

Centre for Developmental and Complex Trauma

MEETING THE TRAUMA NEEDS OF AUTISTIC ADULTS RESOURCE PACK

ONLINE 5th December 2024







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# **ABOUT THIS PACK**

Dear colleagues,

As a part of the webinar we have collated a limited number of resources, to facilitate learnings and practice. For the most part, we have identified a number of peer reviewed journal papers that may be of interest, including those that offer practice based guidance.

We have also included links to a number of psychometric measures that are freely available. These resources are already available on the internet, and can be accessed by members of the general public, as well as by clinicians. Although we are sharing links to them, this is not an indication or endorsement of them over other tools, especially those that need to be purchased.

Practitioners are reminded of their responsibility to ensure that appropriate psychometric measures, as a part of wider information gathering activities, are used responsibly, including ensuring user competence.

We hope the resources are useful and support to develop understanding and practice.



Dr Deborah Morris, Guest Editor, Advances in Autism Director, Centre for Developmental and Complex Trauma Director of Postgraduate Programmes in Trauma, MSc Practitioner in Psychological Trauma, Faculty of Medicine and Health Sciences, University of Buckingham

# Recent articles of interest: Trauma assessment

### Best practices and emerging trends in assessment of trauma in students with autism spectrum disorder

George A. Michna, Sierra M. Trudel, Melissa A. Bray, Jessica Reinhardt, Jessica Dirsmith, Lea Theodore, Zheng Zhou, Ishani Patel, Paul Jones & Matthew L. Gilbert



Children and adolescents with autism have a higher likelihood of being exposed to bullying, abuse, and sexual assault which, through repeated exposure, has been demonstrated to impede academic, social, and physical functioning among this population. However, the complexity of unpacking the characteristics of autism and trauma can pose a challenge for school psychologists in using the most appropriate clinical method of intervention.

This paper summarizes the co-occurrence of autism and trauma in an effort to better inform practitioners and recommends the need for valid and reliable assessments that measure adverse experiences for children with autism.

A practitioner assessment guide of childhood trauma and autism spectrum disorder is also provided to facilitate a comprehensive assessment process.

We conclude that there is a pressing need for more research examining the relationship between autism and trauma by better understanding the relationship of these constructs, and for the development of more effective assessments to provide more evidence-based interventions.

#### EXPERT CONSENSUS REGARDING INDICATORS OF A TRAUMATIC REACTION IN AUTISTIC YOUTH: A DELPHI SURVEY

Connor M. Kerns, Diana L. Robins, Paul T. Shattuck, Craig J. Newschaffer, Steven J. Berkowitz



#### Abstract

Objective: It has been suggested that the sequelae of trauma are under-recognized in youth on the autism spectrum. We aimed to generate expert consensus regarding important trauma indicators, including but not limited to traumatic stress symptoms, in autistic youth. Methods: We recruited 72 experts in autism and/or childhood trauma. Via a 2-round Delphi survey, experts commented on and rated the importance of 48 potential indicators, drawn from PTSD criteria and a broader literature on traumatic sequelae in autism. A revised list of 51 indicators, 18 clinical guidelines developed from expert comments, and summaries of expert qualifications and ratings from Round 1 were submitted to a second round (n = 66; 92% retention) of expert review and rating. Results: Twenty-two indicators reached consensus (>75% round 2 endorsement). Many, but not all, reflected PTSD criteria, including intrusions (e.g., trauma re-enactments in perseverative play/speech), avoidance of trauma-reminders, and negative alterations in mood/cognition (e.g., diminished interest in activities) and in arousal/reactivity (e.g., exaggerated startle). Experts also identified increased reliance on others, adaptive and language regressions, self-injurious behavior, and non-suicidal self-injury as important indicators. Consensus guidelines emphasized the need for tailored measures, developmentally informed criteria, and multiple informants to increase diagnostic accuracy. Conclusions: Expert consensus emphasizes and informs a need for tailored diagnostic guidelines and measures to more sensitively assess traumatic reactions in autistic youth.

# <u>Recent articles of interest: Diagnosis</u>



Katherine E. Reuben, Shannon Self-Brown & Erin Vinoski Thomas

Although many autistic adults show high posttraumatic stress, PTSD is underdiagnosed in this population. This study aims to examine correlates of autistic adults screening positive for PTSD (PTSD +) and predictors of a professional PTSD diagnosis (Diagnosis +) in the PTSD + subgroup.

