utility of autism, neurodiversity

- Little knowledge about what “works” for whom and why
 - Common knowledge that no intervention works for all
- Little known for whom, how autism diagnoses tend to help
- Parental acceptance of child’s autism helps relationship (Kapp et al., 2018)
- Awareness of neurodiversity movement associated with views aligned with it (Kapp et al., 2013)
- Support for normalization associated with more stigma toward autistic people (Gillespie-Lynch et al., 2017)

Stimming study

(Jutel & Nettleton,
2011)

Neurodiversity
book

Diagnosis
as Process

Diagnosis
as
Category

Stimming
study

Consequences
of Diagnosis

Labelling study

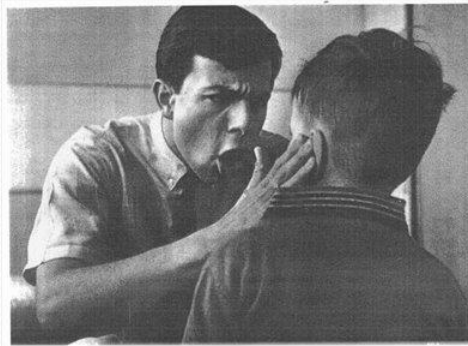
Stimming as autism “symptom”

Factors from autism’s diagnostic criteria

- (Deficits in) social communication
- Restrictive, repetitive behavior and interests
 - **Repetitive sensorimotor behaviours**
 - Insistence on sameness
 - (Perseverative) interests
- Autism may often stem from atypical sensation and movement (Kapp, 2013)
 - Often emphasized by autistic people

Attempts to end stimming

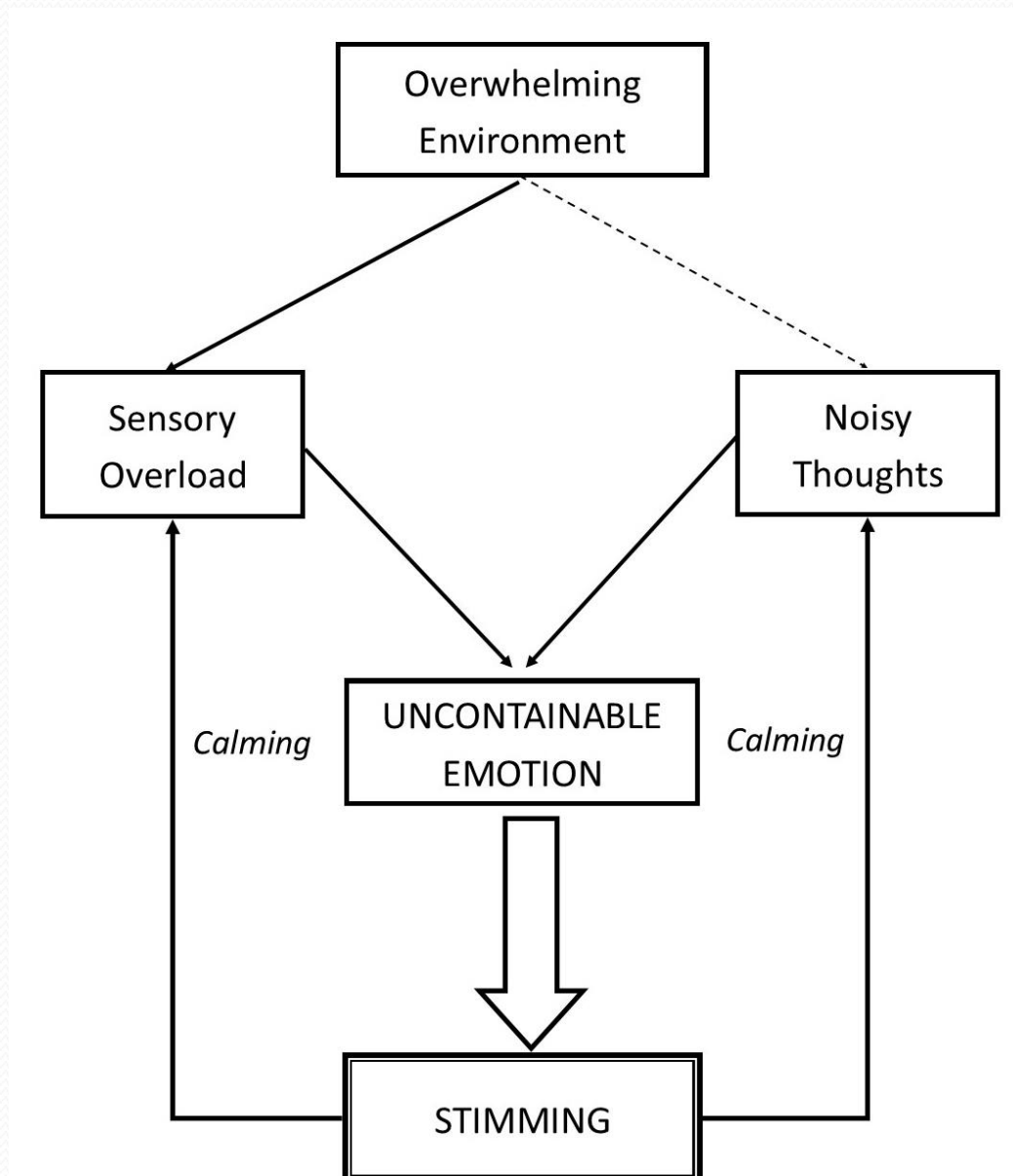
- 1965: “Screams, Slaps, and Love”, *LIFE Magazine*
- 1987: 47% of autistics “indistinguishable from peers”
(Lovaas et al., 1987)
- Present: Judge Rotenberg Center in U.S. still shocks



