

The role of uncertainty in anxiety in children with a diagnosis of Autism Spectrum Disorder

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Anxiety & ASD

- Autistica's Priority Setting Partnership (2016) Top 10 Research Priorities:
 - *Which interventions improve **mental health** or reduce mental health problems in autistic people? How should **mental health interventions** be adapted to the needs of autistic people? (#1)*
 - *What interventions reduce **anxiety** in autistic people? (#4)*
- Anxiety is common in ASD
 - **22% - 84%** of children and **35% -77 %** of autistic adults reported to experience anxiety (White, Oswald, Ollendick, & Scahill, 2009, van Steensel, Bögels et al. 2011, Sterling et al 2008, Mazefsky et al 2008) .

Autism related Anxiety?

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

Connor Morrow Kerns^{1,2}, Philip C. Kendall², Leandra Berry^{1,3}, Margaret C. Souders¹, Martin E. Franklin⁴, Robert T. Schultz¹, Judith Miller¹, and John Herrington¹

- Anxiety around routines (in the absence of generalised worry)
- Unusual specific fears (in the absence of generalised sound/sensory sensitivity) eg babies crying, happy birthday song
- 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) eg mealtime rituals, keep legs uncrossed

Anxiety Scale for Children – ASD (ASC-ASD)

(Rodgers et al 2016)

- 4 subscales (**separation anxiety, performance anxiety, anxious arousal and uncertainty**)
- Preliminary evaluation indicates excellent reliability & validity (Rodgers et al 2016, Keen et al 2018).
- Available in nine languages
- Versions for autistic adults & autistic adults with intellectual disability under development.

ASC-ASD is freely available to download at
<https://research.ncl.ac.uk/neurodisability/>

When are children with ASD anxious?

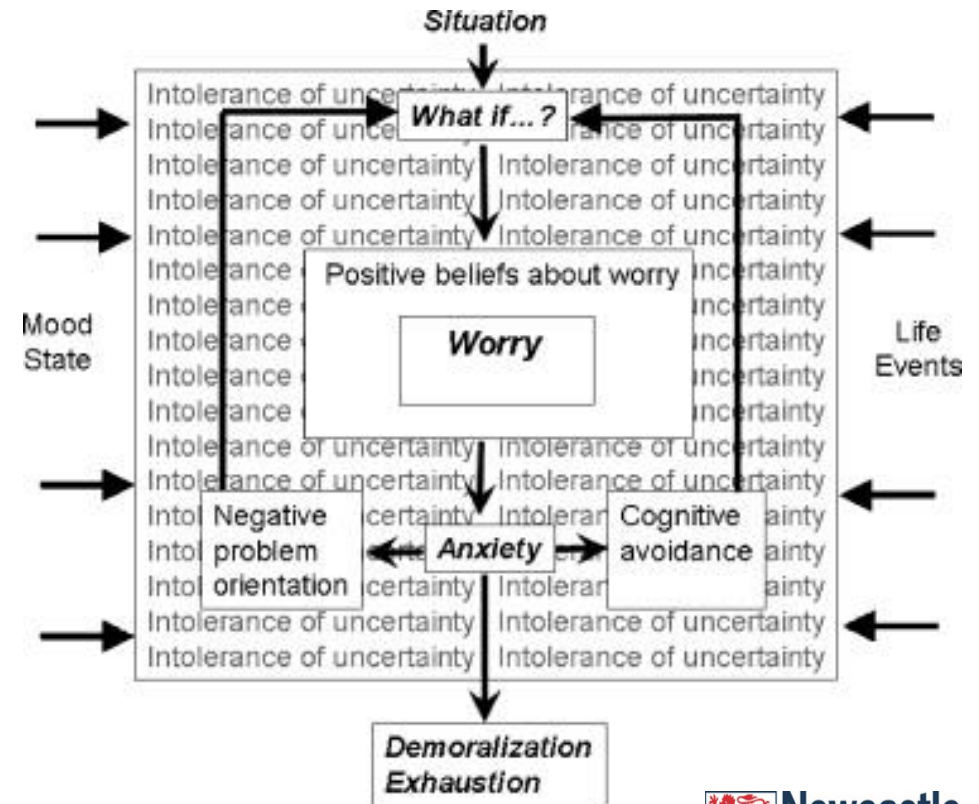
Jamieson (2011)

