

# Autism and Anxiety: Knowns, unknowns and uncertainties

Professor Jacqui Rodgers

Population Health Sciences Institute

Newcastle University

UK

- Employed by Newcastle University, UK full-time; no lived experience
- Various sources of research funding – including from Autistica; NIHR, Wellcome Trust, ESRC; my employment is not directly reliant on funding
- I will present results from a number of research papers describing research undertaken at Newcastle University
- I will mention some measures and interventions we have designed and evaluated; all are available either free of charge or on a ‘not for profit’ basis.



## Just a note...

Identity-first language (e.g. autistic people) is the preferred language of many people on the autism spectrum (Kenny et al., 2016).


In this talk I will use identity-first language to reflect this preference



# Autism and mental health

- Autistic people experience high rates of co-occurring conditions, including mental health conditions (Simonoff et al 2008)
- Today we will focus on **anxiety** (but note depression, self-harm, eating disorders, suicidality etc... are also elevated in autistic people)

# What is anxiety?

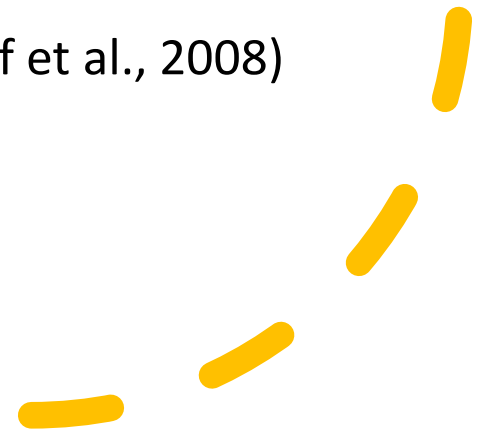
- An emotional state which is characterised by feelings of **apprehension** and **worry**
  - Often associated with **physical sensations** such as **racing heart**, **sweaty palms**, **upset tummy**, **muscle tension**.
  - It can result in a **fight** or **flight** or **freeze** response.
  - Frequent anxiety can lead to **low mood**.
- 

# Anxiety and Autism

- Anxiety is common, 50-70% (van Steensel 2015, Hollocks, et al., 2019, Kerns et al, 2021) – but not inevitable
- Causes significant distress, functional impairment, reduced opportunities and leads to poorer quality of life (Mason et al., 2018)
- Multiple and competing anxiety conditions are common (Trembath et al., 2012, Brice, Rodgers et al 2021)
- Research priority for the autism community (Autistica, 2016)

# Types of anxiety experienced by autistic people

- Some types of anxiety are particularly prevalent for autistic people
  - **specific phobias** (Bitsika & Sharpley, 2015)
  - **social anxiety** (Wood & Gadow 2012, Magiati et al., 2015 )
  - **generalised anxiety** (Simonoff et al., 2008)



But.....

- Measures developed for neurotypical people may not be valid for autistic people (Rodgers et al., 2022)
- Anxiety symptoms are not always consistent with DSM sub-types (Kerns et al., 2014, 2021, Rodgers et al., 2016)
- Complex relationship between autism characteristics and anxiety (White et al 2014, Kerns et al, 2014, Maisel et al., 2016, South & Rodgers 2017)

Published in final edited form as:

*J Autism Dev Disord.* 2014 November ; 44(11): 2851–2861. doi:10.1007/s10803-014-2141-7.

## Traditional and Atypical Presentations of Anxiety in Youth with Autism Spectrum Disorder

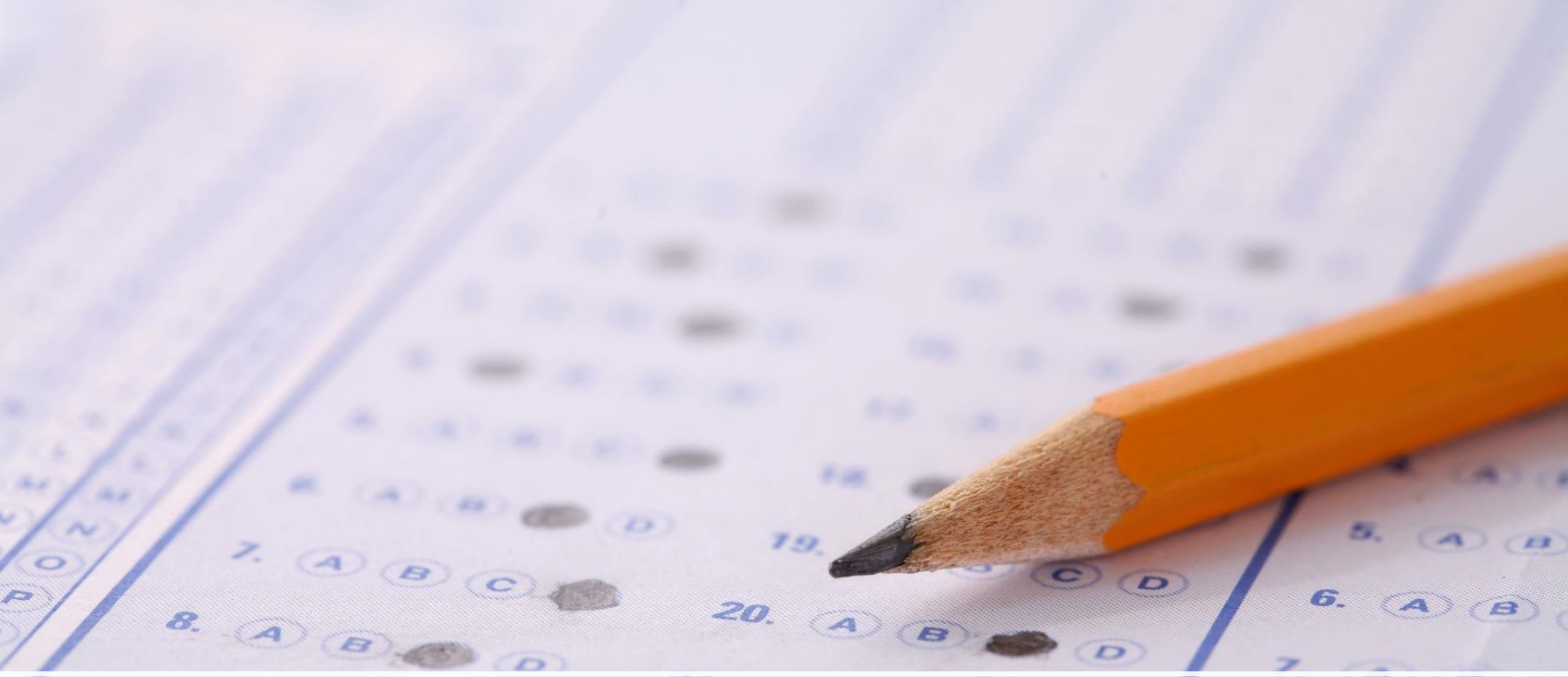
Connor Morrow Kerns<sup>1,2</sup>, Philip C. Kendall<sup>2</sup>, Leandra Berry<sup>1,3</sup>, Margaret C. Souders<sup>1</sup>,  
Martin E. Franklin<sup>4</sup>, Robert T. Schultz<sup>1</sup>, Judith Miller<sup>1</sup>, and John Herrington<sup>1</sup>

Anxiety around  
routines (in the  
absence of generalised  
worry)

Unusual specific fears  
(in the absence of  
generalised  
sound/sensory  
sensitivity)

Social fearfulness (in  
youth who lack an  
awareness of social  
judgment)

Compulsive/ritualistic  
behaviour (in the  
absence of a desire to  
prevent distress/feared  
outcome)



