Intolerance of Uncertainty as a framework for understanding anxiety in ASD

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With thanks to my collaborators....... 

• Professor Mark Freeston
• Professor Mikle South
• Professor Helen McConachie
• Dr Seb Gaigg
• Dr Christina Boulter
• Dr Sarah Wigham
• Dr Emma Honey
• Anna Hodgson
• Renske Herrema
• Max Maisel
• Kevin Stephenson
• Members of the autism community.

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Anxiety in Children with ASD

• is a significant challenge (White et al, 2009, Rodgers et al., 2012a, 2012b).
• affects around 40% of children (van Steensel, Bögels, & Perrin, 2011).
• adds significantly to impairment and reduces quality of life (Wood & Gadow, 2010).
• more urgent than core features of the disorder (White et al., 2010).
The Intolerance of Uncertainty model of anxiety
Dugas, Gagnon, Ladouceur & Freeston, 1998

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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

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Fear of uncertainty......

It’s the reason I am now laid off
It’s the reason I do not drive
It’s the reason I failed at being in the Army
It’s the reason I am Lonely
It’s the reason I will die without having children
and the list goes on and on..........
Is Intolerance of Uncertainty associated with anxiety in ASD?

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

Christina Boulter · Mark Freeston · Milde South · Jacqui Rodgers
Boulter et al 2014: sample

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>TD</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>114</td>
<td>110</td>
<td>124</td>
</tr>
<tr>
<td>Age range (mean)</td>
<td>8-18.7 (12.7)</td>
<td>8.3-18.6 (13)</td>
<td>8-18.7 (1.8)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>100 (87.7%)</td>
<td>83 (75.5%)</td>
<td>183 (81.7%)</td>
</tr>
<tr>
<td>female</td>
<td>14 (12.3%)</td>
<td>27 (24.5%)</td>
<td>41 (18.3%)</td>
</tr>
<tr>
<td>IQ range (N=193)</td>
<td>83-140</td>
<td>75-142</td>
<td>75-142</td>
</tr>
</tbody>
</table>
Measures


• Anxiety: **Spence Children’s Anxiety Scale** (Parent ad Child versions) (Spence, 1998, Nauta, 2004)

• ASD screening: Social Responsiveness Scale (Constantino, 2002)
What did we find?

• **higher** levels of anxiety & IU in the **ASD** group (p<0.001).
• **IU** when entered as a **covariate** explained a **significant** amount of variance (p<0.001)
• the **main effect** of diagnosis was **no longer significant** (p=0.10).
• IU mediated the relationship between ASD diagnosis and anxiety

![Diagram](attachment:image.png)

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How does IU relate to other features of ASD?

The Interplay Between Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted and Repetitive Behaviours in Autism Spectrum Disorder

Sarah Wigham · Jacqui Rodgers · Mkle South · Helen McConachie · Mark Freeston

Published online: 27 September 2014
© Springer Science+Business Media New York 2014
Table 1 Mean and standard deviation total and subscale scores on outcome measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
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<tr>
<td>Age (n = 53)</td>
<td>12.49 (2.3)</td>
</tr>
<tr>
<td>SRS (n = 45)</td>
<td>113.58 (27.67)</td>
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<tr>
<td>FSIQ (n = 49)</td>
<td>106.2 (14.79)</td>
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<tr>
<td>RBQ: sameness behaviours (n = 53)</td>
<td>10.15 (5.49)</td>
</tr>
<tr>
<td>RBQ: repetitive motor behaviours (n = 53)</td>
<td>8.36 (4.99)</td>
</tr>
<tr>
<td>SSP Sensory under responsiveness total (n = 53)</td>
<td>21.08 (6.79)</td>
</tr>
<tr>
<td>SSP Sensory over responsiveness total (n = 53)</td>
<td>62.68 (15.59)</td>
</tr>
<tr>
<td>IUS-P total (n = 53)</td>
<td>37.21 (11.19)</td>
</tr>
<tr>
<td>SCAS-P total (n = 53)</td>
<td>24.15 (15.65)</td>
</tr>
</tbody>
</table>
IU: intolerance of uncertainty; *= significant

Figure 3 Significant indirect paths between the variables
Does IU have face validity?
IU: the fly in the ointment?

• Keefer et al (in press) 43, 8 to 14 years, completed the *Facing Your Fears* CBT programme (Reaven et al., 2012)

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

• IU may be one variable that contributes to poorer treatment response.
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
CUES: Principles

• Tackle the mechanism – IU

• Parent mediated

• Group based

• Developmentally appropriate
CUES Aims

• To develop the young person’s autonomy 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 IU and reduce their use by providing an alternative

• To enable parents to work in a zone of proximal development to support their child

• To encourage reflection and evaluation
CUES Session Outline

• **Session 1** – getting to know each other and introduction to the role of uncertainty

• **Session 2** – thinking about your child’s intolerance of uncertainty and how this relates to features of ASD

• **Session 3** – choosing an everyday non-threatening target situation to tackle IU and starting to identify helpful strategies to tackle your child’s IU

• **Session 4** – developing the use of ‘story boards’ to explore IU

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CUES Session Outline

• **Session 5** – practicing strategies through play to explore IU

• **Session 6** – developing a real-life experiment to explore IU

• **Session 7** – reflecting on progress so far considering aspects that have worked well and areas for further development

• **Session 8** – reviewing progress and the course of the programme and considering how to continue using tools in the future to tackle IU

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## Is CUES Helpful?

