

Recognising and treating anxiety in Autism Spectrum Disorder

**Dr Jacqui Rodgers
Clinical Psychology
Institute of Neuroscience
Newcastle University**

Learning outcomes

- By the end of the session you will have
 - A better understanding of the prevalence and phenomenology of anxiety in autistic children and adults
 - Knowledge of the important interactions between ASD characteristics and anxiety
 - Increased knowledge of ASD specific methods of assessing anxiety
 - Knowledge of the ways in which cognitive behavioural treatments for anxiety need to be adapted to ensure that they are accessible to autistic individuals
 - An understanding of the importance of intolerance of uncertainty in autism and anxiety and how to address it
 - Access to some therapy leaflets and tools

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 autistic children reported to experience anxiety (White, Oswald, Ollendick, & Scahill, 2009, van Steensel, Bögels et al. 2011).
 - **35% -77 %** of autistic adults reported to experience anxiety (Sterling et al 2008, Mazefsky et al 2008) .
- Estimates of the rates of anxiety vary widely
- **Variations may be a consequence of measurement issues**

Jacqui.Rodgers@ncl.ac.uk




The measurement properties of traditional anxiety scales when used with children with ASD

J Autism Dev Disord
DOI 10.1007/s10803-017-3118-0



S.I. : ANXIETY IN AUTISM SPECTRUM DISORDERS

Comparisons of the Factor Structure and Measurement Invariance of the Spence Children's Anxiety Scale—Parent Version in Children with Autism Spectrum Disorder and Typically Developing Anxious Children

Magdalena Glod¹ · Cathy Creswell² · Polly Waite² · Ruth Jamieson^{3,6} ·
Helen McConachie⁴ · Mikle Don South⁵ · Jacqui Rodgers^{1,3} 



Jacqui.Rodgers@ncl.ac.uk

Seeing the wood for the trees.....

- Why might 'traditional' measures not work?
 - Different developmental trajectories in ASD
 - Differential presentations of co-occurring conditions in autism (gaps...)
 - Interactions between autism characteristics and constructs of interest
 - Diagnostic overshadowing
 - Scaling/interpretation issues
 - Etc. etc.....



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^{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 routine (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

- Parallel parent and child versions (24 items each)
- 4 subscales (**separation anxiety**, **performance anxiety**, **anxious arousal** and **uncertainty**)
- Preliminary evaluation indicates that the ASC-ASD (child and parent versions), show promise as reliable and valid measures of anxiety in ASD (Rodgers et al 2016, Keen et al 2018)

ASC-ASD is freely available to download at
<http://research.ncl.ac.uk/cargo-ne/asures.html>

Anxiety Disorders Interview Schedule for Autism Spectrum & Developmental Disorders (ADIS-ASDD)

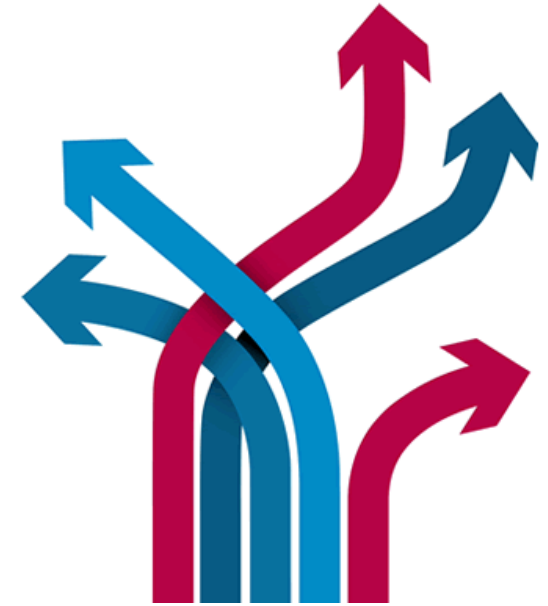
- Kerns, Silverman & Albano – anticipated release 2018, Oxford University Press
- Parent based clinical interview
- Around 90 minutes to conduct
- Based on ADIS
- Designed to support a careful, clearly conceptualised and operationalised assessment of anxiety in autistic young people