**Autism specific anxiety assessments**

# Anxiety Scale for Children – ASD (ASC-ASD) Rodgers et al 2016

ACCIÓN PSICOLÓGICA, diciembre 2020, vol. 17, nº. 2, 71–82. ISSN: 2253-1271 <https://doi.org/10.5944/ap.17.2.28066> 71

ADAPTACIÓN AL ESPAÑOL DE LA ANXIETY SCALE FOR CHILDREN WITH ASD (ASC ASD-P)

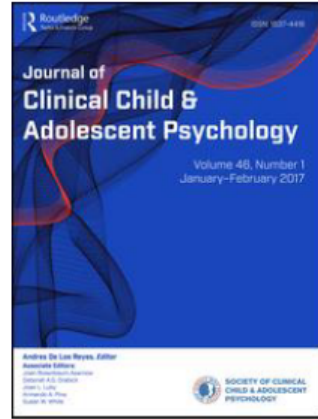
SPANISH ADAPTATION OF THE ANXIETY SCALE FOR CHILDREN WITH ASD (ASC ASD-P)

CARMEN BENEYTEZ-BARROSO<sup>1</sup>, ARACELI DEL POZO-ARMENTI<sup>1</sup>, DOMINGO GARCÍA-VILLAMISAR<sup>1</sup> Y JACQUI RODGERS<sup>2</sup>

- Parallel parent and child versions (24 items each)
- 4 subscales (**separation anxiety, performance anxiety, anxious arousal and uncertainty**)
- Preliminary evaluation indicates good reliability and validity (Rodgers et al 2016, Keen et al 2018)
- Available in 22 languages (including Spanish)

**Freely available to download at**

<https://research.ncl.ac.uk/neurodisability/leafletsandmeasures/anxietyscaleforchildren-asd/>



## Journal of Clinical Child & Adolescent Psychology

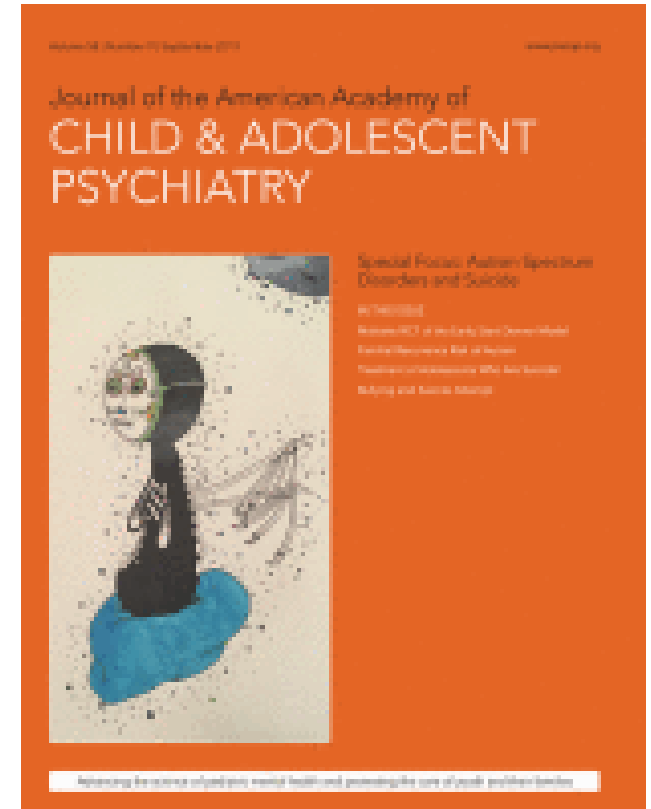
ISSN: 1537-4416 (Print) 1537-4424 (Online) Journal homepage: <https://www.tandfonline.com/loi/hcap20>

# Anxiety Disorders Interview Schedule–Autism Addendum: Reliability and Validity in Children With Autism Spectrum Disorder

Connor Morrow Kerns, Patricia Renno, Philip C. Kendall, Jeffrey J. Wood & Eric A. Storch

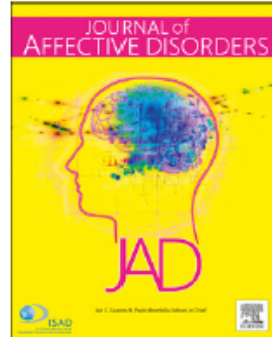
To cite this article: Connor Morrow Kerns, Patricia Renno, Philip C. Kendall, Jeffrey J. Wood & Eric A. Storch (2017) Anxiety Disorders Interview Schedule–Autism Addendum: Reliability and Validity in Children With Autism Spectrum Disorder, *Journal of Clinical Child & Adolescent Psychology*, 46:1, 88-100, DOI: [10.1080/15374416.2016.1233501](https://doi.org/10.1080/15374416.2016.1233501)

- 25 item parent report based on items that are anxiety provoking for autistic children
- Single factor
- Suitable for 5-17 years
- Good reliability and validity



**ELSEVIER**Contents lists available at [ScienceDirect](#)

## Journal of Affective Disorders

journal homepage: [www.elsevier.com/locate/jad](http://www.elsevier.com/locate/jad)

Research paper

### Development of the Macquarie Anxiety Behavioural Scale (MABS): A parent measure to assess anxiety in children and adolescents including young people with autism spectrum disorder

Ramona Toscano, Jennifer L. Hudson\*, Andrew J. Baillie, Heidi J. Lyneham, Lauren F. McLellan

*Centre for Emotional Health, Department of Psychology, Macquarie University, Australia*

# A framework for assessing anxiety in autism

(Kerns et al 2016)

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01

Consider anxiety symptoms in the context of the child's developmental level

02

Assess if anxiety symptoms cause significant impairments separate from autism traits

03

Differentiate anxiety from emotion regulation difficulties and sensory differences

04

Assess whether anxiety symptoms are in addition to traits that might be explained by autism

Received: 5 May 2021 | Revised: 3 August 2021 | Accepted: 4 October 2021

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DOI: 10.1002/pits.22669

**RESEARCH ARTICLE**

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WILEY

# Assessing anxiety in youth with autism spectrum disorder

Lauren J. Moskowitz  | Megan Braconnier

AUTISM IN ADULTHOOD  
Volume 2, Number 1, 2020  
© Mary Ann Liebert, Inc.  
DOI: 10.1089/aut.2019.0044

10.1089/aut.2019.0044 Rodgers et al.  
Type: research-article

**Original Article**

## Development and Initial Evaluation of the Anxiety Scale for Autism-Adults

Jacqui Rodgers, PhD,<sup>1,\*</sup> Kirstin Farquhar, DClin Psy,<sup>2,3,\*</sup> David Mason, MSc,<sup>1</sup>  
Samuel Brice, DClin Psy,<sup>1</sup> Sarah Wigham, PhD,<sup>1</sup> Barry Ingham, DClin Psy,<sup>1,3</sup>  
Mark Freeston, PhD,<sup>2</sup> and Jeremy R. Parr, MB, CHB, MRCPCH, MD<sup>1,3</sup>

The Anxiety Scale for Autism – Adults (ASA-A; Rodgers et al., 2019).  
Freely available from: <https://tinyurl.com/Anxiety-Scale-for-Autism-Adult>

**Available in Spanish**

# Personalised Anxiety Interview Supplement – Autism (PAIS-A) (Brice, Rodgers et al.... In prep)

- A work in progress.....
- An interview supplement that:
  - Can be used alongside any clinical interview for anxiety for adults
  - Is able to identify the triggers and mechanisms of anxiety that are key in autism
  - Is acceptable and feasible to use with autistic people who access mental health services
  - Can inform personalised treatment plans