Self-identified autistic adults (N = 677) completed an online survey on their demographic characteristics, mental health symptoms, and trauma history. T tests and chi-squares were used to compare subgroups, and logistic regression was used to predict diagnosis status.

PTSD + participants were less likely to be employed or to identify as cisgender men, had more mental health symptoms and worse functional impairment, and had experienced a higher number of traumas and more interpersonal trauma. The same was true for Diagnosis + participants, who were also older and more likely to have a marginalized racial/ethnic identity. Among participants who were PTSD +, older age, being a woman or gender minority, being unemployed or on disability, having increased posttraumatic stress, having more co-occurring conditions, and having lower functional impairment predicted being Diagnosis +. The final model explained 35% of variance in diagnosis.

PTSD is associated with significant impairment in autistic adults, but it often goes unrecognized. In particular, autistic cisgender men might be underdiagnosed with PTSD because of gendered stereotypes. High functional impairment may also increase barriers to obtaining an appropriate diagnosis. Future research should include participant treatment history as a potential factor. Clinicians should be aware of these potential signs of PTSD and diagnostic barriers when working with autistic clients.

# Recent articles of interest: Diagnosis

### Examining Rates of Traumatic Events and Posttraumatic Stress Disorder Symptoms Among Autistic Adults



Theresa Andrzejewski, Saily Gomez Batista 1, Tamara Abu-Ramadan, Kaitlyn E Breitenfeldt, Alison U Tassone, Ashley Winch, David C Rozek, Christina G McDonnell

Autistic adults experience high rates of traumatic events and posttraumatic stress disorder (PTSD) symptoms. However, less is known about how autistic adults experience (i.e., by directly experiencing, witnessing, and/or learning about) distinct types of traumatic events (e.g., social, nonsocial traumas). Little research has considered whether the four-factor structure of PTSD symptom domains (e.g., avoidance, intrusions, hypervigilance, negative mood/cognition) can be applied for autistic adults. Lastly, understanding how demographic factors (e.g., gender, race/ethnicity) relate to rates of traumatic events and symptoms among autistic adults is critical for understanding disparities relating to PTSD. Therefore, the current study aims to examine self-reported traumatic events and PTSD symptoms, and identify associations with demographic factors, among autistic adults.

Participants included 276 autistic adults and a nationally representative sample of 361 nonautistic adults who completed online measures, including the Life Events Checklist for DSM-5, Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5), Autism-Spectrum Quotient-Short, and Patient Health Questionnaire-4. Analyses focused on evaluating group differences in traumatic events and symptoms and considered associations with demographic factors.

Autistic adults reported significantly higher rates of directly experiencing, witnessing, and learning about traumatic events than nonautistic adults, including more interpersonal events (e.g., physical assault, sexual assault) and fewer transportation accidents than nonautistic adults. Autistic adults also reported significantly higher levels of all PTSD symptom clusters than nonautistic adults. A confirmatory factor analysis and follow-up invariance analyses of the PCL-5 revealed that the four-factor Diagnostic and Statistical Manual of Mental Health Disorders, Fifth Edition (DSM-5) PTSD symptom subscale structure was equivalent across groups of autistic and nonautistic adults.

Autistic adults experienced more traumatic events and PTSD symptoms overall, particularly more interpersonal traumas and hyperarousal and negative mood/cognition symptoms than nonautistic adults. Future research should examine outcomes of trauma exposure, identify protective factors, and examine efficacy of trauma-focused treatments for autistic individuals, in partnership with autistic adults.

# Autism and attachment disorders – how do we tell the difference?

Claire Davidson, Heather Moran & Helen Minnis



Clinicians assessing children with autism are sometimes faced with a dilemma, especially if there is a definite or suspected history of abuse or neglect: is this autism or attachment disorder?

This is important because the attachment disorders (reactive attachment disorder and disinhibited social engagement disorder) are thought to be caused by abuse or neglect, whereas autism is not.

