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Understanding and preventing suicide in partnership with autistic people

Dr. Sarah Cassidy
@MHAutism




- **Recent research showed that the autism community use a range of terms to describe themselves:**
 - Autistic
 - Aspie
 - On the spectrum
 - Person with autism
- **On the whole, ‘autistic person’ was most preferred by the autism community, and ‘person with autism’ was preferred by professionals (Kenny et al. 2016)**



What brings us here today



Research Article |  Full Access |

Mortality and cause of death of Australians on the autism spectrum

Ye In (Jane) Hwang, Preeyaporn Srasuebkul, Kitty-Rose Foley, Samuel Arnold, Julian N. Trollor



Research Article |  Open Access |  

A 20-year study of suicide death in a statewide autism population


Anne V. Kirby, Amanda V. Bakian, Yue Zhang, Deborah A. Bilder, Brooks R. Keeshin, Hilary Coon



What brings us here today

Correspondence

Understanding and prevention of suicide in autism

Sarah Cassidy , Jacqui Rodgers

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Clinical Psychology Review

Volume 62, June 2018, Pages 56-70



Review

Measurement properties of tools used to assess suicidality in autistic and general population adults: A systematic review

Cassidy, S.A. ^{a, b, c, d, e}, Bradley, L. ^a, Bowen, E. ^d, Wigham, S. ^c, Rodgers, J. ^c

Growing number of ‘counting’ studies

Not enough about *Why*
No validated tools

What should the priorities be?



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Autism Community “Top 10” Priorities

In association with

AUTISTICA

Building brighter futures through autism research



James
Lind
Alliance

Priority Setting Partnerships

Autism Community Priorities

What barriers do autistic people experience when seeking help which may put them at greater risk of suicide?

What are the risk and protective factors for suicide in autism across the lifespan?

To what extent are autistic people not believed about the severity of their distress?

How can we further understand suicide where mental health is not a factor, across the lifespan?

How can we best identify and assess suicidal thoughts and suicidal behaviours in autistic people, in research and clinical practice?

How should interventions be adapted for autistic people and individual presentations?

What is the experience of suicidality in autistic people? Is this experience different to the general population?

How do autistic people seek help when they are in a crisis?

How well do existing models of understanding suicide apply to autistic people?

What is the impact of poor sleep on suicide risk in autistic people, and how can this be measured?



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Assessment / Measurement

Evidence for measurement properties of tools in
autistic people

Adapting suicidality assessment in partnership
with autistic adults



Challenge of Measurement in Autism

- **Alexythymia:** under reporting of suicidality?
- **Theory of Mind, literal interpretation:** over reporting of suicidal feelings?
- **Unique aspects of suicidality in Autism?**

**Involve autistic community in development
of Qs ...**

Review

Measurement properties of tools used to assess suicidality in autistic and general population adults: A systematic review

Cassidy S.A.^{a,b,c,*}, Bradley L.^a, Bowen E.^d, Wigham S.^c, Rodgers J.^c

^a School of Psychology, University of Nottingham, UK

^b Centre for Innovative Research across the Life Course, Coventry University, UK

^c Institute of Neuroscience, Newcastle University, UK

^d Centre for Violence Prevention, Worcester University, UK



Collated evidence of measurement properties for each tool.

Measure	Version	Measurement properties							Interpretability	
		Internal Consistency	Reliability	Content validity	Structural validity	Hypothesis testing	Criterion validity	Responsiveness	Cross-cultural validity	Differences in scores between groups
SBQ-R	V2	+++			+++	+	++			Y
BSS	—	+++*	?		+++	+/-	+/-		++	Y
C-SSRS	Self-report					—	+/-			
	Interview	+/-	+/-		+++	++	+++	++	+	
SITBI	—		+/-			—			?	