## Autism related anxiety constructs

- Sensory differences
- Alexithymia
- Intolerance of Uncertainty
- Restricted and Repetitive Behaviours

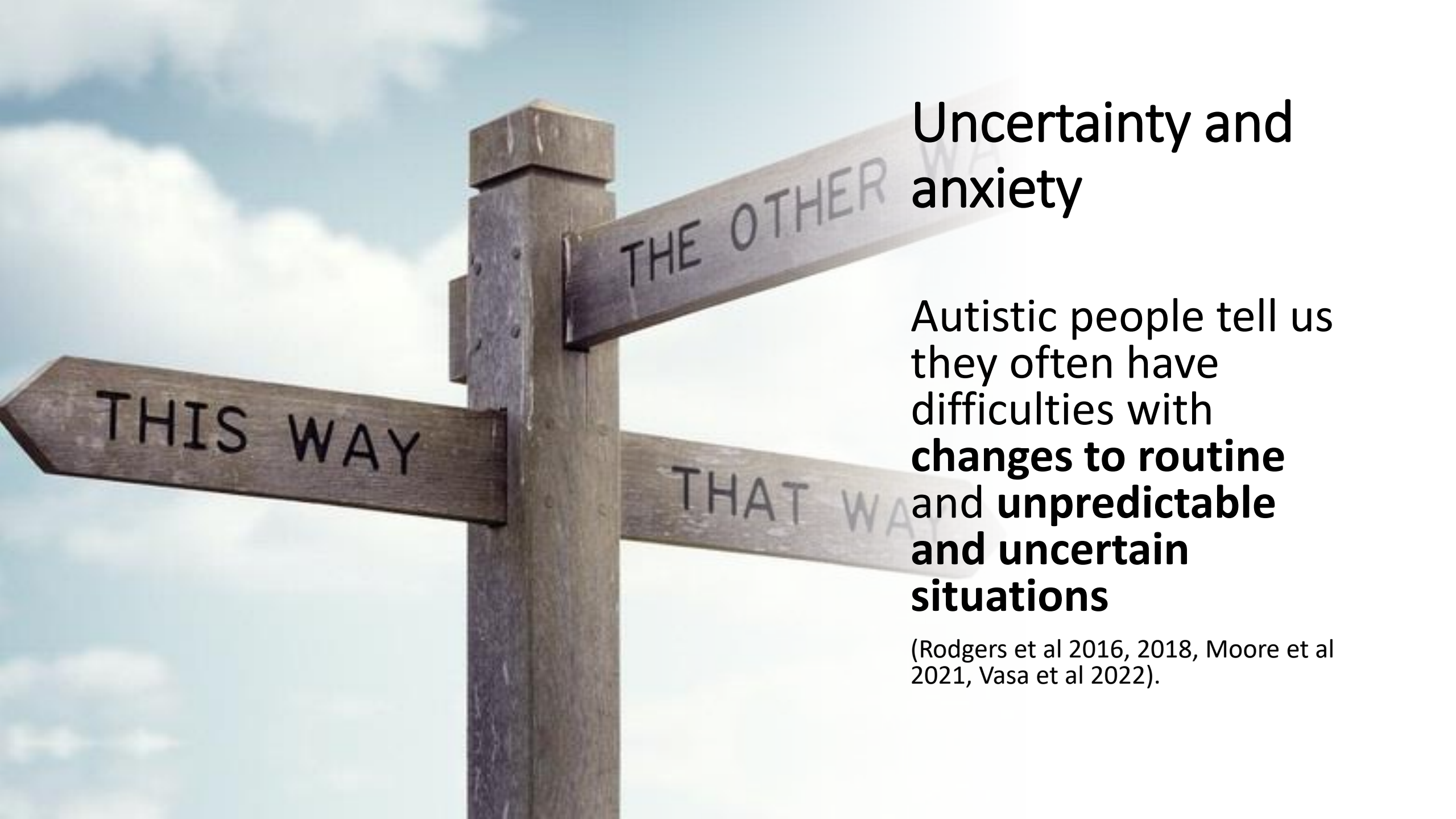
# Sensory differences and anxiety

- Approximately 90% of autistic people experience sensory differences (Leekam et al., 2006)
- Anxiety related to sensory hypersensitivity is frequently reported (Reynolds & Lane, 2009; Green & Ben-Sasson, 2010; Ben-Sasson et al., 2008, Lidstone et al 2014, Wigham et al 2015,)
- Sensory related anxiety may be associated with uncertainty (MacLennen et al 2021, Moore et al., 2022)



# Alexithymia

- Autistic people may experience difficulties identifying and describing emotions - alexithymia (Kinnaird et al., 2020)
- Difficulties in *identifying* feelings associated with anxiety symptom severity (Oakley et al., 2020)
- Developing emotion awareness may be an important aspect of anxiety intervention programmes for autistic people (National Institute of Health & Care Excellence, 2013)



## Uncertainty and anxiety

Autistic people tell us they often have difficulties with **changes to routine and unpredictable and uncertain situations**

(Rodgers et al 2016, 2018, Moore et al 2021, Vasa et al 2022).

# Difficulties with uncertainty & anxiety...



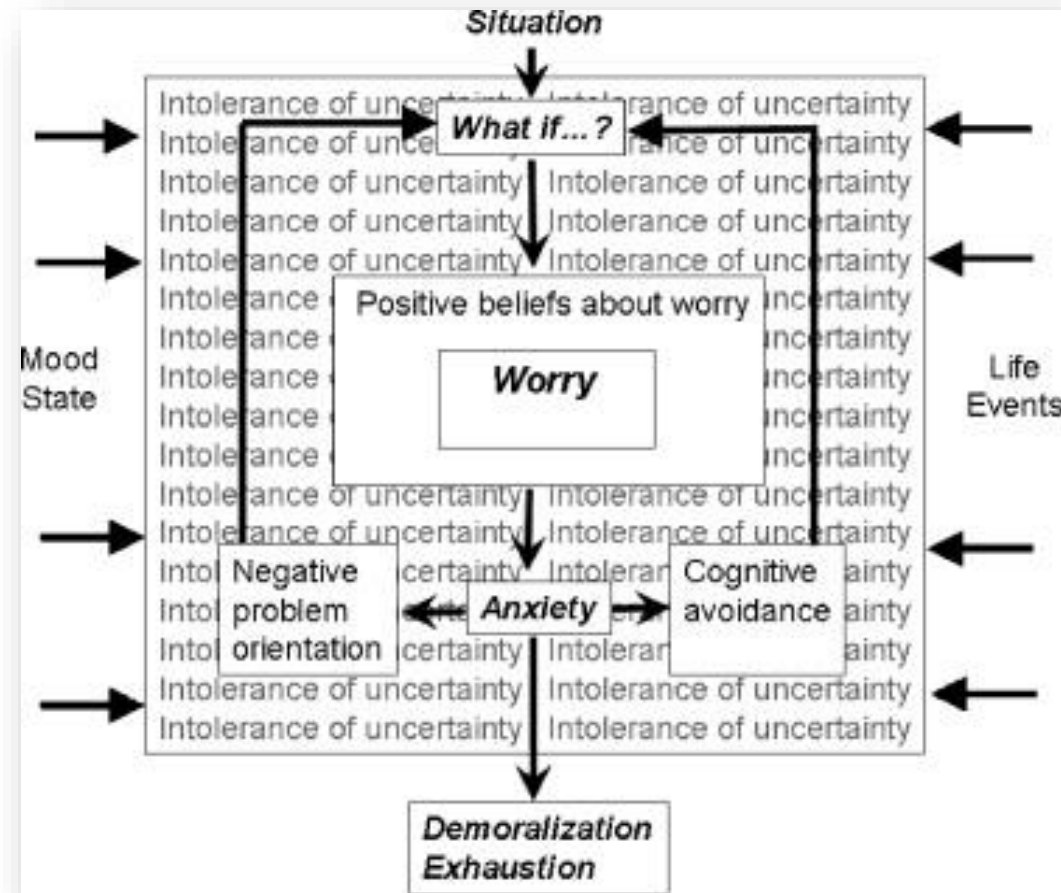
- Uncertain situations are experienced as stressful, upsetting and threatening