We discuss the Coventry Grid, a clinical tool aiming to aid differentiation between autism and attachment disorders. We examine the small body of empirical studies focusing on this differential diagnosis and find that the Coventry Grid can be regarded as an evidence-based tool.

We also discuss preliminary findings regarding a relatively unstructured observational method involving two assessors who engage the child in jokes and playful social dilemmas, which might help clinicians elicit the information required to complete the Coventry Grid.

### Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events



Freya Rumball, Francesca Happé & Nick Grey

Research to date suggests that individuals with autistic spectrum disorder (ASD) may be at increased risk of developing post-traumatic stress disorder (PTSD) following exposure to traumatic life events. It has been posited that characteristics of ASD may affect perceptions of trauma, with a wider range of life events acting as possible catalysts for PTSD development. This study set out to explore the nature of "trauma" for adults with ASD and the rates of self-reported PTSD symptomatology following DSM-5 and non-DSM-5 traumas-the latter being defined as those that would not meet the standard DSM-5 PTSD trauma Criterion A.

Fifty-nine adults with ASD who reported exposure to traumatic events took part in the study, which involved completing a series of online questionnaires. Thirty-three individuals reported experiencing a "DSM-5" traumatic event (i.e., an event meeting DSM-5 PTSD Criterion A) and 35 reported a "non-DSM-5" traumautic event.

Trauma-exposed ASD adults were found to be at increased risk of PTSD development, compared to previous general population statistics, with PTSD symptom scores crossing thresholds suggestive of probable PTSD diagnosis for more than 40% of ASD individuals following DSM-5 or non-DSM-5 traumas.

A broader range of life events appear to be experienced as traumatic and may act as a catalyst for PTSD development in adults with ASD. Assessment of trauma and PTSD symptomatology should consider possible non-DSM-5 traumas in this population, and PTSD diagnosis and treatment should not be withheld simply due to the atypicality of the experienced traumatic event.

# The comorbidity between autism spectrum disorder and post-traumatic stress disorder is mediated by brooding rumination

Ofer Golan, Nirit Haruvi-Lamdan, Nathaniel Laor & Danny Horesh



Lay abstract

Autism spectrum disorder is a neurodevelopmental condition characterized by social communication difficulties and restricted repetitive behaviors. Individuals with autism spectrum disorder are often diagnosed with other psychiatric conditions, including attention deficit hyperactivity disorder, anxiety, and depression. However, research on post-traumatic stress disorder among individuals with autism spectrum disorder is scarce. Nonetheless, studies have shown that those with autism spectrum disorder may face an increased risk of exposure to traumatic events. Separate lines of research in autism spectrum disorder and post-traumatic stress disorder have shown that the two may share several vulnerability factors. One of those is ruminative thinking, that is, one's tendency to re-hash thoughts and ideas, in a repetitive manner.

This article examined the role of two rumination types as potential factors connecting autism spectrum disorder and post-traumatic stress disorder: brooding (continuously comparing one's current condition to one's desired condition) and reflection (an introspective effort to cognitively solve one's problems). A total of 34 adults with autism spectrum disorder (with no intellectual impairment) and 66 typically developing adults completed questionnaires assessing post-traumatic stress disorder symptoms and rumination.

The results showed increased post-traumatic stress disorder symptoms in adults with autism spectrum disorder, compared to typically developing adults. Brooding rumination was also higher among those with autism spectrum disorder. Finally, brooding, but not reflection, served as a mechanism connecting autism spectrum disorder and posttraumatic stress disorder, that is, those with autism spectrum disorder showed increased brooding, which in turn predicted more post-traumatic stress disorder symptoms.

This study has potential clinical implications. Rumination and cognitive inflexibility, which are common in autism spectrum disorder, could exacerbate post-traumatic symptoms among individuals with autism spectrum disorder who experience traumatic events. Interventions targeting brooding rumination and cognitive flexibility may assist in alleviating post-traumatic symptoms in individuals with autism spectrum disorder.

### Are PTSD and autistic traits related? An examination among typically developing Israeli adults



Nirit Haruvi-Lamdan, Shiri Lebendiger, Ofer Golan & Danny Horesh

Previous research indicates that individuals with Autism Spectrum Disorder (ASD) face an increased risk of experiencing traumatic events. Autistic Traits (AT), characteristic of ASD, are continuously distributed across the general population. Our main objective was to examine the association between AT and PTSD (Post Traumatic Stress Disorder), a topic rarely assessed before.