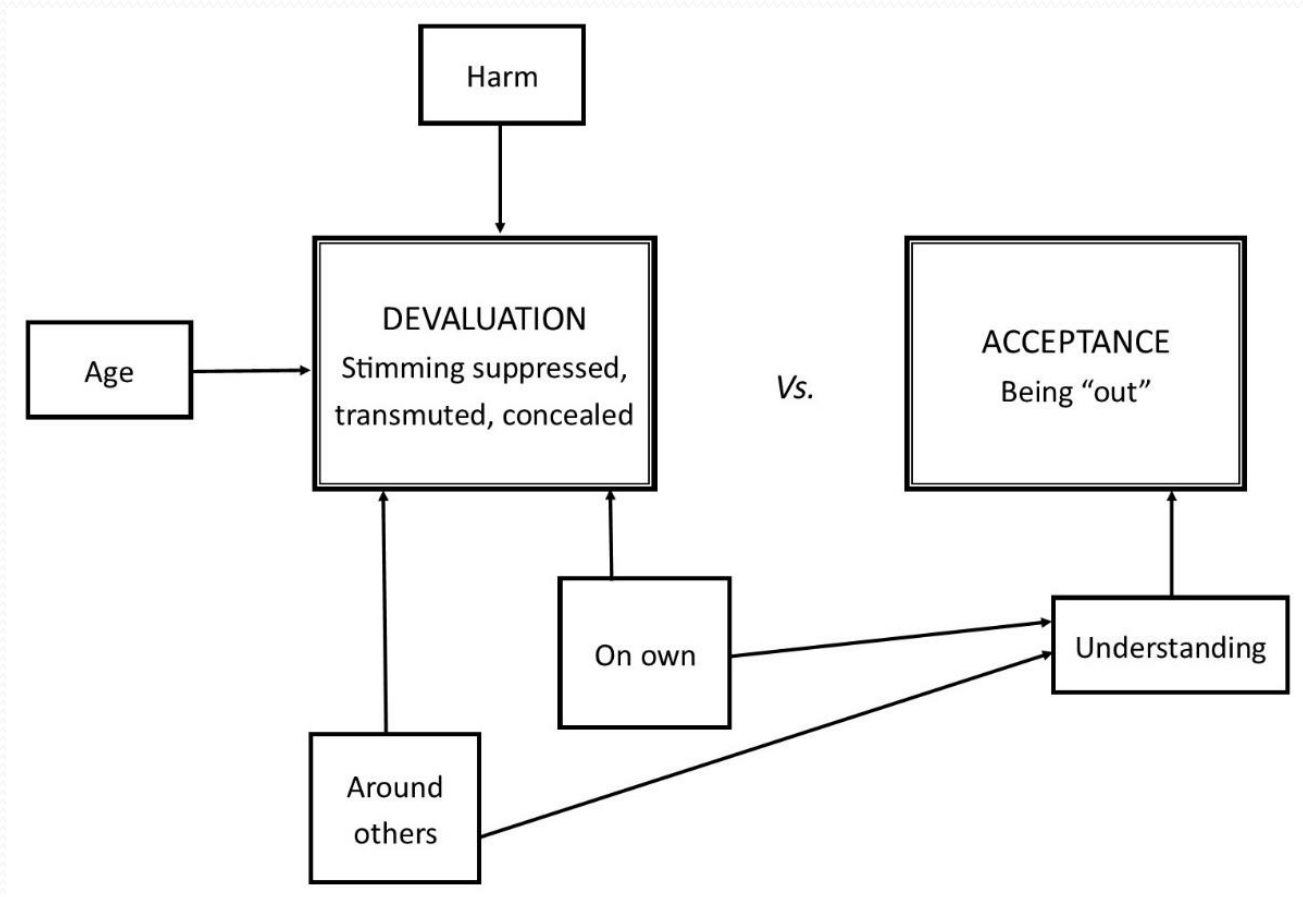
Methods of stimming study (Kapp et al., in preparation)