Repetitive behaviours and anxiety

- Autistic children and adults who are experiencing difficulties with anxiety may engage more than usual in **repetitive behaviours** (Rodgers et al., 2012, Wigham, Rodgers et al., 2015, Joyce, Rodgers et al 2017, Rodgers et al submitted)
- These might be **physical** (e.g. spinning, rocking hand flapping) or **cognitive** (e.g. special interests, hobbies, routines)
- Perhaps this is an attempt to **self soothe** or make the world **more predictable**?
- An increase in these behaviours may be an important tell-tale sign of anxiety

Emerging research in pathways to anxiety in ASD

- Sensory difficulties
- Alexithymia
- Emotion dysregulation
- Executive function – esp. cognitive inflexibility
- Attentional bias
- Anxious imagery
- **Intolerance of Uncertainty.....**



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 (IU), Anxiety and Autism



- IU seems to be an important process mechanism in the development and maintenance of anxiety in autistic children (Boulter et al 2014) and adults (Maisel et al 2016)
- Hodgson et al (2016) IU is recognisable to parents of autistic children and associated with their child's anxiety
- IU mediates the relationship between sensory processing difficulties and repetitive behaviours (Wigham et al 2015)
- Joyce et al (2017) IU is associated with anxiety and repetitive behaviours by autistic adolescents

CBT for Anxiety in autistic Children : The evidence



- Adapted CBT has been shown to help reduce anxiety in autistic children in a small number of Randomised Controlled Trials (RCTs) (e.g. McConachie et al. 2014, Chalfant et al 2007, Reaven et al 2012, Sofronoff et al, 2005, Sung et al , 2011, Storch et al 2015, Wood et al 2009, 2015).
- Effect sizes are moderate (Ung et al 2015 pooled hedges $g=0.47$)
- It is important to determine what factors influence treatment response.....

Treatments for Anxiety in ASD

- Useful adaptations to CBT may include:
 - 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 special interests



Using CBT for Anxiety in ASD



"My ability to adapt is the key to my success."

- CBT programmes require adaptation (Reaven, 2011)
 - Therapists may experience difficulties establishing therapeutic alliance
 - Autistic children may have problems with
 - high-level language,
 - cognitive flexibility
 - taking turns in group situations,
 - understanding their own and others' emotions,
 - how to plan ahead.



IU: the fly in the ointment?



- Keefer et al (2017) autistic children/adolescents (8-14 years, n=43), 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:


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





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}

jacqui.rodgers@ncl.ac.uk

Is Cues helpful?

		Group	mean – pre (sd)	mean – post (sd)	ES	Pooled ES
Child	IUS-P (child IU)	1 (n=6)	57.50 (18.30)	49.50 (22.70)	0.39	
		2 (n=5)	46.80 (19.30)	40.70 (17.70)	0.33	0.36
	SCAS (child anxiety)	1	48.70 (3.90)	46.00 (5.50)	0.57	
	ASC-ASD (child anxiety)	2	28.30 (10.60)	23.30 (9.80)	0.49	0.53
Parent	IUS-12 (parent IU)	1	28.80 (7.10)	20.80 (5.30)	1.28	
		2	50.20 (13.80)	48.00 (13.00)	0.16	0.72
	DASS (parent wellbeing)	1	26.00 (11.30)	17.00 (10.30)	0.83	
		2	23.70 (18.40)	18.30 (11.40)	0.35	0.59

Adulthood, Anxiety and Autism



- High prevalence of mental health difficulties in autistic adults (Bradley et al., 2004)
- Anxiety is a very common co-occurring difficulty (Davis et al., 2011).
- Sterling et al (2008) 35% of autistic 18-44 year olds had anxiety.
- Mazefsky et al (2008) 77% of autistic adults ASD met criteria for an anxiety disorder.
- No specific treatments for anxiety in autistic adults

Anxiety
+ Autism

CUES-A Programme[©]



RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION

Method

- Single Case Experimental Design: 4 autistic adults
- CUES-A – 3 phases:
 - Phase 1: Baseline measurement
 - Phase 2: 8 CBT 1:1 sessions, weekly
 - Phase 3: Four week follow-up and feasibility interview
- Target IU related Situation Monitoring – assessed via daily diaries
- Outcomes Measures – Depression (PHQ9), Anxiety (GAD7), Stress (DASS-21), IU (IUS-12) & Restricted Repetitive Behaviours (RBQ-2A) completed at initial session and 1 month follow-up