One hundred and three college students from 3 academic areas, previously found to be associated with different degrees of AT, completed self-report questionnaires tapping PTSD (the PCL-5; PTSD Checklist for DSM-5), AT (AQ; the Autism Spectrum Quotient), and traumatic life events.

AT were positively associated with all PTSD symptom clusters, except for avoidance. The association between imagination difficulties and PTSD was moderated by gender. Among participants meeting the PTSD cutoff, those with the highest AT levels reported a PTSD symptomatic profile with an increased dominance of hyper-arousal symptoms.

The AT-PTSD association reported here may be attributed to several factors, including increased victimization associated with AT, as well as shared vulnerability factors for both conditions, including impairments in social cognition. Further research is needed in order to understand the associations between these two conditions, considering gender differences, and possible shared underlying mechanisms.

### Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored cooccurrence of conditions



Nirit Haruvi-Lamdan, Danny Horesh, Shani Zohar, Meital Kraus and Ofer Golan

People with Autism Spectrum Disorder show an increased risk of experiencing traumatic events, particularly social victimization. However, Autism Spectrum Disorder and Post-Traumatic Stress Disorder co-occurrence was hardly studied. We examined exposure to traumatic life events and Post-Traumatic Stress Disorder symptoms in adults with Autism Spectrum Disorder vs typical adults.

Two groups took part in this study: Twenty-five adults with Autism Spectrum Disorder and 25 typical adults of similar age and male to female ratio. Participants completed questionnaires on potentially traumatic life events of social and nonsocial nature, as well as on Post-Traumatic Stress Disorder symptoms related to their most distressing event. Participants also filled out an autism traits questionnaire.

Results showed a higher Post-Traumatic Stress Disorder rate in the Autism Spectrum Disorder group (32%) compared with the typical group (4%). Individuals with Autism Spectrum Disorder reported more Post-Traumatic Stress Disorder symptoms, particularly re-experiencing and increased physiological arousal, compared with typical adults, although the latter was elevated only in females with Autism Spectrum Disorder. Participants with Autism Spectrum Disorder, especially females, reported more negative life events, particularly social events, than typical adults. Sixty percent of Autism Spectrum Disorder participants, but only 20% of typical participants, chose a social event as their most distressing event.

Individuals with Autism Spectrum Disorder who were also suspected as having Post-Traumatic Stress Disorder (based on their questionnaires) presented poorer social skills compared with those with Autism Spectrum Disorder alone. Results indicate that individuals with Autism Spectrum Disorder are more susceptible to trauma and Post-Traumatic Stress Disorder, particularly due to social stressors. Females with Autism Spectrum Disorder may be especially vulnerable to Post-Traumatic Stress Disorder. Autistic masking refers to some autistic individuals' tendency to hide, suppress, or camouflage their autistic traits, autistic identity, or autism diagnosis. Autistic masking also may include unconscious or conscious attempts to mimic the behavioral, cognitive, or sensory styles of nonautistic neurotypical people and to suppress natural forms of autistic behavior, cognition, and reactions to sensory experiences. Since autistic people are a stigmatized minority in many neurotypical dominated societies, passing as nonautistic through autistic masking may be an attempt to avoid autism stigma and a reaction to previous interpersonal trauma. Increased autistic masking behaviors are associated with reports of increased depression, anxiety, burnout, and exhaustion in autistic people, and thus, exploring the roots and impact of autistic masking is an important mental health topic.

This study investigated the relationships between autistic masking and depression, anxiety, gender identity, sexual orientation, interpersonal trauma, self-esteem, authenticity, and autistic community involvement. Participants were autistic adults (n = 342) recruited through autistic social media groups.

This study found that higher self-reported autistic masking behaviors were associated with higher reports of past interpersonal trauma, greater anxiety and depression symptoms, lower self-esteem, lower authenticity, and lower participation within the autistic community. Autistic masking was not associated with gender identity or sexual orientation.

The results of this study highlight the relationship between autistic masking and past interpersonal trauma, finding that autistic masking behavior is associated with mental health, self-esteem, and authenticity risks for autistic adults. We call into question the teaching of autistic masking strategies in therapies and education programs for autistic people based on the negative associations with autistic masking presented in this study and other research in this field.