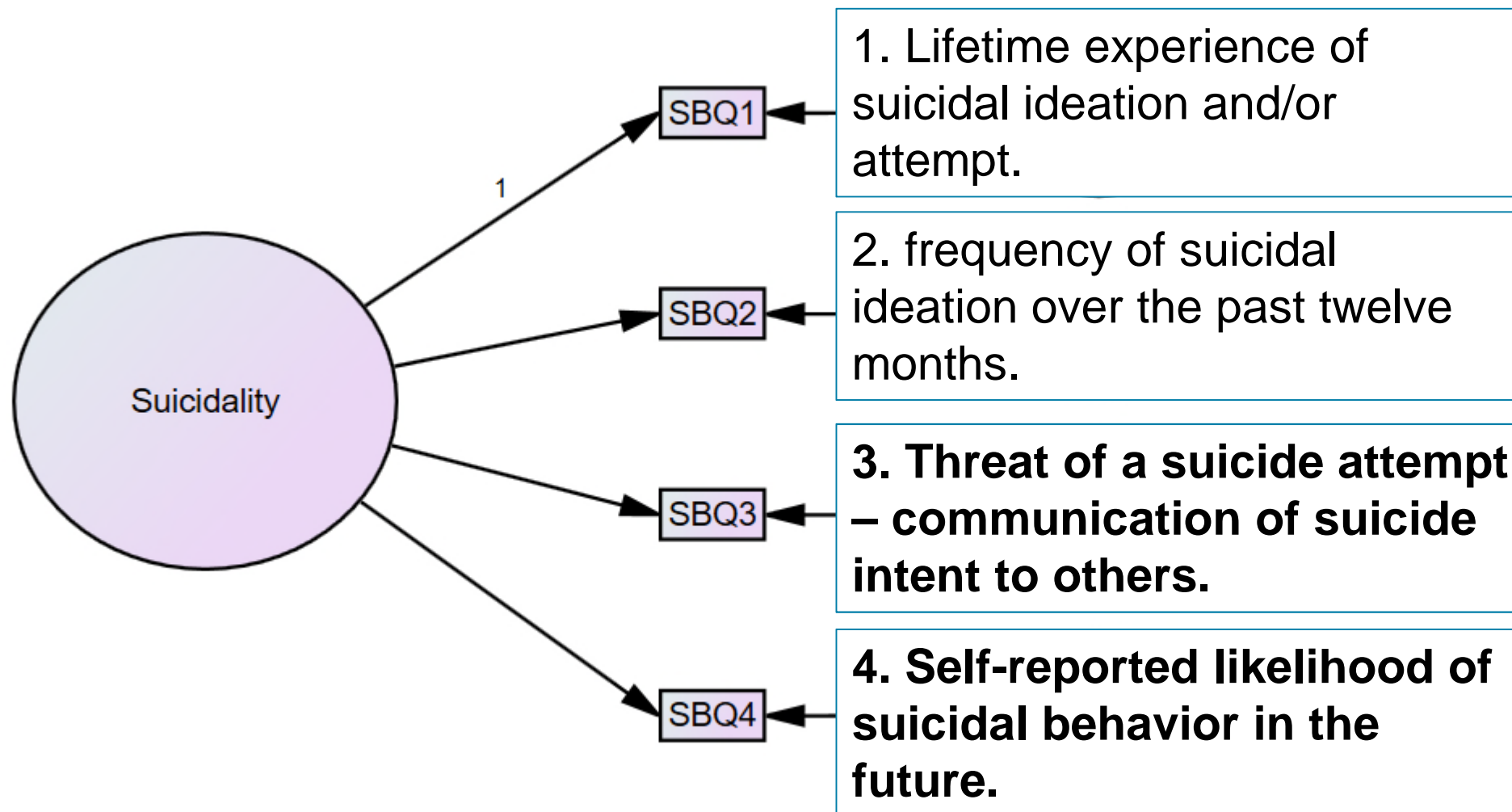
- No suicidality assessment tools developed or validated in autistic adults
- SBQ-R could be useful candidate tool to adapt for research



Research Questions

- Does the SBQ-R capture the same thing in autistic and non-autistic adults?
- Do autistic adults interpret the SBQ-R questions as expected?
- If not, can we adapt the questions in partnership with autistic adults?
- Does this make the tool more appropriate for future suicide in autism research?

Does the SBQ-R capture the same thing?



Cassidy, S. A., Bradley, L., Bowen, E., Wigham, S., & Rodgers, J. (2018). Measurement properties of tools used to assess suicidality in autistic and general population adults: A systematic review. *Clinical Psychology Review*.



How do autistic adults interpret the SBQ-R items?