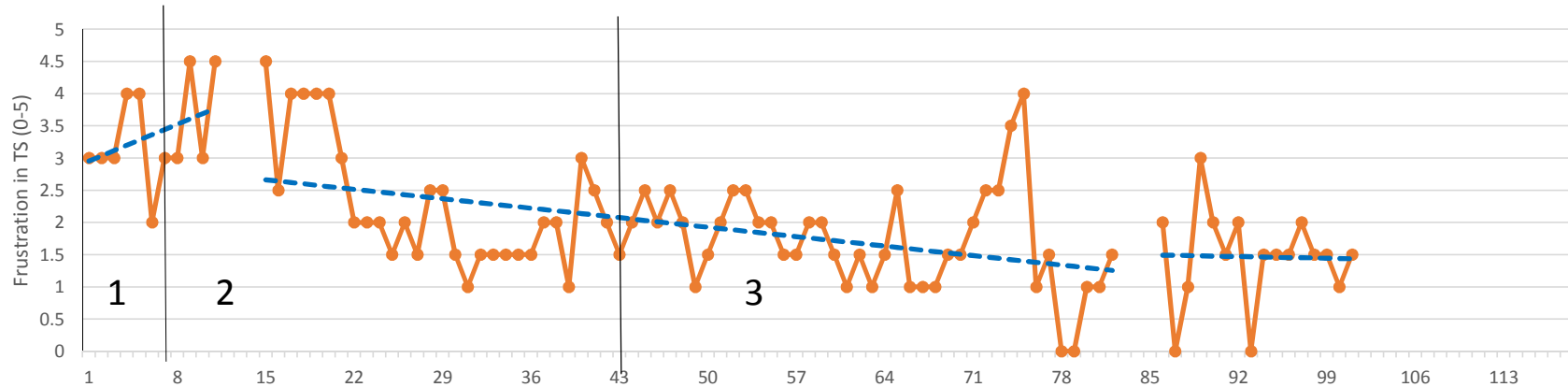
jacqui.rodgers@ncl.ac.uk

Case Study

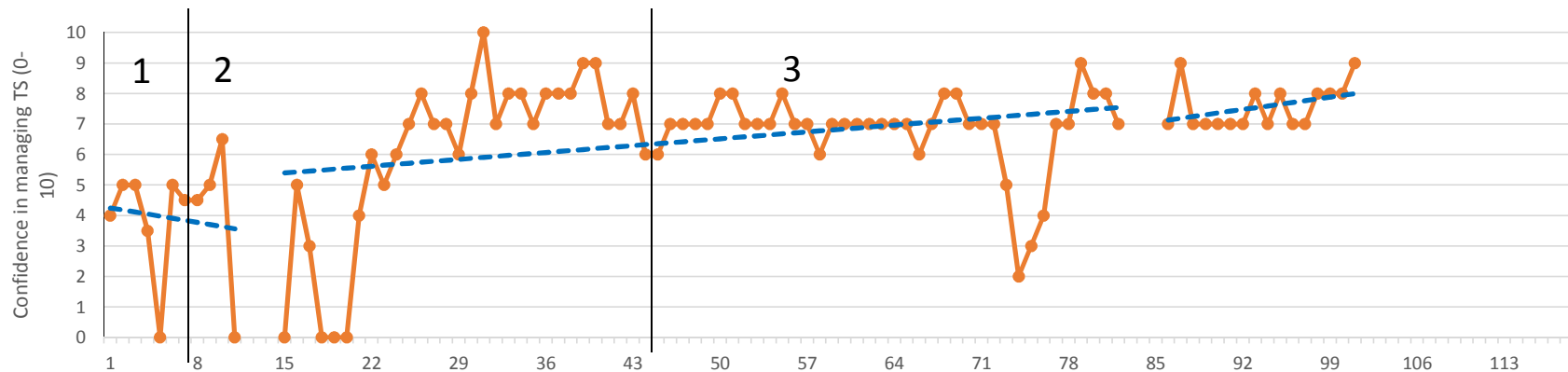


- Adam*
- Target Situation: “Other people making decisions which impact on me (particularly at work)” – Daily Diaries completed via online survey
- Uncertainty around decisions being made which are out of his control, how this might affect him, what if he doesn’t agree with their decision, what might happen next?
- Clinically meaningful scale: frustration about target situation
- Treatment Approach: Psycho-education on fight/flight model, relaxation strategies for anger, Progressive Muscle Relaxation and Tension Release, Mindfulness Strategies to manage IU

Case Study Results



If you were to experience your target situation, how anxious would you feel?