# Trauma Assessment Measures

**Note:** Currently, there exists no validated measures for the diagnostic assessment of trauma symptoms in autistic people. In consideration of this current limitation, several tools for the assessment of PTSD, CPTSD and other trauma presentations, validated in general population samples, are signposted.

### **INTERNATIONAL TRAUMA QUESTIONNAIRE**

"The **International Trauma Questionnaire** (ITQ) is a brief, simply worded measure, focusing only on the core features of PTSD and CPTSD, and employs straightforward diagnostic rules. The ITQ was developed to be consistent with the organizing principles of the ICD-11, as set forth by the World Health Organization, which are to maximize clinical utility and ensure

international applicability through a focus on the core symptoms of a given disorder."

The full version of the ITQ can be freely accessed at:

https://www.traumameasuresglobal.com/itq

	International	Trauma	Questionnaire
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Instructions: Please identify the experience that troubles you most and answer the questions in relation to this experience.

Brief description of the experience

When did the experience occur? (circle one)

- less than 6 months ago
- b. 6 to 12 months ago
- c. 1 to 5 years ago
- d. 5 to 10 years ago
- e. 10 to 20 years ago
- f. more than 20 years ago

Below are a number of problems that people sometimes report in response to traumatic or stressful life events. Please read each item carefully, then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
P1. Having upsetting dreams that replay part of the experience or are clearly related to the experience?	0	1	2	3	4
P2. Having powerful images or memories that sometimes come into your mind in which you feel the experience is happening again in the here and now?	0	1	2	3	4
P3. Avoiding internal reminders of the experience (for example, thoughts, feelings, or physical sensations)?	0	1	2	3	4
P4. Avoiding external reminders of the experience (for example, people, places, conversations, objects, activities, or situations)?	0	1	2	3	4
P5. Being "super-alert", watchful, or on guard?	0	1	2	3	4
P6. Feeling jumpy or easily startled?	0	1	2	3	4
In the past month have the above problems:					
P7. Affected your relationships or social life?	0	1	2	3	4
P8. Affected your work or ability to work?	0	1	2	3	4
P9. Affected any other important part of your life such as parenting, or school or college work, or other important activities?	0	1	2	3	4



#### **INTERNATIONAL TRAUMA QUESTIONNAIRE - CHILD AND ADOLESCENT VERSION**

"The International Trauma Questionnaire Child and Adolescent Version (ITQ-CA) is a brief, simply-worded measure of PTSD and CPTSD symptoms for use with people aged 7 to 17 years. As with the International Trauma Questionnaire, the ITQ-CA was developed to be consistent with the organizing principles of the ICD-11, as set forth by the WHO, which are to

maximize clinical utility and ensure international applicability through a focus on the core symptoms of a given disorder"

The full version of the ITQ-CA can be freely accessed at:

https://www.traumameasuresglobal.com/itqca

International Trauma Questionnaire – Child and Adolescent Version (ITQ-CA) Ages 7 - 17 years

After filling out the events form, which event is bothering you the most now?

Below are problems people can have after an upsetting or a stressful event. Thinking about that event, Circle 0, 1, 2, 3 or 4 for <u>how much</u> the following things have bothered you in the <u>past month</u>

0 = Never / 1 = A little bit / 2 = Sometimes / 3 = A lot / 4 = Almost Always

	Never	A little Bit	Some times	A lot	Almost always
1. Bad dreams reminding me of what happened.	0	1	2	3	4
2. Pictures in my head of what happened. Feels like it is happening right now.	0	1	2	3	4
3. Trying not to think about what happened. Or to not have feelings about it.	0	1	2	3	4
<ol> <li>Staying away from anything that reminds me of what happened (people, places, things, situations, talks).</li> </ol>	0	1	2	3	4
5. Being overly careful (checking to see who is around me).	0	1	2	3	4
6. Being jumpy.	0	1	2	3	4

Please mark yes or no whether the above problems interfered with:

	YES	NO
Getting along with friends		
Getting along with family		
Your school work		
Anything else that is important to you (hobbies, other relationships)		
Your general happiness		

	Never	A little Bit	Some times	A lot	Almost always
7. Having trouble calming down when I am upset (angry, scared or sad).	0	1	2	3	4
8. Not being able to have any feelings or feeling empty inside.	0	1	2	3	4



"The International Trauma Exposure Measure (ITEM) is a checklist developed to measure exposure to several traumatic life events in a manner consistent with the definition of trauma exposure in the 11th version of the International Classification of Diseases.