- **Unfamiliar or unpredictable situations e.g.** holiday to an **unfamiliar** destination, family or school excursions, shopping, school transitions
- **Performance-related situations**, e.g. **novel** schoolwork,
- **New** leisure activities, such as sports clubs and after school activities.
- **Social Situations e.g.** social visits, interacting with peers
- **Unusual events e.g. sudden or unexpected** events, such as having a flat tyre or the Metro breaking down
- Situations/decisions in which the outcome is **uncertain**



What is Intolerance of Uncertainty (IU)?

- How individual perceives information in **uncertain** or **ambiguous** situations
- An assumption that **uncertainty** is **stressful** and **upsetting**
- Uncertain events are **negative** and should be **avoided** at all costs



Intolerance of Uncertainty, Anxiety and Autism: What does our research tell us?

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 - Is important in the development of anxiety in autistic children (Boulter et al 2014) and adults (Maisel et al 2016)

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 - Is recognisable to parents of autistic children and associated with their child's anxiety (Hodgson et al, 2016)
 - **Is associated with anxiety and repetitive behaviours by autistic adolescents (Joyce et al 2017) and adults (Rodgers et al 2018)**

Max and the unexpected fire alarm



Max doesn't like loud noises, such as alarms. He lives near a hospital and he can hear the fire alarm going off from his garden on a Friday morning when they test it. **If Max knows** the fire alarm will go off and **he can cope** with the noise of the alarm, if he stays indoors.

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Max finds this **very distressing** and he runs inside. He is very frightened about the alarm going off again **unexpectedly** and won't play in the back garden anymore **just in case** the alarm goes off.

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Max is becoming **increasingly reluctant** to visit places where alarms might go off.

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Lucy missed school the next day because she **doesn't know what will happen** because she hasn't completed her homework.

Intolerance of Uncertainty: the fly in the ointment?



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S.I. : ANXIETY IN AUTISM SPECTRUM DISORDERS

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

Amy Keefer^{1,2} · Nicole L. Kreiser^{1,2} · Vini Singh¹ · Audrey Blakeley-Smith³ ·
Amie Duncan⁴ · Catherine Johnson¹ · Laura Klinger⁵ · Allison Meyer⁶ ·
Judy Reaven³ · Roma A. Vasa^{1,2}