How confident do you feel about managing your target situation?

jacqui.rodgers@ncl.ac.uk

Single case Experimental Design: Tau – U analysis

Phase	Phase A vs B					Phase B vs C			
Participant	Tau	SD Tau	Z Score	p		Tau	SD Tau	Z Score	p
Participant 1	0.177	0.252	0.702	.482		0.272	0.171	1.588	.112
Participant 2	0.734	0.189	3.887	.001		0.069	0.161	0.433	.665
Participant 3	0.326	0.185	1.758	.078		0.273	0.149	1.829	.067
Participant 4	-0.017	0.144	-0.121	.904		0.590	0.164	3.589	.003
Combined	0.264	0.091	2.905	.004		0.298	0.080	3.706	.0002

Reliable and Clinically Significant Change

Note: * Indicates below clinical cut-off before treatment

Scale	Participant 1			Participant 2			Participant 3			Participant 4		
	IS	FU	Outcome	IS	FU	Outcome	IS	FU	Outcome	IS	FU	Outcome
PHQ-9 Depression	4*	4	No change	10.5	4	Recovered	11	3	Recovered	16	12	No change
GAD-7 anxiety	6*	0	Improved	9	7	No change	12	5	Recovered	18	14	No change
IUS-12	36	27	Recovered	43	32	Recovered	52	39	Improved	46	39	No change
Stress Scale	9	9	No change	15.5	7	Improved	18	3	Improved	15	11	Improved
RBQ-2A Repetitive behaviours	38	26	Improved	56	44	Improved	38	26	Improved	49	42	Improved

jacqui.rodgers@ncl.ac.uk

Ongoing work

- Adaptation of ASC-ASD for use with autistic adults with and without co-occurring intellectual disability
- Pilot RCT of Personalised Anxiety treatments for Autistic Adults (PAT-A), including a focus on IU
- Pilot RCT of Coping with Uncertainty in Everyday Situations – CUES
- Further development of CUES-Adult



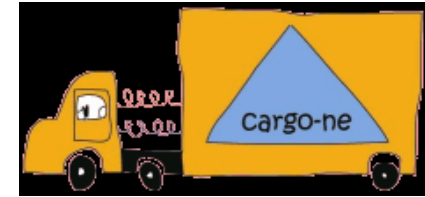
bwc29296996 Barewalls ©

jacqui.rodgers@ncl.ac.uk

AUTISTICA

Building brighter futures through autism research

Some (hopefully) useful tools – available on cargo-ne




- **Anxiety Scale for Children – ASD (ASC-ASD)**
- ***Therapy Passport for Parents*** - this document can be used by parents/carers to record important information about their child that they think might be helpful to therapists working with them. It can be used in conjunction with Therapy Passport for Teens
- ***Therapy Passport for Teens*** - this document can be used by autistic young people to record important information that they think might be helpful to therapists working with them. It can be used in conjunction with Therapy Passport for Parents
- ***A few things about me for therapy*** - this document can be used by autistic people to record important information that they think might be helpful to therapists working with them.
- ***Top tips for Therapy*** - This document provides guidance for therapist working with autistic young people
- **What autistic people would like therapists to know** - This document was developed in collaboration with autistic adults to provide therapists with information that they may find useful.

Summary

- Anxiety is very common in autistic people
- When present it is often complex and interacts in important ways with autism related characteristics
- Care must be taken in the assessment of anxiety for autistic people
- Intolerance of uncertainty may be an important feature of anxiety for autistic individuals
- CBT interventions may be effective but will require adaptation and consideration should be given to incorporating a focus on IU

Thanks to.....

Northumberland, Tyne and Wear 
NHS Trust

Scottish
autism

AUTISTICA
Building brighter futures through autism research



Northumbria Healthcare 
NHS Foundation Trust



The Children's
FOUNDATION
IMPROVES CHILDREN'S HEALTH IN NORTH EAST ENGLAND

jacqui.rodgers@ncl.ac.uk

The Baily Thomas
Charitable Fund