The ITEM measures exposure to 21 different traumatic life events across different developmental periods: childhood, adolescence, and adulthood"

The full version of the ITEM can be freely accessed at:

https://www.traumameasuresglobal.com/item

#### International Trauma Exposure Measure

**Instructions**: We are interested in knowing if you experienced any of the following traumatic life events during different periods of your life. Please read each description and indicate if it occurred during childhood, adolescence, and/or adulthood.

		Die	l this event happer	1.000
		before or	during your	after your time
		during your	time in	in secondary
		time in primary	secondary	school
		school	school	(after the age of
		(up to age 12)	(between ages	18)
			13-18)	
1.	You were diagnosed with a life-			
	threatening illness.			
2.	Someone close to you died in an			
	awful manner.			
3.	Someone close to you was diagnosed			
	with a life-threatening illness or			
	experienced a life-threatening			
	accident.			
4.	Someone threatened your life with a			
	weapon (knife, gun, bomb etc.)			
5.	You were physically assaulted			
	(punched, kicked, slapped, mugged,			
	robbed etc.) by a parent or			
	guardian.			
6.	You were physically assaulted			
	(punched, kicked, slapped, mugged,			
	robbed etc.) by someone other than			
	a parent or guardian.			
7.	You were sexually assaulted (rape,			
	attempted rape, or forced sex acts) by			
	a parent or guardian.			
8.	You were sexually assaulted (rape,			
	attempted rape, or forced sex acts) $\mathbf{b}\mathbf{y}$			
	someone other than a parent or			
	guardian.			
9.	You were sexually harassed (received			
	other types of unwanted sexualized			
	comments or behaviours).			
10.	You were exposed to war or combat			
	(as a soldier or as a civilian).			
11.	You were held captive and/or			
	tortured.			



#### INTERNATIONAL ADJUSTMENT DISORDER QUESTIONNAIRE

""The International Adjustment Disorder Questionnaire (IADQ) is a brief, simply-worded measure, focusing only on the core features of Adjustment Disorder, and employs straightforward diagnostic rules. The IADQ was developed to be consistent with the organizing principles of the ICD-11, as set

forth by the World Health Organization, which are to maximize clinical utility and ensure international applicability through a focus on the core symptoms of a given disorder."

The full version of the IADQ can be freely accessed at:

https://www.traumameasuresglobal.com/iadq

#### THE INTERNATIONAL ADJUSTMENT DISORDER QUESTIONNAIRE (IADQ)

Below is a list of stressful life events that you may have experienced. Please indicate <u>any of the following</u> events that are currently applicable to you:

n cı	irrently experiencing	Yes
1.	Financial problems (e.g., difficulty paying bills, being in debt).	
2.	Work problems (e.g., unemployment, redundancy, retirement, problems/conflicts	
	with colleagues, change of job role).	
3.	Educational problems (e.g., difficulty with course work, deadline pressure).	
4.	Housing problems (e.g., stressful home move, difficulty finding a secure residence,	
	lack of secure residence).	
5.	Relationship problems (e.g., break-up, sparation or divorce, conflict with family or	
	friends, intimacy problems).	
6.	My own health problems (e.g., illness onset or deterioration, medication issues,	
	injury or disability).	
7.	A loved one's health problems (e.g., illness onset or deterioration, medication	
	issues, injury or disability).	
8.	Caregiving problems (e.g., emotional stress, time demands).	
9.	Some other problem not mentioned above.	