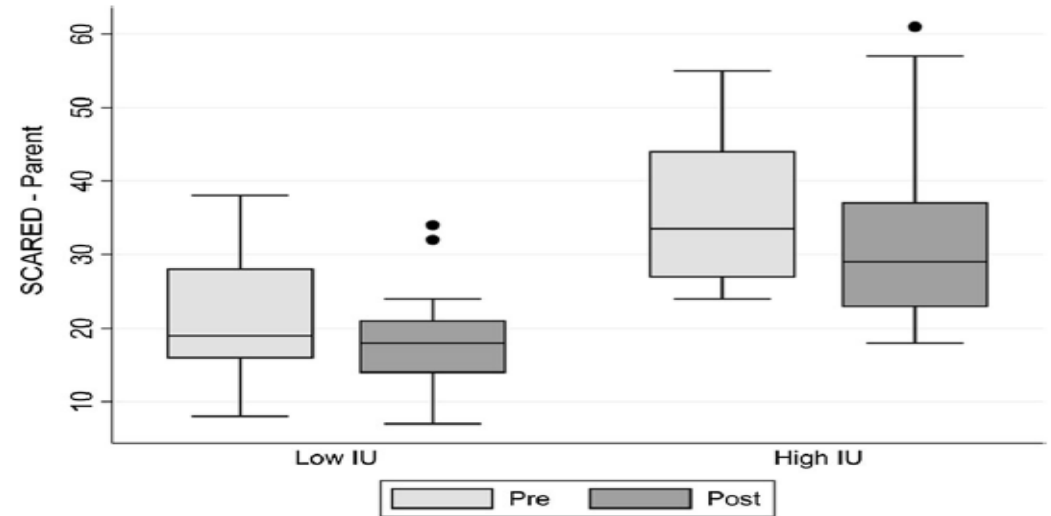


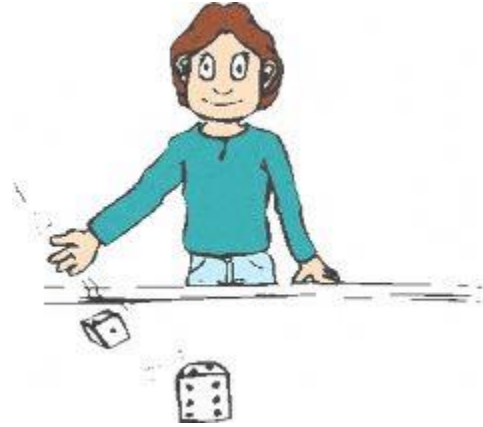
Fig. 2 Change in anxiety following intervention in low versus high IU groups

How do you cope with uncertainty?



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Coping with Uncertainty in Everyday Situations (CUES)



A parent based group intervention for children with Autism Spectrum Disorder

Jacqui Rodgers, Anna Hodgson, Emma Honey, Mark Freeston

What is CUES about?

- Manualised programme
- 8, 2 hours sessions
- Delivered to parents in groups
- Tackling the mechanism – IU
- Developmentally appropriate



CUES Aims

- To develop the young person's independence through the promotion of **flexibility** and tolerance to **everyday uncertainty**
- To enable the child to become more able to **tolerate** uncertainty, rather than attempting to reduce uncertainty
- To identify **less helpful** strategies that maintain intolerance of uncertainty and reduce their use by providing a toolbox of alternatives
- To enable parents support their child to manage uncertainty



What do families think of CUES?



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DOI 10.1007/s10803-016-2924-0



S.I. : ANXIETY IN AUTISM SPECTRUM DISORDERS

Towards a Treatment for Intolerance of Uncertainty in Young People with Autism Spectrum Disorder: Development of the Coping with Uncertainty in Everyday Situations (CUES©) Programme

Jacqui Rodgers^{1,4} · Anna Hodgson^{2,3} · Kerry Shields^{2,3} · Catharine Wright⁴ ·
Emma Honey^{2,3} · Mark Freeston^{2,3}

ROOT

- Cues was found to be acceptable and feasible to deliver to families
- Preliminary results indicated positive improvements in parent and child IU and parent wellbeing
- Parents provided positive feedback about
 - the content of the sessions
 - the usefulness of the materials
 - The opportunity to work alongside other parents

Our current study



1. We want to find out how acceptable and feasible it is to offer CUES via NHS services.
2. Parents of children aged 6-16 years who have a diagnosis of ASD and are experiencing anxiety will be recruited
3. Parents are allocated (by computer) to receive CUES or Understanding Autism
4. We are comparing CUES to an alternative programme (Understanding Autism)
5. Parents and young people complete some assessment at the beginning and after the programmes and then again six months later

What next?



- We have adapted CUES to make it inclusive and suitable for parents of children who have a diagnosis of ASD and intellectual disability (CUES-2)
- We have developed a version of CUES for autistic adults (CUES-A, Rodgers 2018)
- With support from Autistica we are evaluating CUES-A, as part of a study of Personalised Anxiety Treatments for Autistic Adults (PAT-A)
- We are adapting CUES-A to make it suitable for adolescents with a diagnosis of ASD (CUES-Ad)

Summary

- Anxiety is common and complex in children and adults with ASD
- Intolerance of uncertainty.....
 - Is important in the development and maintenance of anxiety in ASD
 - Is recognisable to parents and adults on the spectrum
 - May be amenable to intervention in both children and adults (parent mediated or individual)



AUTISTICA

Building brighter futures through autism research

Northumberland, Tyne and Wear



NHS Trust

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