- Uncertain events are believed to be negative and should be avoided



- Difficulties with uncertainty contribute to a range of anxiety disorders – transdiagnostic construct



# Anxiety, Uncertainty & Autism

J Autism Dev Disord (2014) 44:1391–1402  
 DOI 10.1007/s10803-013-2001-x

ORIGINAL PAPER


## Intolerance of Uncertainty as a Framework for Understanding Anxiety in Children and Adolescents with Autism Spectrum Disorders

Christina Boulter · Mark Freeston · Mikle South · Jacqui Rodgers



Review

## The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis

Autism  
 1–12  
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 DOI: 10.1177/1362361320932437  
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Richard Jenkinson<sup>1</sup>, Elizabeth Milne<sup>1</sup> and Andrew Thompson<sup>2</sup>

Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-022-05744-3>

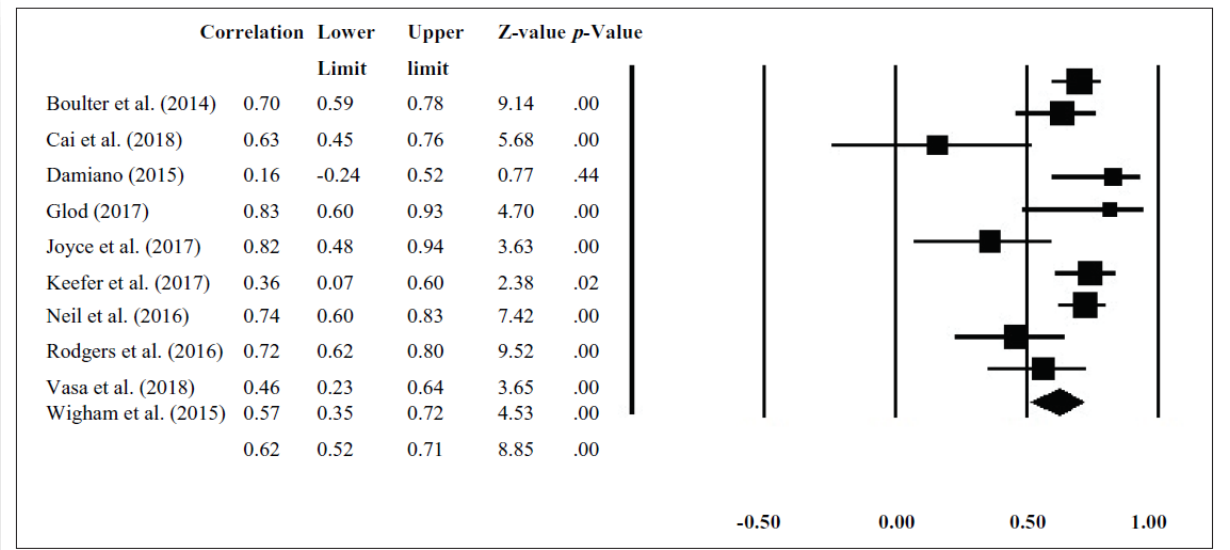
ORIGINAL PAPER



## Exploring the Symptom Profiles of Intolerance of Uncertainty in Autistic Children

Amy Keefer<sup>1,2</sup>, Vini Singh<sup>1</sup>, Yeon Sik Jang<sup>3</sup>, Leigh Alon<sup>3</sup>, Madison Surmacz<sup>4</sup>, Calliope Hologue<sup>1</sup>, Stewart H. Mostofsky<sup>2,6,7</sup>, Roma A. Vasa<sup>1,2</sup>

Accepted: 2 September 2022  
 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022



# Caregiver perspectives on the impact of uncertainty on the everyday lives of autistic children and their families

Jane Goodwin , Priyanka Rob, Mark Freeston, Deborah Garland, Victoria Grahame, Ashleigh Kernohan, Marie Labus, Malcolm Osborne, Jeremy R Parr, Catharine Wright and Jacqui Rodgers

Autism

1–12

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DOI: 10.1177/13623613211033757


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# Repetitive behaviours and anxiety

- Anxious autistic people may engage **more than usual** in restricted, repetitive behaviours (Rodgers et al., 2012, Wigham, Rodgers et al., 2015, Joyce, Rodgers et al 2017, Glod, Rodgers et al 2019, Hwang et al.,2020, Moore et al., 2022)
- Rigid thinking styles, and restricted and repetitive behaviours may make autistic people '*stuck*' in anxious ways of thinking (Kerns et al 2014, Vasa et al 2016).



A close-up photograph of several people's hands and forearms, all reaching towards the center and overlapping to form a supportive circle. The lighting is warm and soft, highlighting the textures of the skin and the fabric of their clothing. The background is blurred, focusing attention on the central gesture of unity.

# Psychological Therapies for Anxiety

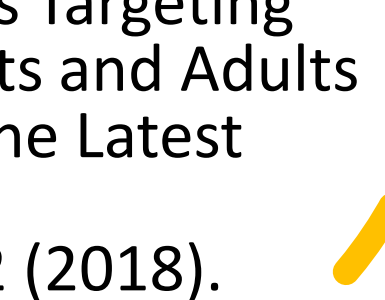
- Psychological therapies for anxiety have demonstrated mixed efficacy for autistic children and adults (Spain et al., 2015) and their improvement is a community priority (Autism Top Ten, 2016)
- To be acceptable & effective – mental health services must adapt to meet the individual's needs (NICE, 2012; Walters, Loades & Russell, 2016)
  - Basic/ essential adjustments to promote accessibility (Brice et al., 2021)
  - Psychological therapies must go a step further and take into account autism related anxiety mechanisms (e.g. IU and alexithymia)

# Psychosocial treatments for anxiety for autistic people

- Emerging evidence for the effectiveness of adapted CBT for anxiety (Sharma *et al.*, 2021 for review)
- Some growing evidence for mindfulness therapies (Hartley *et al.*, 2019 for review)

