Identity after an autism diagnosis: gender, self-esteem and wellbeing

Kirsten Corden[1], Rebecca Brewer[1] & Eilidh Cage[2]

[1]Royal Holloway, University of London [2]University of Stirling

ROYAL HOLLOWAY UNIVERSITY OF LONDON

UNIVERSITY of STIRLING

Background

- Many people receive an autism diagnosis in **adulthood** – something often noted as emotionally impactful, with a lack of post-diagnostic support (Huang et al., 2020). Females are also more likely to be misdiagnosed or diagnosed late (Mandy et al., 2012).
- **Personal identity** includes characteristics that define an individual and differentiate them from others. Autistic personal identity is an individual's sense of whether autism is part of 'who I am' (versus autistic social identity, identifying with other autistic people)
- Earlier diagnosis may link with more positive self-concepts, but it is unclear whether this relates to *age* at diagnosis, or the *time elapsed* since diagnosis for understanding and adaptation.
- Less is known about how autistic personal identity relates to aspects of **psychological functioning**, such as self-esteem and mental wellbeing. Research has shown relationships between autistic social identity and these variables (Cooper et al., 2017).
- **Hypotheses**: **(1)** more positive personal autistic identity will relate to higher **(a)** self-esteem and **(b)** wellbeing and **(2)** earlier diagnosis and longer time elapsed since diagnosis will relate to more positive personal autistic identity.

Methods

- 152 autistic adults from the UK (Female n = 118, male n = 30, non-binary/transgender n = 4). Mean age = 31.41 (SD = 10.38).
- Mean age of diagnosis 26.3 (SD = 11.2; range 6 – 62). Participants had received their diagnoses on average 5.24 years previously (SD =5.36, range 0 – 48).
- Participants completed an online survey including the following measures:
  - **Autistic characteristics:** Ritvo Autism & Asperger Diagnostic Scale (RAADS-14; Eriksson et al., 2013)
  - **Self-esteem:** Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965).
  - **Mental wellbeing:** Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007).
  - **Personal identity:** Questionnaire on Disability Identity & Opportunity (QDIO; Darling & Heckert, 2010). This measure has two subscales: **autism pride** (pride in autism as part of self) and **dissatisfaction/exclusion** (rejecting autism as part of self)
- Participants answered one qualitative question: **"How did receiving an autism diagnosis affect how you think and feel about yourself?"**

Findings

Hypothesis 1a: Regression analyses showed greater autism pride predicted higher self-esteem (p=.014, Fig 1), and more exclusion/ dissatisfaction predicted lower self-esteem (p=.001, Fig 2).

Hypothesis 1b: Greater exclusion/ dissatisfaction predicted lower wellbeing (p=.002, Fig 3).

Hypothesis 2: Regression analyses found that as number of years since diagnosis increased, exclusion/ dissatisfaction decreased (p<.001, Fig 4).

Qualitative responses (n = 54) were analysed using content analysis. The three most commonly reported categories and their sub-categories were:

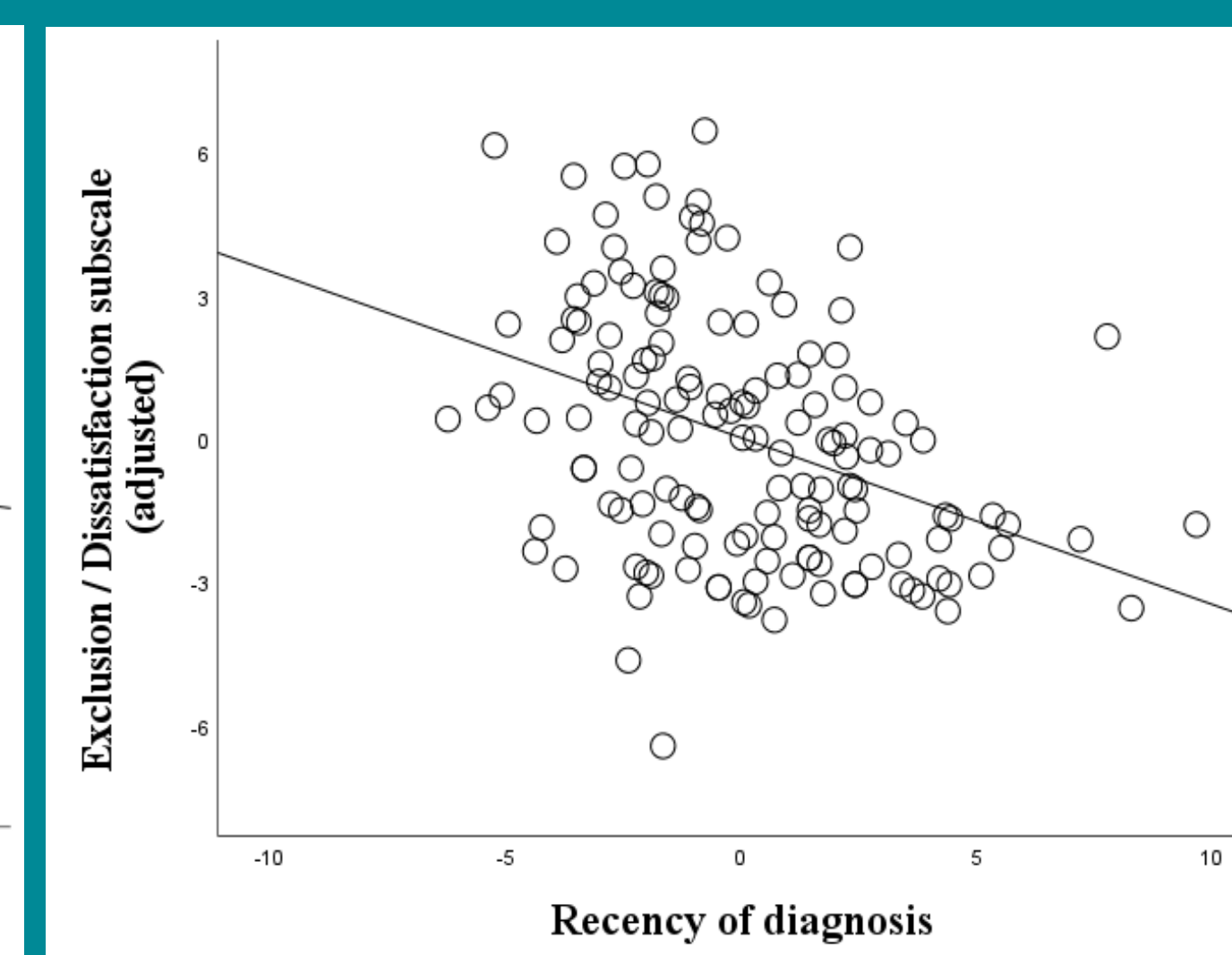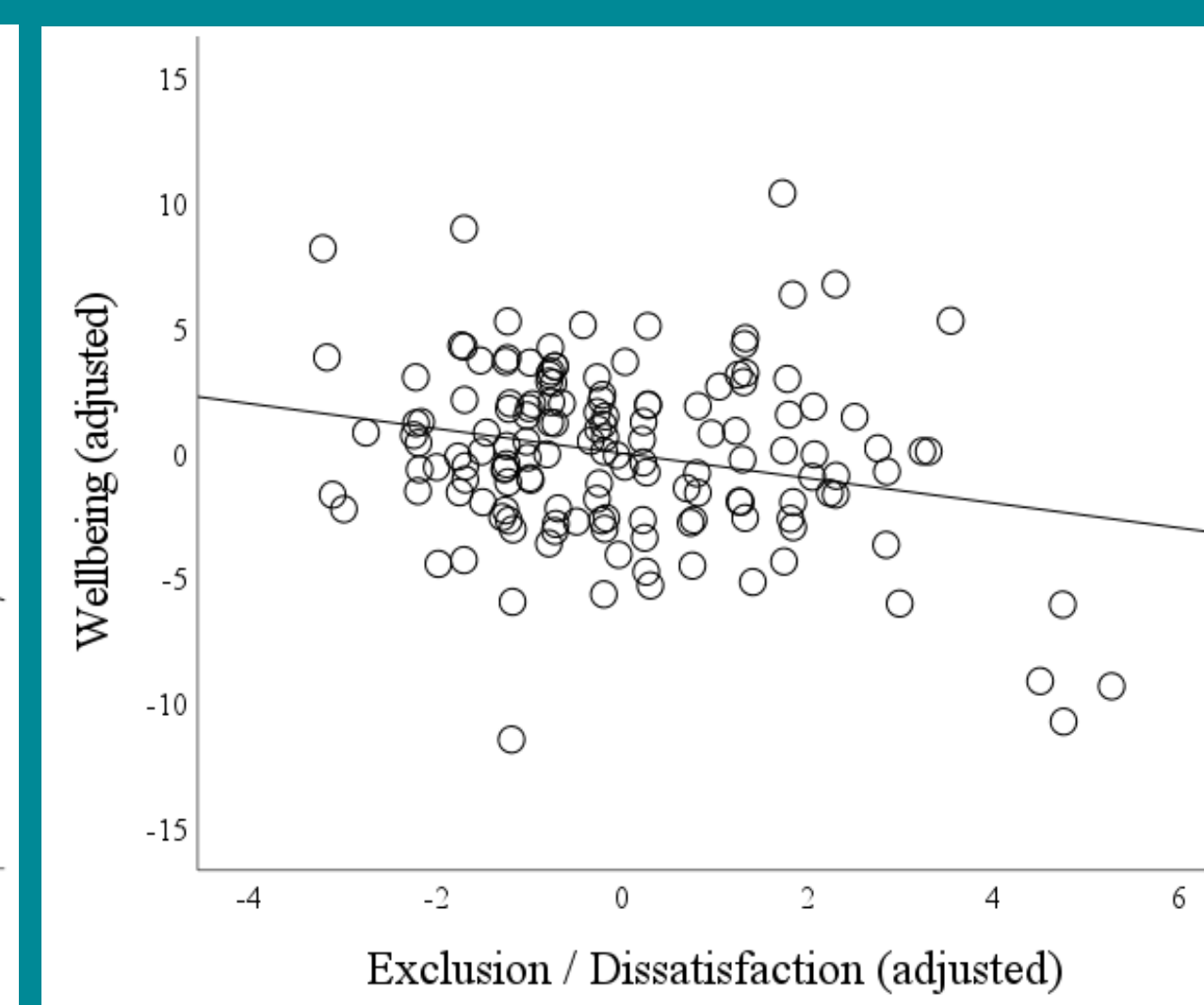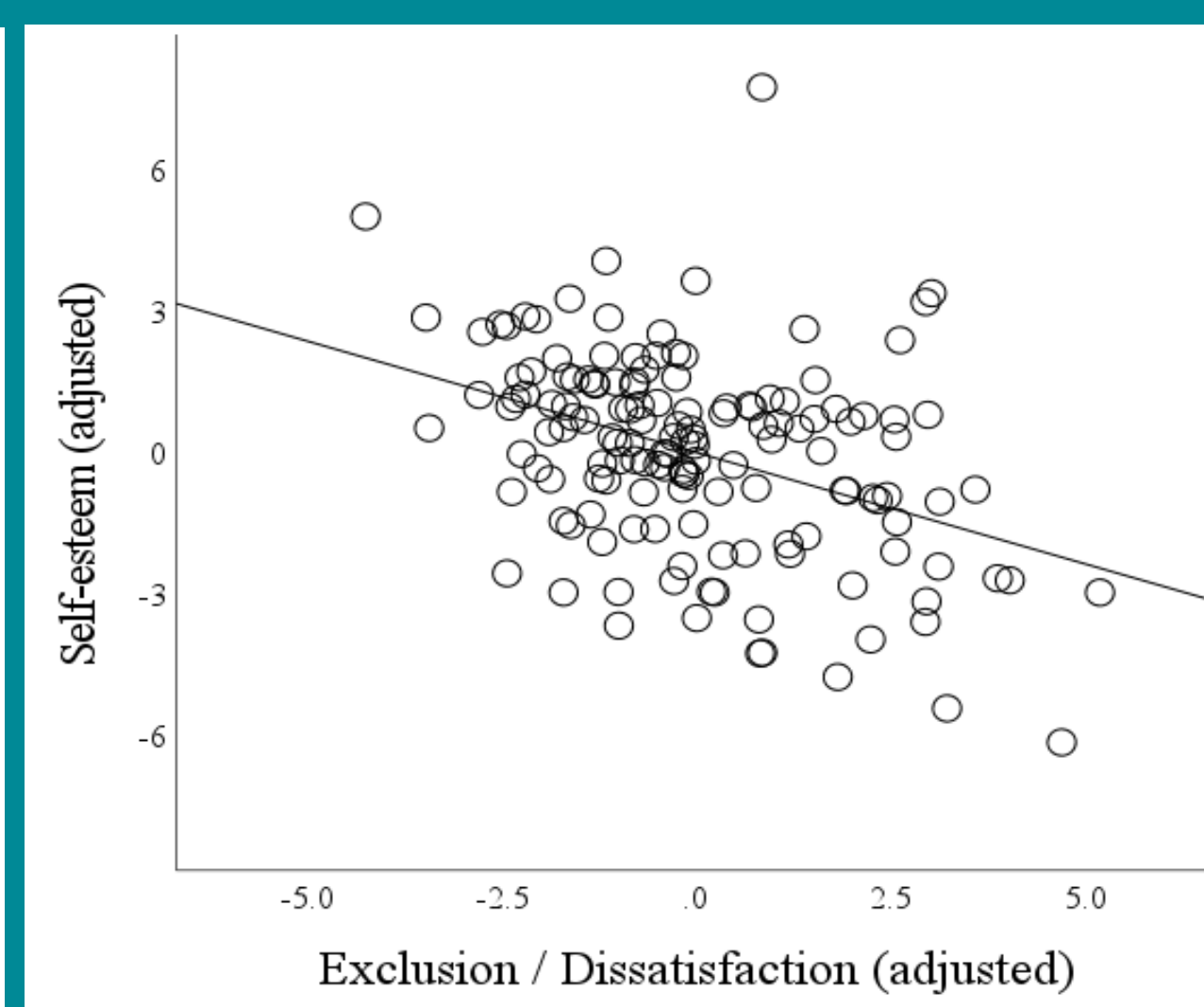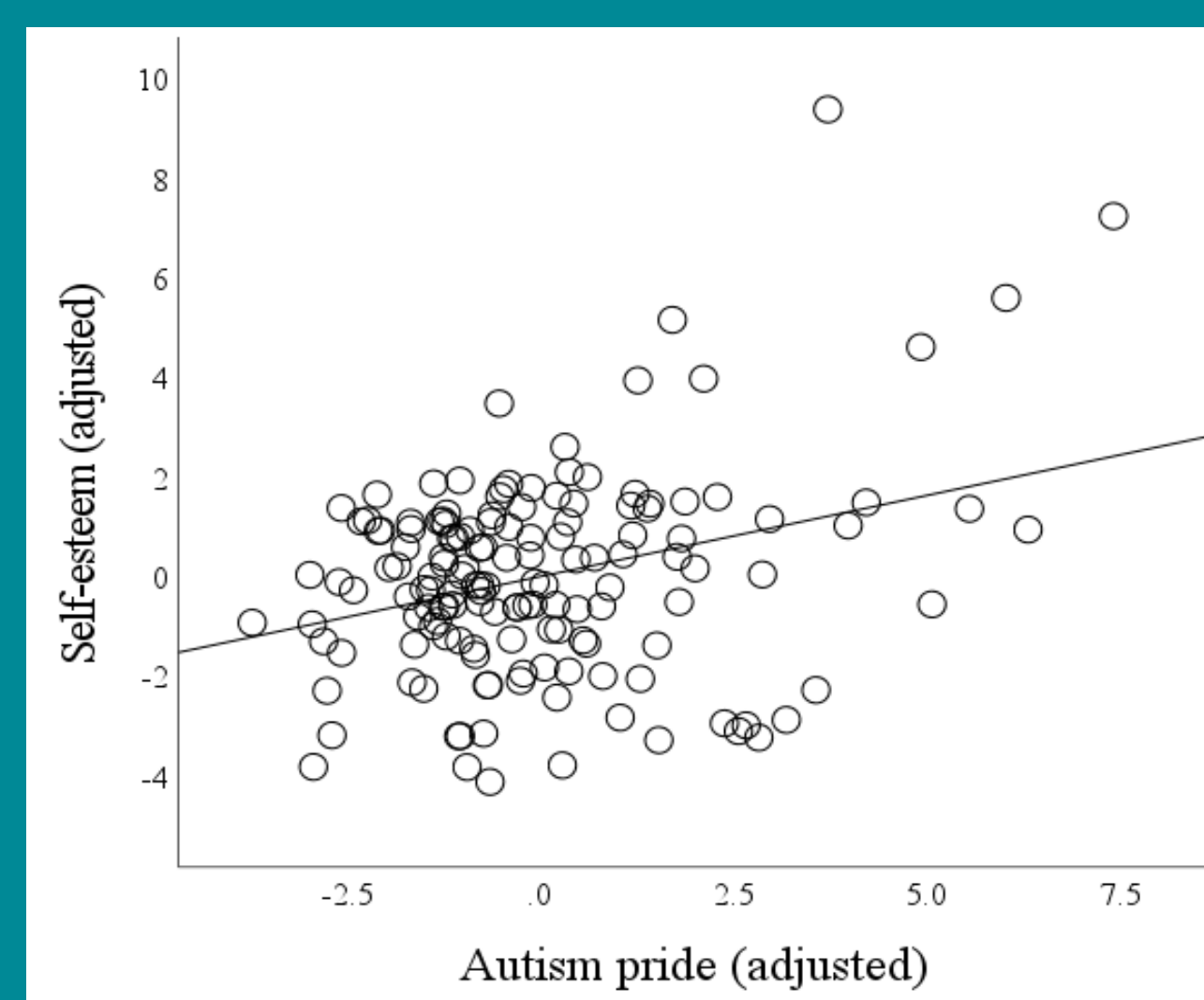| Adjustment process	Self-exploration	Learning & support needs
Making sense of it all over time: *"It changed everything. Things finally made sense."*	Knowing and understanding who I am: *"I think probably the diagnosis has helped me more than not as I know myself better."*	I've learned a lot: *"It took time, but I read around a lot, learned online"*
Emotional reaction to diagnosis: *"I felt relieved"; "I was upset, confused and angry."*	Being myself: *"[I'm] letting myself be the real me."*	More support needed post-diagnosis: *"It was frustrating that there was nobody to help me through"*
Permanence of difficulties: *"Sometimes now I feel a bit sad about my autism because I know I am always going to find things difficult"*	Feeling the same about myself: *"Diagnosis only confirmed what I felt about myself."*	Late identification: *"It was a double edged sword though as it also caused anger since no one has noticed for so long."*

Fig 1. Self-esteem & autism pride

Fig 2. Self-esteem and exclusion/dissatisfaction

Fig 3. Wellbeing and exclusion/dissatisfaction

Fig 4. Recency of diagnosis & exclusion/dissatisfaction

Note: All figures are partial regression plots, controlling for other variables in the model, including gender. Gender on its own did not predict the outcome variables and our sample is biased towards females.

Key points: After receiving an autism diagnosis, supporting autistic people to explore how being autistic relates to 'who I am' is important for psychological functioning. There is an emotional adjustment and adaptation process, and with time there is more satisfaction in autistic personal identity. There is a clear need for more high-quality information and support post-diagnosis.