1. Have you ever thought about or attempted to kill yourself? (check one only)

- ☐ 1. Never
- ☐ 2. It was just a brief passing thought
- ☐ 3a. I have had a plan at least once to kill myself but did not try to do it
- ☐ 3b. I have had a plan at least once to kill myself and really wanted to die
- ☐ 4a. I have attempted to kill myself, but did not want to die
- ☐ 4b. I have attempted to kill myself, and really hoped to die

“Something missing” between a brief passing thought and plan.

2. How often have you thought about killing yourself in the past year? (check one only)

- ☐ 1. Never
- ☐ 2. Rarely (1 time)
- ☐ 3. Sometimes (2 times)
- ☐ 4. Often (3-4 times)
- ☐ 5. Very Often (5 or more times)

“Am I really bad?”

“Does not capture the intensity of the thought or the length or time”

3. Have you ever told someone that you were going to commit suicide, or that you might do it? (check one only)

- ☐ 1. No
- ☐ 2a. Yes, at one time, but did not really want to die
- ☐ 2b. Yes, at one time, and really wanted to die
- ☐ 3a. Yes, more than once, but did not want to do it
- ☐ 3b. Yes, more than once, and really wanted to do it

“Who would you tell?”

But an important question!

4. How likely is it that you will attempt suicide someday? (check one only)

- | | |
|--|---|
| <input type="checkbox"/> 0. Never | <input type="checkbox"/> 4. Likely |
| <input type="checkbox"/> 1. No chance at all | <input type="checkbox"/> 5. Rather likely |
| <input type="checkbox"/> 2. Rather unlikely | <input type="checkbox"/> 6. Very likely |
| <input type="checkbox"/> 3. Unlikely | |

“It’s a future question and you don’t know what’s going to happen”

Important, but “impossible to answer”



Adapting the SBQ-R with autistic adults

1. A) Have you ever thought about or attempted to end your life? *Tick one box only.*

- ☐ Never
- ☐ It was just a brief passing thought
- ☐ I have seriously thought about ending my life, but did not plan how or try to do it
- ☐ I have planned how to end my life, but did not try to do it
- ☐ I have attempted to end my life

2. How often on average have you experienced intense thoughts about ending your life in the past 12 months? *Tick one box only.*

Never	Less than once a month	Once a month	2-3 times a month	Once a week	2-6 times a week	1 or more times a day
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3. When you have intense thoughts about ending your life, how long per day does this typically last? *Tick one box only.*

Not Applicable	Less than 5 minutes	Less than 1 hour	1-4 hours	5-8 hours	More than 8 hours
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4. When you experience intense thoughts about ending your life, how likely are you to act on them? *Tick one box only.*

Not Applicable	No chance at all	Very Unlikely	Rather unlikely	Rather Likely	Very Likely
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5. A) Have you ever told anyone that you:

	Not Applicable.	No.	Yes, once.	Yes, more than once.
Were thinking about ending your life				
Were going to attempt to end your life				
Had attempted to end your life				

Added in a stage between a brief passing thought and a plan
Simplified language
Follow up Q's: impulsivity, plans, and access to means

Full range of frequency of suicidal thoughts captured in the past year
Capture perseverative thoughts

Made question a little less abstract.
~50% find the visual useful.

Include communication of intent and past attempts.
Simplified response options.
Follow up Qs: Who did you tell? Why have you never told anyone?



Is the adapted tool more appropriate?

- Evidence for capturing a similar construct in autistic and non-autistic adults
- Tool adapted in partnership with autistic people better for research involving BOTH autistic and non-autistic people!
- Tool is validated for use in research
- Brief assessment tools should not be used to inform treatment decisions – poor predictors of future suicide attempts (Quinlivan et al, 2019, 2017).

Card sort task for self-harm (CaTS)