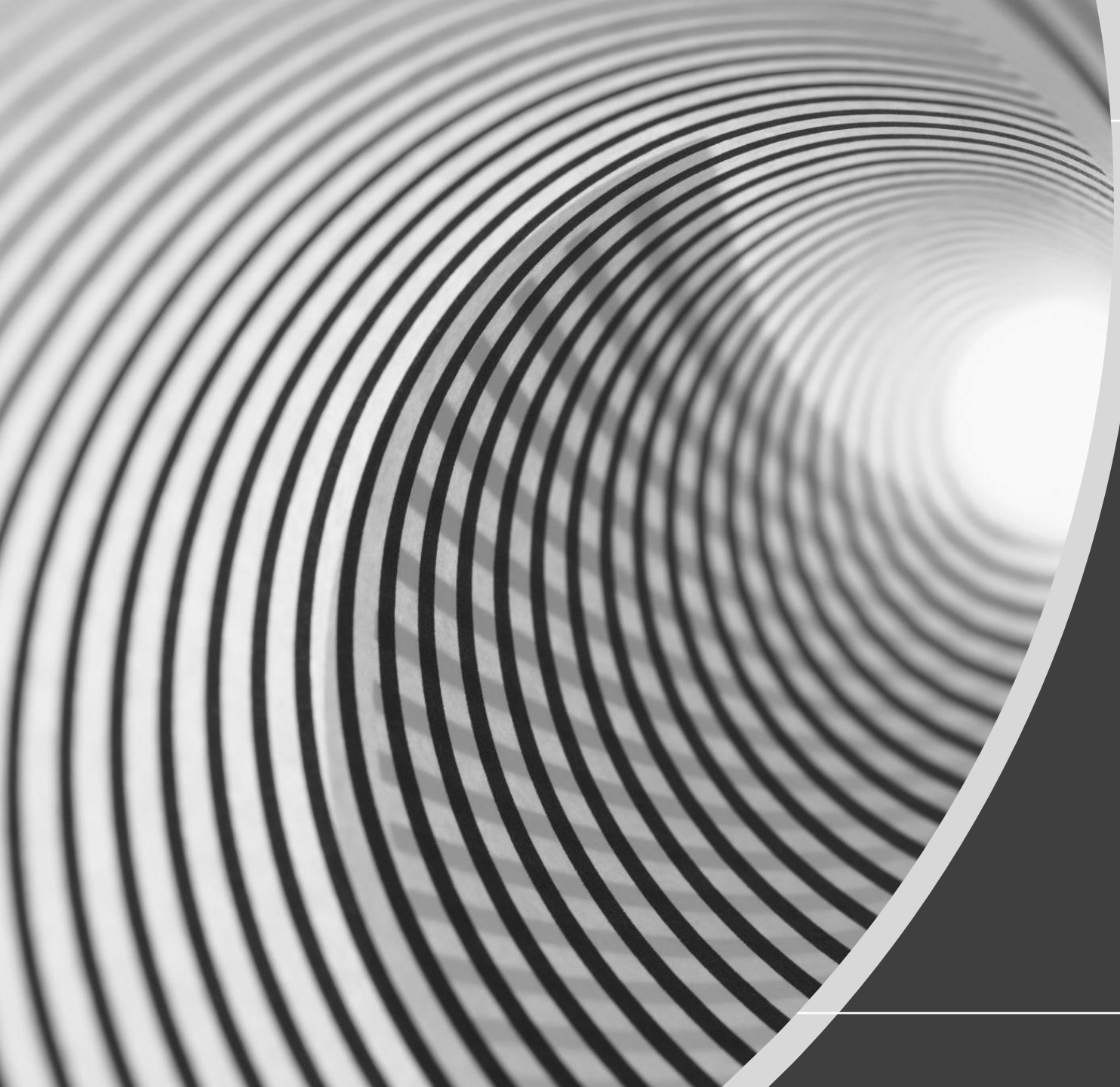
Great review paper:

White, *et al.* Psychosocial Treatments Targeting Anxiety and Depression in Adolescents and Adults on the Autism Spectrum: Review of the Latest Research and Recommended Future Directions. *Curr Psychiatry Rep* 20, 82 (2018).



# Practical Adaptations to CBT for autistic children

- Emotion recognition training
- Mindfulness to address anxiety sensitivity/distress intolerance
- Relaxation strategies
- Visual supports and structured worksheets
- A more concrete and structured approach
- Repetition
- Video modelling, for hard to grasp concepts
- Simplified cognitive activities (e.g. multiple-choice worksheets for teaching helpful and unhelpful thinking)
- Involving a parent or carer to support the implementation
- Incorporating interests



Theoretical  
adaptations  
Let's circle back to  
uncertainty.....

# Is uncertainty: the fly in the ointment?

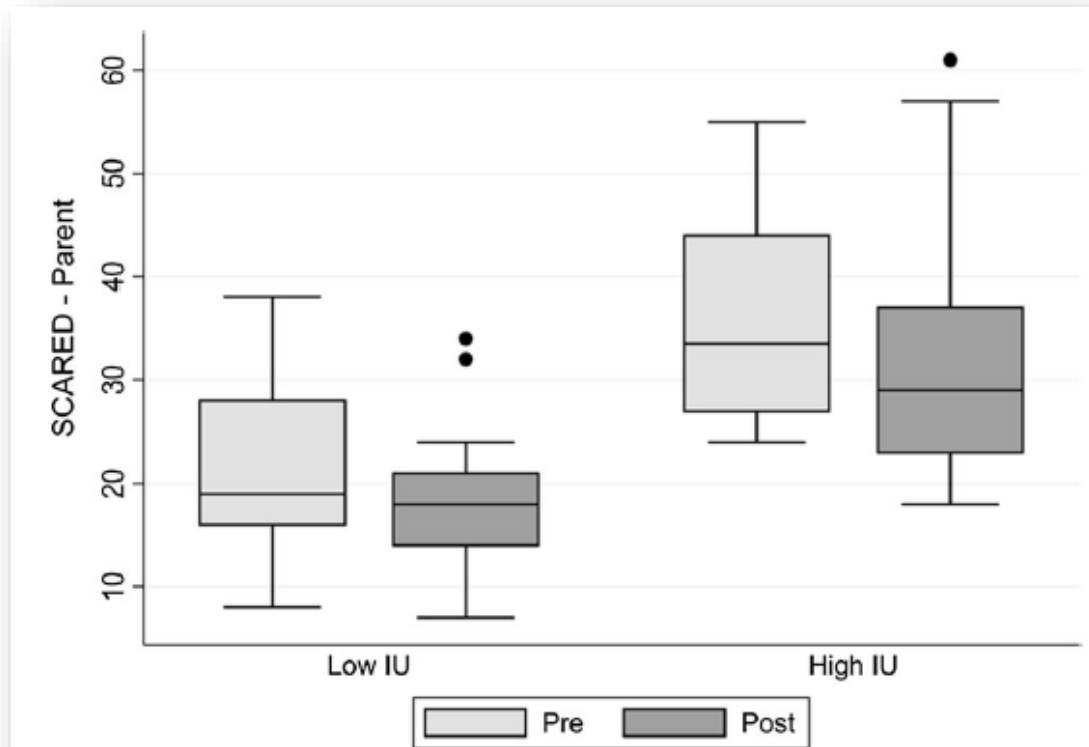


Fig. 2 Change in anxiety following intervention in low versus high IU groups

Higher levels of pre-intervention IU predicted higher anxiety and worry pre and post-intervention.

J Autism Dev Disord (2017) 47:3949–3958  
DOI 10.1007/s10803-016-2852-z

S.I. : ANXIETY IN AUTISM SPECTRUM DISORDERS

## Intolerance of Uncertainty Predicts Anxiety Outcomes Following CBT in Youth with ASD

Amy Keefer<sup>1,2</sup> · Nicole L. Kreiser<sup>1,2</sup> · Vini Singh<sup>1</sup> · Audrey Blakeley-Smith<sup>3</sup> · Amie Duncan<sup>4</sup> · Catherine Johnson<sup>1</sup> · Laura Klinger<sup>5</sup> · Allison Meyer<sup>6</sup> · Judy Reaven<sup>3</sup> · Roma A. Vasa<sup>1,2</sup>

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Judy Reaven<sup>3</sup> · Roma A. Vasa<sup>1,2</sup>

These findings suggest that targeting responses to uncertainty may improve outcomes for autistic young people experiencing anxiety.

Higher levels of pre-intervention IU predicted higher anxiety and worry pre and post-intervention.