This section should be completed only if you have answered 'Yes' to at least one of the events above. The following statements reflect problem that people sometimes experience in relation to a stressful life event(s). Thinking about the stressful life event(s) you identified above, please indicate **how much you have been bothered by each of the following problems in the past month**:

	Not at all	A little bit	Moderately	Quite a bit	Extremely
10. I worry a lot more since the stressful event(s).	0	1	2	3	4



#### **INTERNATIONAL PROLONGED GRIEF DISORDER SCALE**

"The WHO ICD-11 Working Group on Disorders specifically associated with stress developed clinical guidelines for the prolonged grief disorder (PGD) (Maercker et al. 2013). These guidelines are structured following the remit of the new ICD-11 to provide: a narrative definition, to include cultural features, to provide core symptoms and be easy to use in the clinical setting (Reed 2010).

The IPGDS seeks to operationalize the ICD-11 definition of PGD in a self-report questionnaire format. The threshold for clinical diagnosis of PGD is currently under investigation."

The full version of the IPGDS can be freely accessed at:

https://www.traumameasuresglobal.com/ipdgs



International Prolonged Grief Disorder Scale (IPGDS) Killikelly, Stelzer, Zhou and Maercker (2019 in preparation)

**Instruction:** Using the scale below, please choose the answer that best describes how you have been feeling over the **past week**.

#### Standard Scale

	Not at all (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)
1. I am longing or yearning for the deceased.	1	2	3	4	5
<ol> <li>I am preoccupied with thoughts about the deceased or circumstances of the death.</li> </ol>	1	2	3	4	5
<ol> <li>I have intense feelings of sorrow, related to the deceased.</li> </ol>	1	2	3	4	5
<ol> <li>I feel guilty about the death or circumstances surrounding the death.</li> </ol>	1	2	3	4	5
5. I am angry over the loss.	1	2	3	4	5
<ol> <li>I try to avoid reminders of the deceased or the death as much as possible (e.g., pictures, memories).</li> </ol>	1	2	3	4	5
<ol> <li>I blame others or the circumstances for the death (e.g., a higher power).</li> </ol>	1	2	3	4	5
<ol> <li>I have trouble or just don't want to accept the loss.</li> </ol>	1	2	3	4	5
9. I feel that I lost a part of myself.	1	2	3	4	5
<ol> <li>I have trouble or have no desire to experience joy or satisfaction.</li> </ol>	1	2	3	4	5
11. I feel emotionally numb.	1	2	3	4	5
<ol> <li>I have difficulties engaging in activities I enjoyed prior to the death.</li> </ol>	1	2	3	4	5
<ol> <li>Grief significantly interferes with my ability to work, socialize or function in everyday life.</li> </ol>	1	2	3	4	5
14. My grief would be considered worse (e.g., more intense, severe and/or of longer duration) than for others from my community or culture	1	2	3	4	5

15. When did the loss occur? (circle one)

a. less than 6 months ago

b. 6 to 12 months ago

c. 1 to 5 years ago

d. 5 to 10 years ago

- e. 10 to 20 years ago
- f. more than 20 years ago



## <u> Trauma Assessment Measures - Intellectual Disabilities</u>

**Note:** Several tools have been developed for the assessment of trauma symptoms in people with intellectual disabilities, as a comorbidity that may present with autism.

### LANCASTER AND NORTHGATE TRAUMA SCALES

The Lancaster and Northgate Trauma Scales (LANTS) is 'a self-report and an informant measure of the effects of traumatic life events on people with intellectual disabilities'. The measure utilises visual scales to increase accessibility. Three initial screening questions are included in the measure to check validity and comprehension prior to completion of the full measure.

Information about the LANTS and its development can be accessed at:

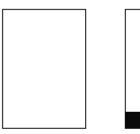
https://view.officeapps.live.com/op/view.aspx? src=https%3A%2F%2Fnrl.northumbria.ac.uk%2Fid%2Feprint%2F10667%2F1 %2FLANTS-ReliabilityandValidityPaper-SUBMITTED(March2011).doc&wdOrigin=BROWSELINK\_



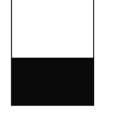
### 2. I feel down e.g. I feel sad, I cry a lot, and don't enjoy

things.

