

#### **Empathy Measurement in Autism**

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# **The Empathy Controversy**

"while we [autistic people] are lumbered with the idea that we lack empathy, a lot of autistic people see allistics as lacking empathy towards us. The pathologising of autism dictates that this mismatch its usually only seen and written about in one direction [against autistic people]" – Yenn Purkis.

"Our understandings of empathy in autism are limited by the measures we use" - Jess



### Why is this important?

- Empathy deficit assumptions affect every autistic individual
- Countless empathy interventions for autistic individuals

#### **Quotes from Autistic Adults**

"Pre-diagnosis, my disability advisor encouraged me to pursue psychology. Post-diagnosis she told me I wouldn't even finish undergrad because I cannot understand other people. I suddenly didn't have empathy" – Anonymous

"The widespread belief that autistics don't experience &/or express empathy delayed our [Mum + 3 children] diagnoses by 20 years. That's a lot of years of unnecessary trauma & life challenges based on misinformation" - Anonymous



#### Non-literal Language in Empathy Measures

- Empathy Quotient (EQ) item:
  - "People often tell me that I went too far in driving my point home in a discussion"
- Such language not difficult for all autistic individuals but important to consider
- Known-groups validity
- Distributive justice: "fair distribution of the benefits and burdens of research" (NHMRC, 2018)



#### **Research Aims**

- Evaluate the quality of empathy self-reports
- Evaluate the evidentiary support for an empathy deficit in autism
- Highlight non-literal language as a potential issue



## Methodology

Systematic Literature Review (SLR)

- Collates all relevant studies on a topic
- Allows researchers to evaluate the body of evidence
- Strict methodology to prevent bias

#### This SLR

Collate and evaluate all relevant studies on empathy self-reports



## Methodology

- Developed protocol (method) and registered on PROSPERO
- Conducted searches in 8 relevant databases
  - Broad search strategy
  - Aimed to capture all English empathy self-reports
  - Aimed to capture all avail. info about their quality with autistic & NT samples



## Methodology

#### **Excluded Articles:**

- Other clinical groups (e.g. schizophrenia)
- Only one component of empathy (e.g. theory of mind)
- Not a self-report
- No info on measure quality

COSMIN Methodology – to evaluate evidence of measure quality



## **Preliminary Results**

- 23 articles excluded did not evaluate the measure
- 33 articles included, with 6 self-reports identified
- Non-literal language; EQ ≈ 40%, IRI ≈ 42%
- **0** evaluated bias or interpretability for autistic samples



# **Preliminary Results**

			Structural Validty	Int	ernal Consistency	Cross-cultural validity/Measur Re	liability	Measurement Error	Cri	terion Validity		Hypoethsis Testing	Responsiveness
References	Group	Country	N Method. Quali	t Result (rating) - + N	Method. (Result (+-?	N Method. (Result (+- N	Method. (Result	N Method. (	Result N	Method.	Result	N Method. (Result	N Method. (Result
Baron-Cohen & Wh	Study 1 Autist	UK			90 Very Good (?) Cronba		90 Doubtful Test rete	S'				90 Inadequa (?) No h	/F
	Study 1 Contro	UK			90 Very Good (?) Cronba		90 Doubtful Test rete	5				90 Inadequa (?) No h	/F
	Study 2 Male	UK			71 Very Good (?) Cronba							71 Adequate (?) No h	/F
	Study 2 Femal	UK			126 Very Good (?) Cronba							126 Adequate (?) No h	/F
Baron-Cohen et al.,	Study 1 - Publ	UK, Canad	da									103 Doubtful (?) No h	/F
	Study 1 - Unde	UK										174 Doubtful (?) No h	/F
	Study 2 - AS/H	UK										47 Doubtful (?) No h	/F
	Study 2 - Cont	UK										47 Doubtful (?) No h	/F
Baron-Cohen, 2015	Group 1 - Auti	stic										395 Inadequa (?) No h	/F
	Group 2 - Cont	trol										320 Inadequa (?) No h	/F
Byrd-Craven	Uni students				233 Very Good (?) Cronba							233 Doubtful (?) No h	/F
Calvi	Uni students				224 Very Good (?) Cronba					224 Very Good	(-) Correla	224 Doubtful (-) Only	6.
Cunningham et al.,	ASD - 2 treatm	ent group	s		38 Very Good (?) Cronba							38 Very Good [Null hy	pc
Levin	Group 1 - ASD											15 Inadequa (?) No h	/F
	Group 2 - Cont	trol										? Inadequa (?) No h	/F
Lyons	Community									226 Doubtful	(-) EQ Cog	226 Inadequa (?) No h	/F
Mansour	Aspergers adu	ılt			32 Very Good (?) Cronba							32 Doubtful (-) Only	3:
		ow Asperg	ger's participants		32 Very Good (?) Cronba							32 Doubtful (-) Only	3:
	HFA											40 Adequate (+) Resu	ltı
	Control											37 Adequate (+) Resu	ltı
Sucksmith	Parents of ASE	)										310 Doubtful (?) No h	/F
	ASD											329 Doubtful (?) No h	
	Control											187 Doubtful (?) No h	/F
Swickert	College studer	nts			94 Very Good (?) Cronba								
	Retirement co	mmunity			62 Very Good (?) Cronba								
Webb	Uni students				347 Very Good (?) Cronba								
Wheelwright, 2006	Uni students		1761 Doubtful	(?) - not all infor								1761 Doubtful (?) No h	
	ASD Adults		125 Doubtful	(?) - not all infor								125 Doubtful (?) No h	•
Williams	Study 1											278 Adequate (?) No h	/E
	Study 2											20 Adequate (?) No h	/F



Measurement quality/this research:
Not just empathy.
Not just autism.

#### **Final Points**

- Measurement quality an issue for all research and practice
- Ethically obliged to use measures with demonstrated:
  - Reliability and validity in your population
  - Demonstrated fairness (unbiased) and interpretability in your population
- Understand the impact of measurement issues on your conclusions
  - Especially when researching vulnerable, pathologised populations
  - Especially when the conclusion could affect them negatively



#### **Find out more:**

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