<table>
<thead>
<tr>
<th>Study</th>
<th>Group</th>
<th>n</th>
<th>mean - pre</th>
<th>sd</th>
<th>mean -post</th>
<th>sd post</th>
<th>ES (based on pooled SD)</th>
<th>Pooled ES</th>
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<tbody>
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<td>IUS-P</td>
<td>1</td>
<td>57.50</td>
<td>18.30</td>
<td>49.50</td>
<td>22.70</td>
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<tr>
<td></td>
<td></td>
<td>2</td>
<td>46.80</td>
<td>19.30</td>
<td>40.70</td>
<td>17.70</td>
<td>0.33</td>
<td>0.36</td>
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<tr>
<td></td>
<td>SCAS</td>
<td>1</td>
<td>48.70</td>
<td>3.90</td>
<td>46.00</td>
<td>5.50</td>
<td>0.57</td>
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<tr>
<td></td>
<td>ASC-ASD</td>
<td>2</td>
<td>28.30</td>
<td>10.60</td>
<td>23.30</td>
<td>9.80</td>
<td>0.49</td>
<td>0.53</td>
</tr>
<tr>
<td>Parent</td>
<td>IUS-12</td>
<td>1</td>
<td>28.80</td>
<td>7.10</td>
<td>20.80</td>
<td>5.30</td>
<td>1.28</td>
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<tr>
<td></td>
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<td>2</td>
<td>50.20</td>
<td>13.80</td>
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<td>13.00</td>
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<td>0.72</td>
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<tr>
<td></td>
<td>DASS</td>
<td>1</td>
<td>26.00</td>
<td>11.30</td>
<td>17.00</td>
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<td>0.83</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>23.70</td>
<td>18.40</td>
<td>18.30</td>
<td>11.40</td>
<td>0.35</td>
<td>0.59</td>
</tr>
</tbody>
</table>

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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 Rodgers¹,4✉ • Anna Hodgson²,³ • Kerry Shields²,³ • Catharine Wright⁴ • Emma Honey²,³ • Mark Freeston²,³
Anxiety in adults with ASD....... 

• is also very common (Davis et al., 2011).
• Sterling et al (2008) 35% of 18-44 year olds with ASD had anxiety.
• Mazefsky et al (2008) 77% of adults with ASD met criteria for an anxiety disorder.
• Research with adults with ASD is significantly lacking.
Journal of Abnormal Psychology

Modeling the Cognitive Mechanisms Linking Autism Symptoms and Anxiety in Adults

Max E. Maisel, Kevin G. Stephenson, Mkle South, Jacqui Rodgers, Mark H. Freeston, and Sebastian B. Gaigg


CITATION
Maisel et al, 2016

![Diagram showing the relationship between Autism Symptoms, Emotional Acceptance, Alexithymia, Intolerance of Uncertainty, and Anxiety, with statistical significances indicated]

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Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders

Mikle South and Jacqui Rodgers

*Departments of Psychology and Neuroscience, Brigham Young University, Provo, UT, USA, Institute of Neuroscience, Newcastle University, Newcastle, UK

Figure 1. Exploratory model of possible pathways related to intolerance of uncertainty and anxiety in ASD. Evidence is growing for IU as a significant mediator of anxiety in ASD samples.
The *Uncertain Futures* Study

- Phase 1 - explored worries adults on the autism spectrum and their family members may have about the future and what would be helpful to manage these concerns

- Phase 2 – Single case design study of the delivery of the Coping with Uncertainty in Everyday Situations - Adult (CUES-A) intervention to help manage negative affect in relation to uncertain situations
The *Uncertain Futures* Study Phase 2: Aim

- To adapt and deliver our Cognitive Behaviour Therapy (CBT) based intervention programme targeting uncertainty for adults on the autism spectrum: *Coping with Uncertainty in Everyday Situations – Adult (CUES-A).*
The *Uncertain Futures* Study: Methodology

- Single Case Experimental Design: 4 autistic adults

- CUES-A - 8 session, weekly intervention programme
  - Plus initial session and follow-up feasibility interview

- Target IU related Situation Monitoring – assessed via daily diaries

- Outcomes Measures – Depression, anxiety, stress IU & RRB (PHQ-9, GAD-7, DASS-21, IUS-12, RBQ-2A)
The *Uncertain Futures* Study: Intervention

- 8 individual, hour long CBT sessions, adapted based on client need
- Techniques included
  - Emotion recognition/emotional literacy work
  - Cognitive re-structuring,
  - Mindfulness,
  - Behavioural experiments,
  - Behavioural activation.
- Daily diaries were kept throughout (3 week baseline, 8 week programme, plus 1 month Fu)

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The *Uncertain Futures* Study: Preliminary Findings

- Engagement and retention was excellent – 100% (N=4)
- Improvements in
  - tolerance and management of uncertainty – from Daily Diaries
  - Changes in standardised measures, e.g. reduction in RRB
- Feedback – Participants valued:
  - Experience and process of therapy
  - practical strategies and psycho-education
  - individualisation of sessions
  - collaborative approach
- Engagement in therapy with adults on the autism spectrum is achievable
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  
  • Mediates between core features of ASD, such as sensory atypicalities and repetitive behaviours  
  • Is recognisable to parents and adults on the spectrum  
  • May be amenable to intervention in both children and adults (parent mediated or individual)

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