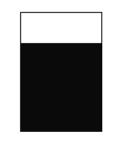
No





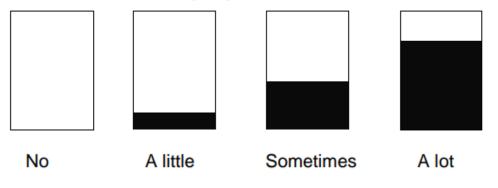


Sometimes



A lot

3. Worries have been going round and round in my head.



### **INTERNATIONAL TRAUMA QUESTIONNAIRE - INTELLECTUAL DISABILITIES**

'An initial and preliminary 23-item version of the International Trauma Questionnaire (ITQ: Cloitre, Roberts, Bisson, & Brewin, 2015) operationalized the narrative descriptions of Posttraumatic Stress Disorder (PTSD) and Complex PTSD (CPTSD), as defined in the 11th version of the International Classification of Diseases (ICD-11). This is an adapted version for people with intellectual and other developmental disabilities. It was developed with an advisory group of people with intellectual disabilities and autism. This version should be administered as a semi-structured interview'.

The Trauma Information Form (Hall, Jobson and Langdon, 2014). should first be completed to ensure that the respondent understands what is meant by the word "trauma", and the traumatic event that you are asking them about. The TIF can be downloaded from the following link:

http://wrap.warwick.ac.uk/132892/

The full version of the ITQ-ID can be freely accessed at:

#### https://www.traumameasuresglobal.com/itq

<u> International Trauma Questionnaire – Intellectual Disabilities</u>								
<b>Instructions:</b> Please identify the experience that troubles the person most by using the Trauma Information Form, administered as a semi-structured interview. Refer to the pictorial prompt sheet as required.								
Record the trauma here:								
<ul> <li>When did the experience occur? (circle one)</li> <li>a. less than 6 months ago</li> <li>b. 6 to 12 months ago</li> <li>c. 1 to 5 years ago</li> <li>d. 5 to 10 years ago</li> <li>e. 10 to 20 years ago</li> <li>f. more than 20 years ago</li> </ul>								
"I'm going to read some problems that people who have had trauma struggle with; can you tell me whether you have had any of these problems in the last month by saying yes, sometimes, or no when I ask the question?"	No	Sometimes	Yes					
1. Are you having nightmares about the bad things that happened to you?	0	1	2					
2. Are you having memories about the bad things which pop into your head and scare you?	0	1	2					
3. Have you tried not to think about the bad things?	0	1	2					
4. Have you tried not to go to places that remind you of the bad things that happened?	0	1	2					
5. Have you felt really scared a lot of the time?	0	1	2					
6. Have you felt really jumpy?	0	1	2					
"In the last month, have the things we just talked abo	ut:"							

7. Meant that you fell out with your friends?	0	1	2	
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# INTERESTED IN TAKING PART IN RESEARCH ON AUTISM SPECTRUM DISORDER?

### Researcher: Verity Chester, University of East Anglia

Research Supervisor: Dr Karen Bunning, University of East Anglia

We are looking for people to take part in a study "Social Problem Solving in Autism Spectrum Disorder and Behaviour" (IRAS Project ID: 174027)



- To be eligible to participate, you need to be:
  - Over 18
  - Have a diagnosis of Autism Spectrum Disorder or Asperger Syndrome.
- If you have a criminal record, including (a history of arrests, cautions or convictions), unfortunately you cannot participate.
- The research involves completing a number of questionnaires and computer tasks. A relative, carer or staff member who knows you will also be asked to complete a questionnaire about your emotional health and behaviour.

If you would like to participate, have any questions or would like to discuss the project further. Verity can be contacted by email at <u>v.chester@uea.ac.uk</u>.



# CALL FOR EXPRESSION OF INTEREST IN TRAUMA ASSESSMENT VALIDATION PROJECT



Currently, there exists no validated measures for the assessment of trauma symptoms in autistic people.



Consequently, clinicians are required to rely on tools developed for use in general population samples, which may not be appropriate for autistic people.

### What are we doing about this?

The Centre for Developmental and Complex Trauma (CDCT) are at the early stages of developing a validation study of the International Trauma Questionnaire (ITQ; Cloitre et al., 2018) for autistic people.

The project will look to identify whether the ITQ is an appropriate tool for identifying trauma symptoms in this population.

To support the development and delivery of this project, we are looking to hear from healthcare professionals and experts by experience who would be interested in getting involved.

### Interested?

Simply scan the QR (or head to: https://forms.office.com/e/YJrWSMWkn2) to complete the expression of interest form.









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