- 32 autistic adults participated in the study
 - 20 in semi-structured interviews
 - 12 in focus groups in two sites (six participants each)
- They answered questions about what stims they have, why they engage in them, and social reactions to them
- Thematic analysis used to analyse the data (Braun & Clarke, 2006)

Results: Stimming is a self-managing process



Results (continued): (De)stigmatisation of stimming



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” (research participant)



Labelling study

(Jutel & Nettleton, 2011)

Neurodiversity book

Diagnosis as Process

Diagnosis as Category

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Labelling study

The association between disclosing autism and adolescent perceptions of an autistic peer

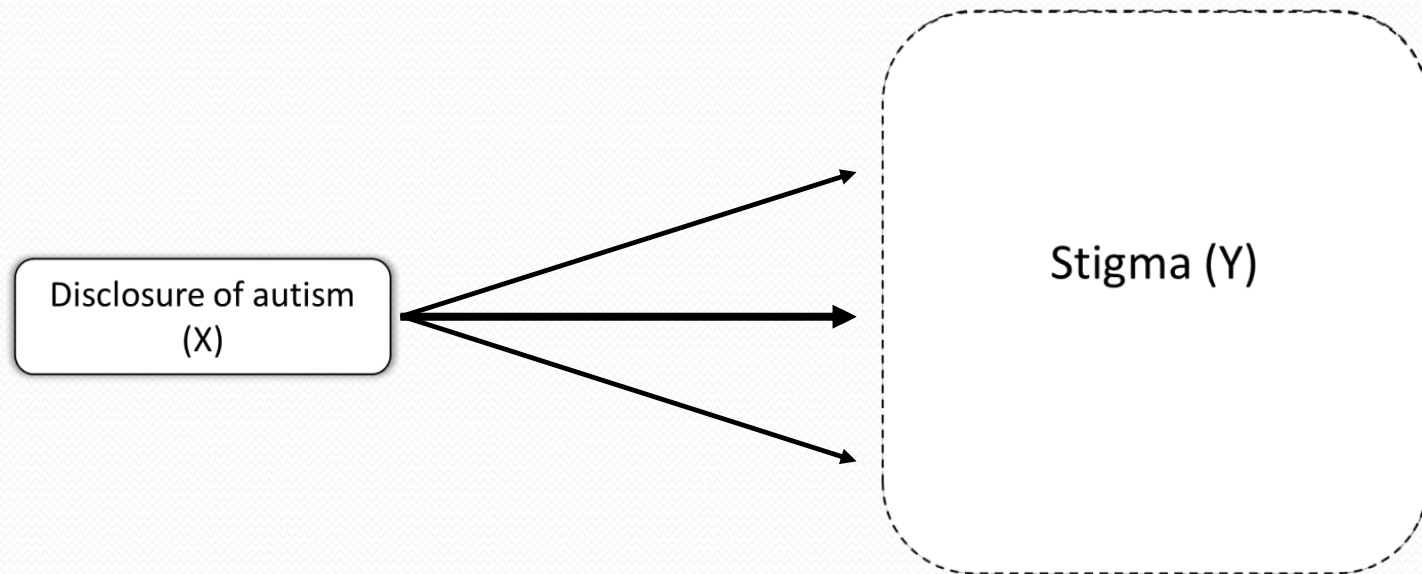
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Background & Rationale