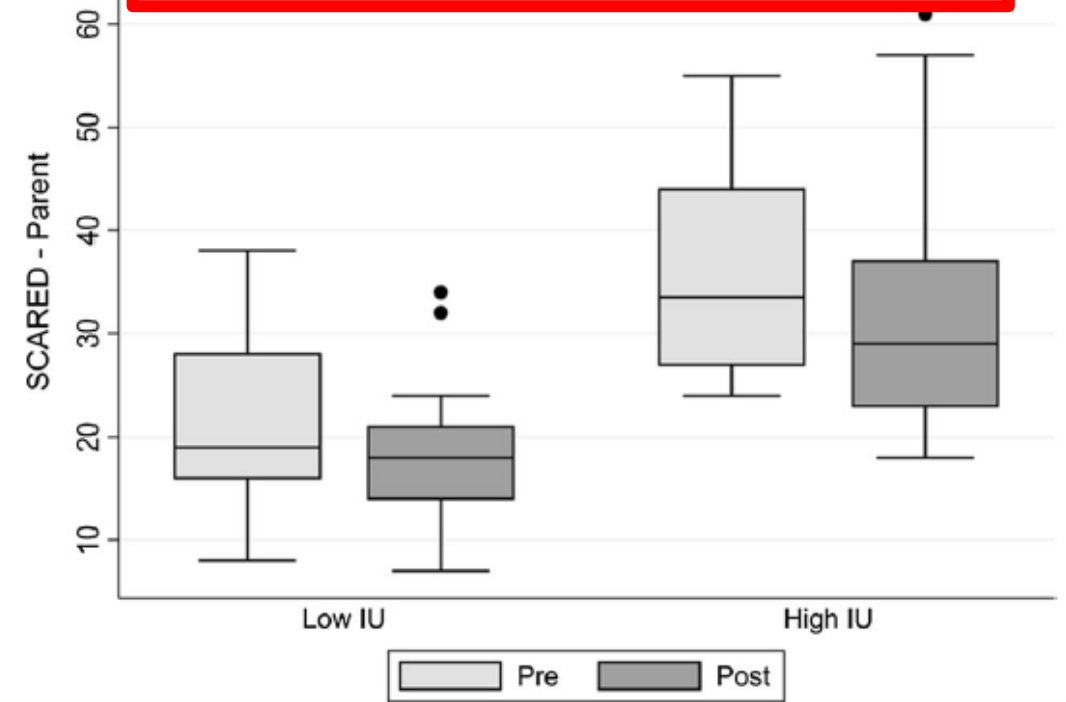


Fig. 2 Change in anxiety following intervention in low versus high IU groups

# Coping with Uncertainty in Everyday Situations (CUES<sup>©</sup>)



Parent Group Programme for  
Parents of Autistic Children

8 week programme


Therapist Training Manual

Jacqui Rodgers  
Anna Hodgson  
Jane Goodwin  
Mark Freeston

Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-022-05645-5>

ORIGINAL PAPER

## Coping with uncertainty in everyday situations (CUES<sup>©</sup>) to address intolerance of uncertainty in autistic children: an intervention feasibility trial

Jacqui Rodgers<sup>1</sup>  · Jane Goodwin<sup>1</sup> · Deborah Garland<sup>2</sup> · Victoria Grahame<sup>3</sup> · Lucy Isard<sup>4</sup> · Ashleigh Kernohan<sup>5</sup> · Marie Labus<sup>6</sup> · Mr Malcolm Osborne<sup>7</sup> · Jeremy R Parr<sup>1</sup> · Priyanka Rob<sup>1</sup> · Catharine Wright<sup>8</sup> · Mark Freeston<sup>9</sup>

# AUTISTICA

Building brighter futures through autism research

## The Principles:

# Coping with Uncertainty in Everyday Situations (CUES<sup>©</sup>)

- We cannot make the world an entirely certain place
- Tackle the uncertainty mechanism
- Develop strategies to cope with and manage everyday uncertainty
- Reduce reliance on strategies that aim to reduce uncertainty (avoidance, over-preparation, impulsivity)
- Provide a personalised approach to coping with uncertainty

# Conclusions

- Parents found CUES to be acceptable and would recommend it to others
- Trained practitioners were able to deliver CUES with fidelity to the manual
- There were no adverse events associated with the programme
- There was some preliminary evidence of improvement in functioning associated with uncertainty related treatment targets

**The study was not fully powered and therefore we cannot draw conclusions regarding clinical and cost effectiveness.**

Parr et al. *Trials* (2020) 21:265  
<https://doi.org/10.1186/s13063-020-4161-2>

Trials

**STUDY PROTOCOL**

**Open Access**



## Treating anxiety in autistic adults: study protocol for the Personalised Anxiety Treatment–Autism (PAT-A<sup>©</sup>) pilot randomised controlled feasibility trial

Jeremy R. Parr<sup>1,2\*</sup>, Samuel Brice<sup>1\*</sup>, Patrick Welsh<sup>2</sup>, Barry Ingham<sup>1,2</sup>, Ann Le Couteur<sup>1</sup>, Gemma Evans<sup>2</sup>, Alexander Monaco<sup>1</sup>, Mark Freeston<sup>3</sup> and Jacqui Rodgers<sup>1</sup>