Risk / Protective Factors

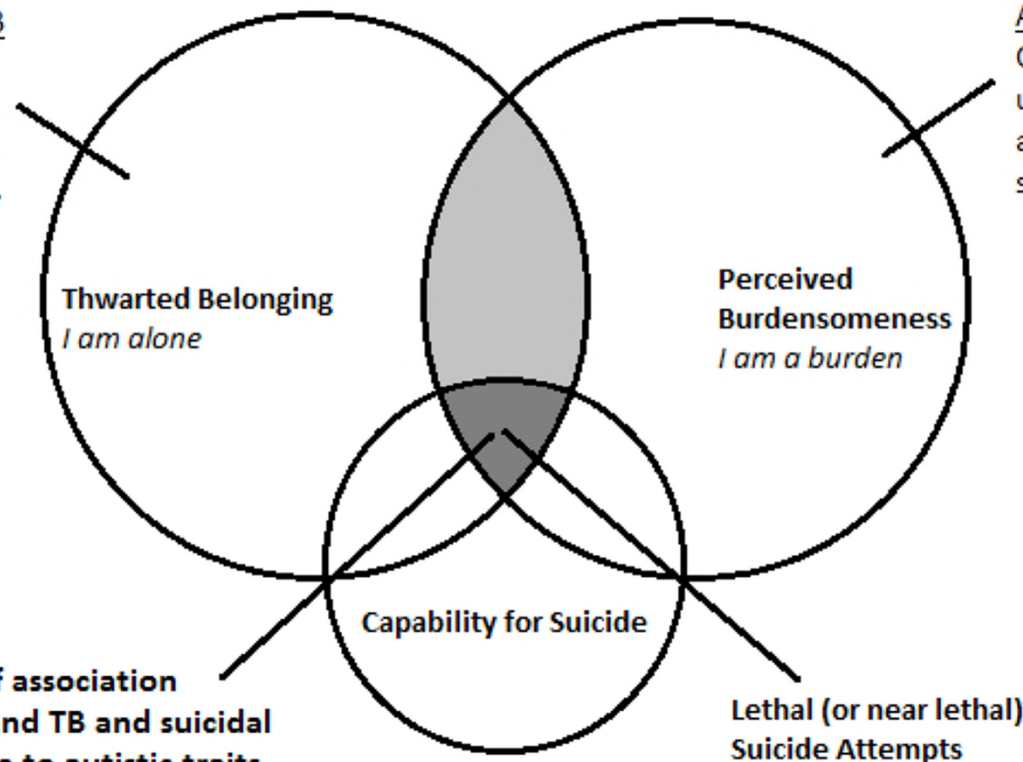
How applicable are existing models?

What risk markers may be unique or shared
between autism and the gen pop?

Are Autistic Traits Associated with Suicidality? A Test of the Interpersonal-Psychological Theory of Suicide in a Non-Clinical Young Adult Sample

M. K. Pelton and S. A. Cassidy 

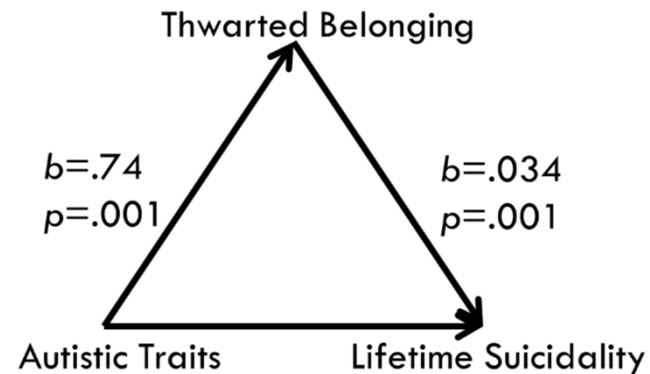
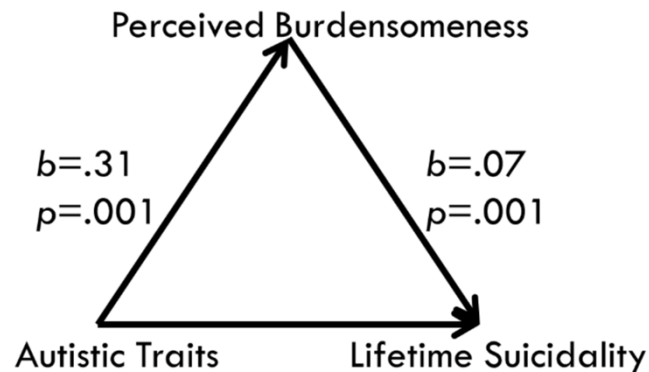
Autistic traits predict TB
Increased risk of social isolation, loneliness, difficulties establishing reciprocal relationships.