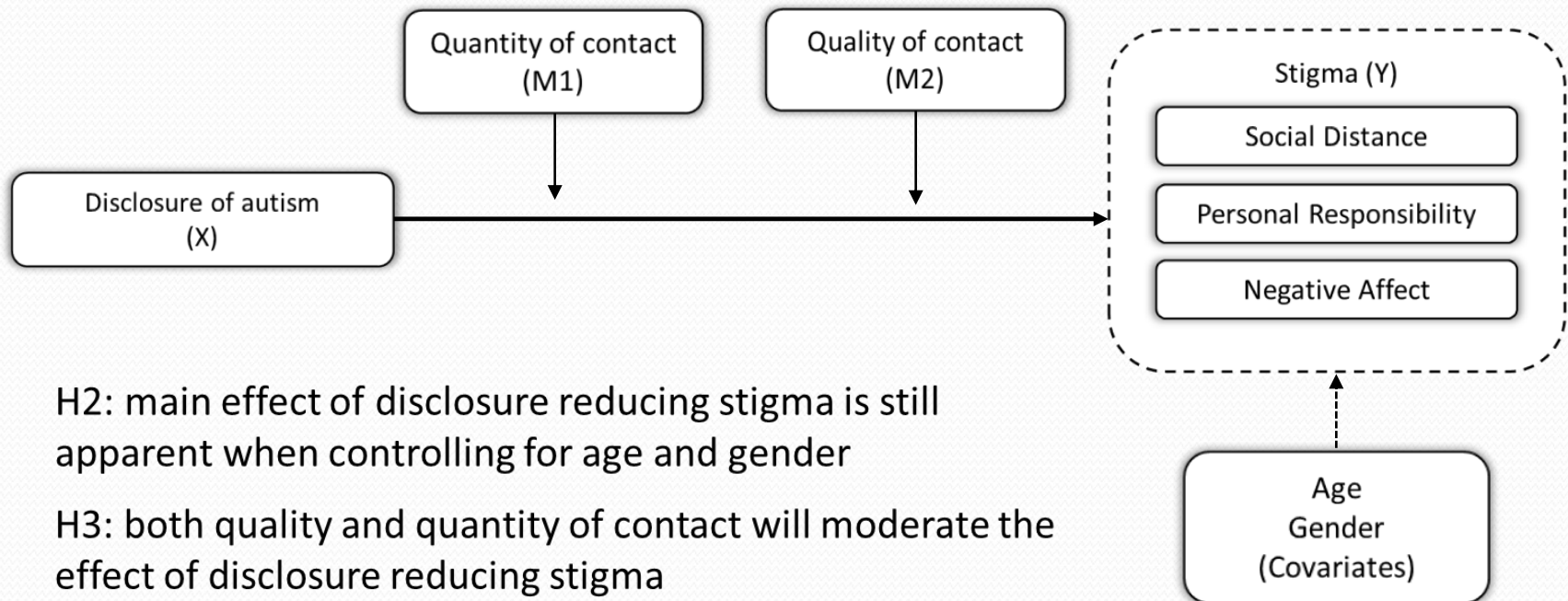
- Disclosing label of autism may reduce stigmatization
- But: label might itself stigmatize
- Disclosing reduces stigmatizing by adults; mixed evidence whether this is true for adolescents
- Contact reduces stigma; prior contact may moderate effect of disclosure
- Lack of research into effect of disclosure alone
- Provide guidance for autistic adolescent/parent when considering whether to disclose