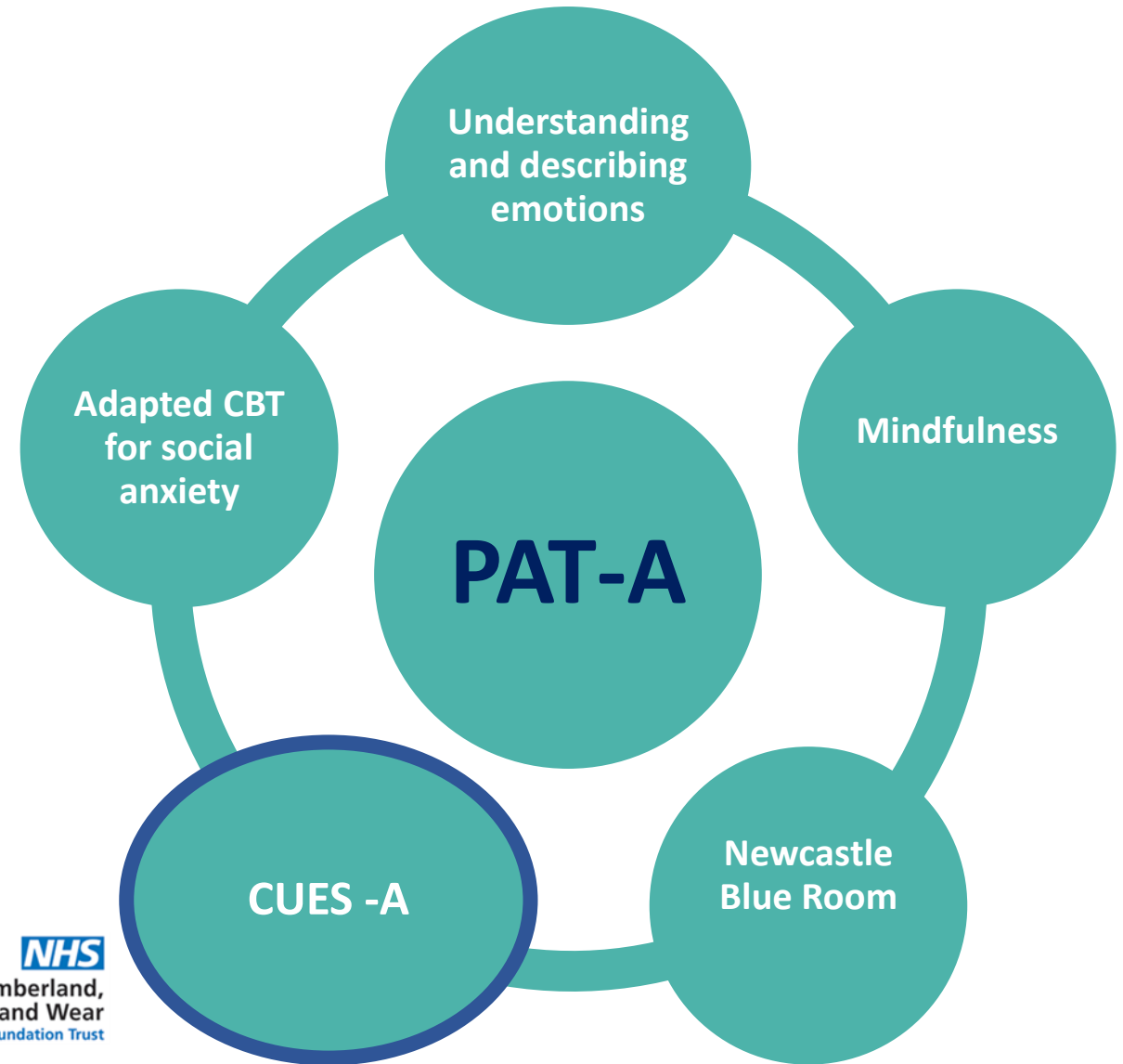


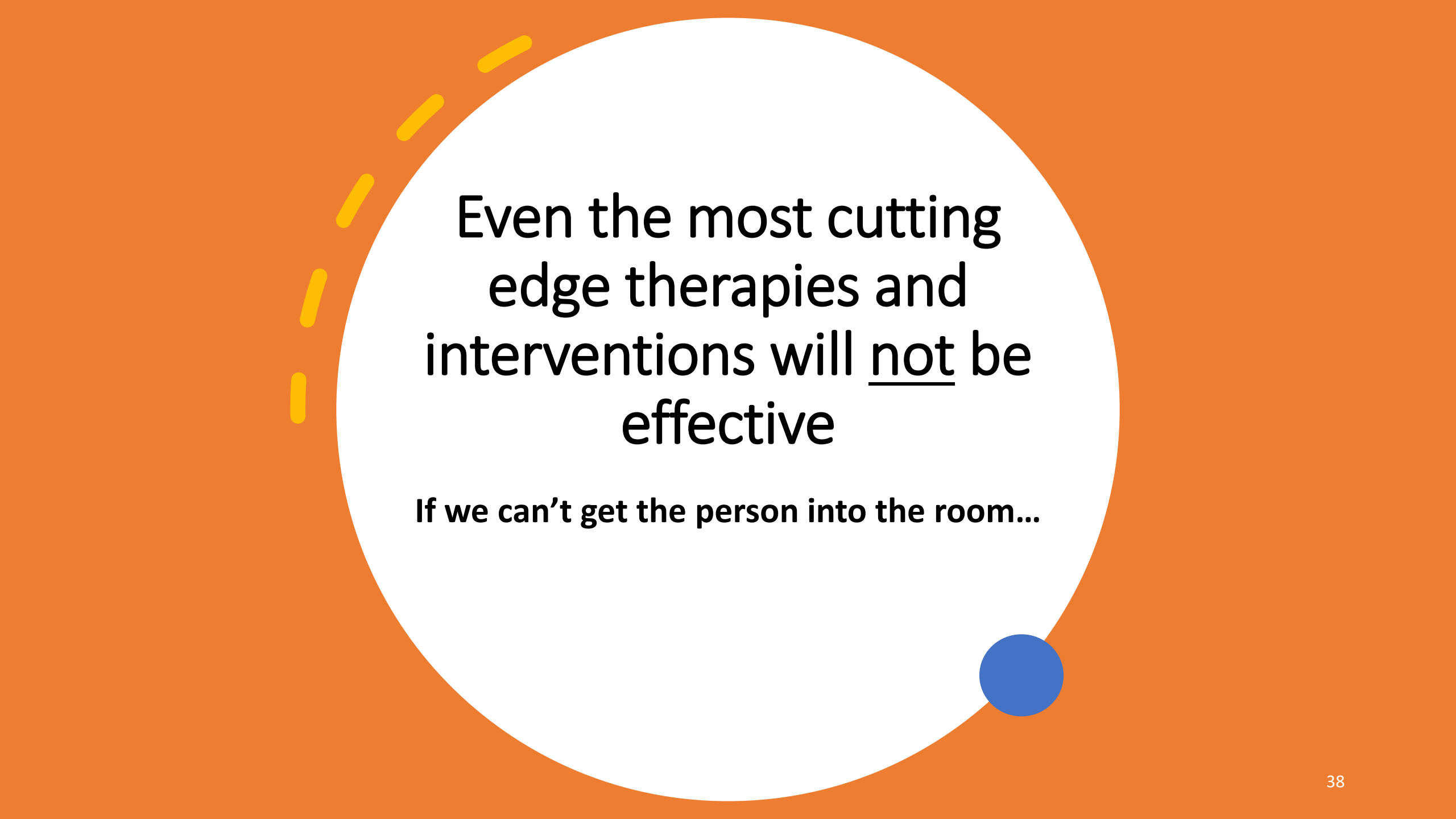
Dr Sam Brice

**AUTISTICA**

Building brighter futures through autism research

**NHS**  
Cumbria, Northumberland,  
Tyne and Wear  
NHS Foundation Trust





Even the most cutting  
edge therapies and  
interventions will not be  
effective

**If we can't get the person into the room...**

# Autistic people need access to effective healthcare

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Autistic people are more likely to experience a range of physical and mental health conditions

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Average life expectancy 12 years lower than neurotypical people (Hirvikoski et al., 2016)

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Many autistic people face disadvantages to healthcare access

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Engagement/ satisfaction with services is often lower

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Poorer treatment outcomes are common


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Improving all aspects of healthcare is a research priority for the community

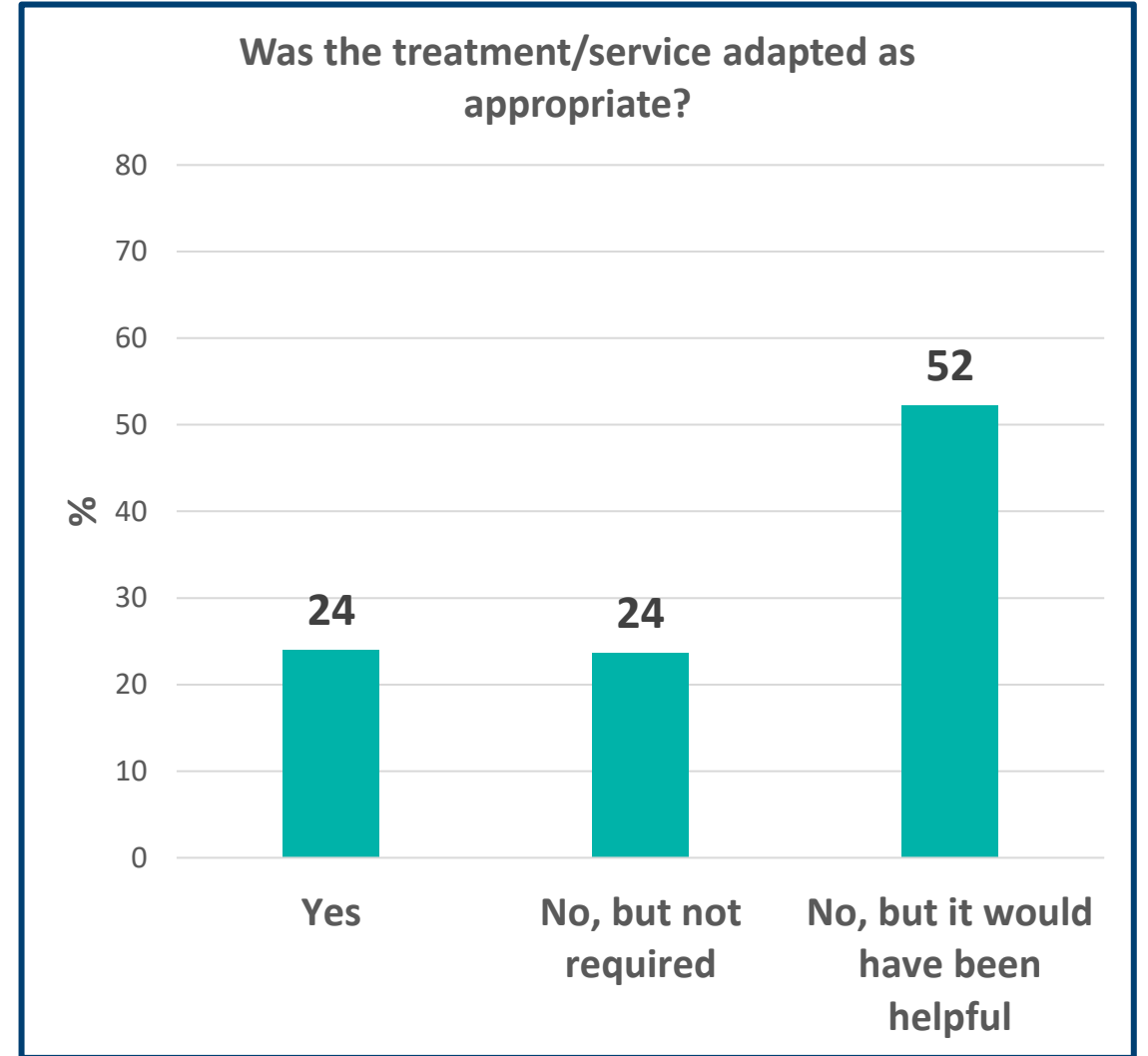
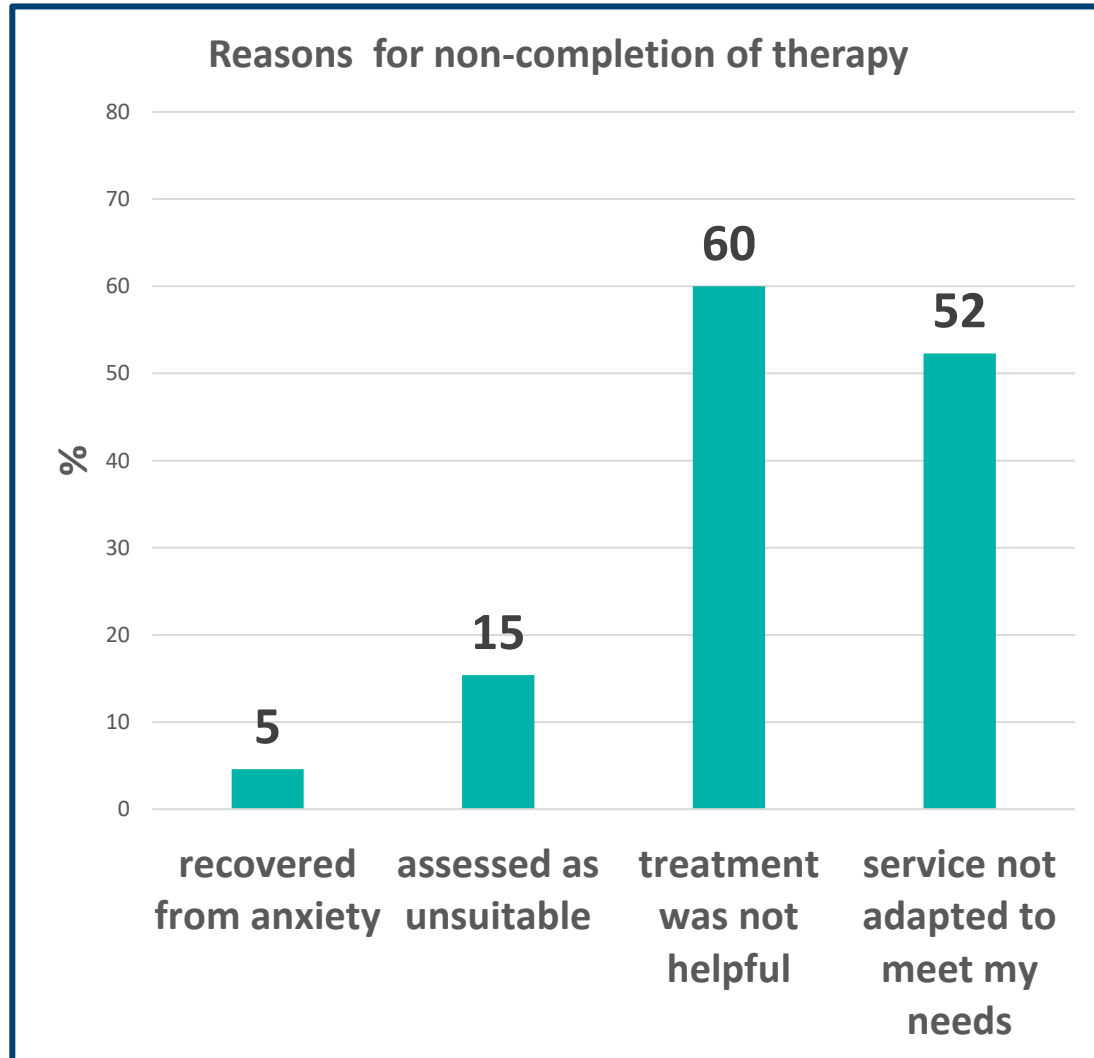
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# BMJ Open The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys

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Samuel Brice ,<sup>1</sup> Jacqui Rodgers,<sup>1</sup> Barry Ingham,<sup>1,2</sup> David Mason,<sup>1</sup> Colin Wilson,<sup>1</sup> Mark Freeston,<sup>3</sup> Ann Le Couteur,<sup>1</sup> Jeremy R Parr<sup>1,2</sup>

# Are treatments being adapted?



“the room not being so dark/hot, it was too quiet which increased anxiety. even holding it in a more casual setting instead of two chairs a table facing each other, which is really awkward”

“Training in Autism, Understanding Autism ”

“clearer instructions as what to expect including photos and details of practitioner in advance”

“Asking to grade feelings on a 1 to 10 scale is meaningless”

“Quieter therapy rooms. Same room each session. No pictures on walls/distractions. No patterned carpets or upholstery. No radio in waiting area.”

“Clearer language. What am I actually being asked?”

“Email communication, communication support to help me open up”

“We need time and not medication”

“Recognition that my feeling of difference might be due to actual difference and not misperceived”

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Effective communication with and by professionals and between services often not present

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Sensory differences are not considered

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Autism training often lacking in health care professionals

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Complex referral pathways/ systems, lack of specialist services

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Telephone triage /appointments are problematic

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Change & uncertainty in services

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+Anxiety not taken into account

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Adaptations not routinely on the agenda

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## In Conclusion.....

- Anxiety is common for autistic people
  - Anxiety may be harder to spot using traditional measures
  - Anxiety may be complex and multi-faceted
  - Transdiagnostic constructs, such as intolerance of uncertainty and alexithymia may be important
  - Interventions and support may need to be adapted to make them suitable for autistic people
  - Systemic barriers to accessing healthcare need to be addressed
- 



Muchas gracias!