Hypotheses: Direct effect



H1: disclosing autism reduces the stigmatization of the autistic adolescent

Hypotheses: Moderated effect



Method

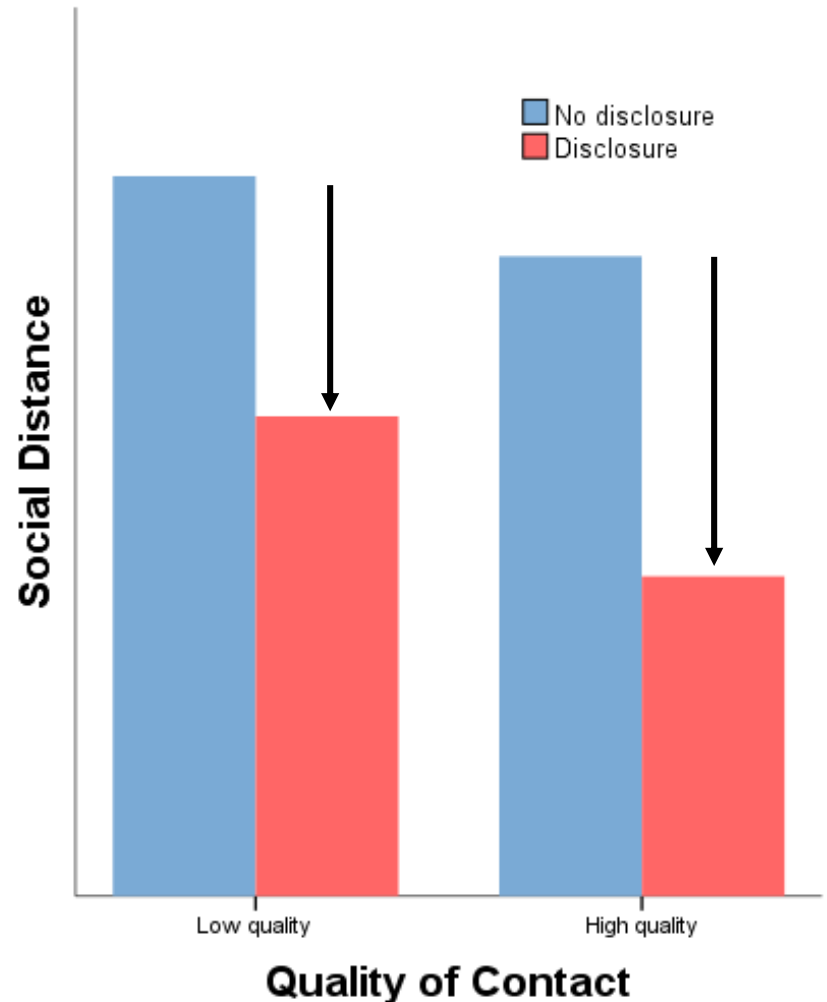
- Secondary data analysis, using data from Exploring Diagnosis Labelling Project
- 250 participants, in Year 7 (11-12 years) & Year 10 (14-16 years)
- Vignette & questionnaire study
- Autistic vignette – with or without label of ‘autism’, so label effect isolated from ‘autistic behaviours’

Proposed analysis

- Test effect of disclosure on stigma measures
- Control for age & gender
- Test for moderation by quality/quantity of contact
- Multi-level modelling, using class-level measure of quantity of contact
- Mediation analysis – personal responsibility on direct effect

Expected results

- Stigmatization lower in autism disclosure condition
- Effect still present when age and gender added as covariates
- Contact moderates effect of disclosure – reduction of stigma in disclosure condition is bigger when have high quality and/or quantity of contact



Theoretical implications

- If stigma is reduced in disclosure condition: supports H₁ that disclosure reduces stigmatization, supporting attribution theory
- If stigma is increased in disclosure or no effect of disclosure: disproves H₁, supports alternative hypothesis from labelling theory
- If contact moderates main effect: supports H₃, prior contact improves effect of disclosure

Practical implications

- Guidance as to whether best for autistic adolescents to disclose at school
- If disclosure reduces stigma then could be recommended at diagnosis
- Illuminates possible circumstances under which disclosure has effect

Neurodiversity book

(Jutel & Nettleton,
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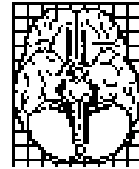
Labelling study

“Stories from the Frontline”

- Monograph in progress (Palgrave Macmillan, 2019)
- Book to feature accounts from autistic community members, neurodiversity activists about their actions
 - 12 chapters collected, 6 more expected
- Analysis (historical, thematic, critical) to surround core
- For academia, practitioners, autism community



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.

- Satirical page, part of autistics.org
- “Diagnostic criteria for 666.00 Neurotypic Disorder”
 - Impairment in independent social interaction
 - Impairment in communication and imaginative activity
 - Marked restriction in activity
 - E.g. “inability or lack of understanding for or interest in stereotyped body movements, e.g., hand-flicking or -twisting, spinning, head-banging (except for during certain types of rock concerts), complex whole-body movements”

Judge Rotenberg Center protests

- Shain Neumeier, Lydia Brown lead protests against U.S. “school” that electrically shocks as punishment
- “To create a society in which not only is there no JRC, but also nothing remotely comparable, these more accepted goals and practices [compliance and institutionalisation] have to be challenged just as unequivocally as shock devices.” (Neumeier and Brown)



Questions? Comments?



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