Results

- **163 General population young adults (18-30 years) completed online survey**



- **Autistic traits associated with lifetime suicidality, through thwarted belonging and perceived burden.**

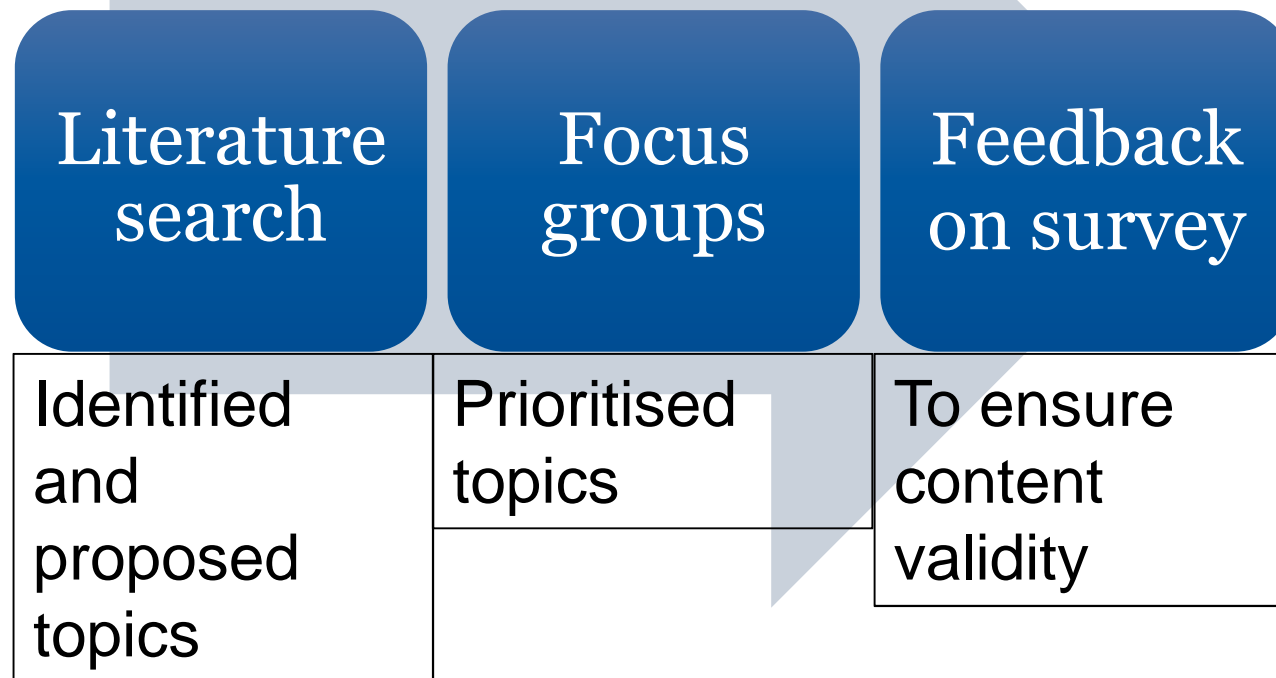


**Potential for IPTS to explain increased
suicidality in autism ...**

BUT, could it be expanded?

**Important to ask autistic people about their
experience**

- **Mental Health in Autism (MHAutism):**
Participatory research project to increase understanding of mental health, self-injury and suicidality in autism



RESEARCH

Open Access

Risk markers for suicidality in autistic adults



Sarah Cassidy^{1,2,3*}, Louise Bradley², Rebecca Shaw^{2,4} and Simon Baron-Cohen^{3,5}

Table 3 Hierarchical regression with diagnostic group (ASC vs. general population) predicting SBQ-R

	B	SE B	β
Step 1			
Constant	12.408	1.135	
Sex	-.635	.460	-.074
Age	-.070	.020	-.188*
Step 2			
Constant	13.591	1.382	
Employed	-.768	.395	-.090
Satisfaction with living arrangements	-.045	.008	-.280*
≥ 1 developmental condition	.827	.567	.066
Depression	2.856	.482	.339*
Anxiety	.898	.474	.110
Step 3			
Constant	8.918	1.630	
Diagnostic group	2.038	.408	.249*

Note: $R^2 = .041$ for step 1, $\Delta R^2 = .334$ for step 2, $\Delta R^2 = .045$ for step 3 ($p < .001$).

* $p < .001$. $N = 333$

Predictors of SBQ-R scores:

1. Autism diagnosis (4.5%)
2. Autistic traits in the gen pop (3.2%)

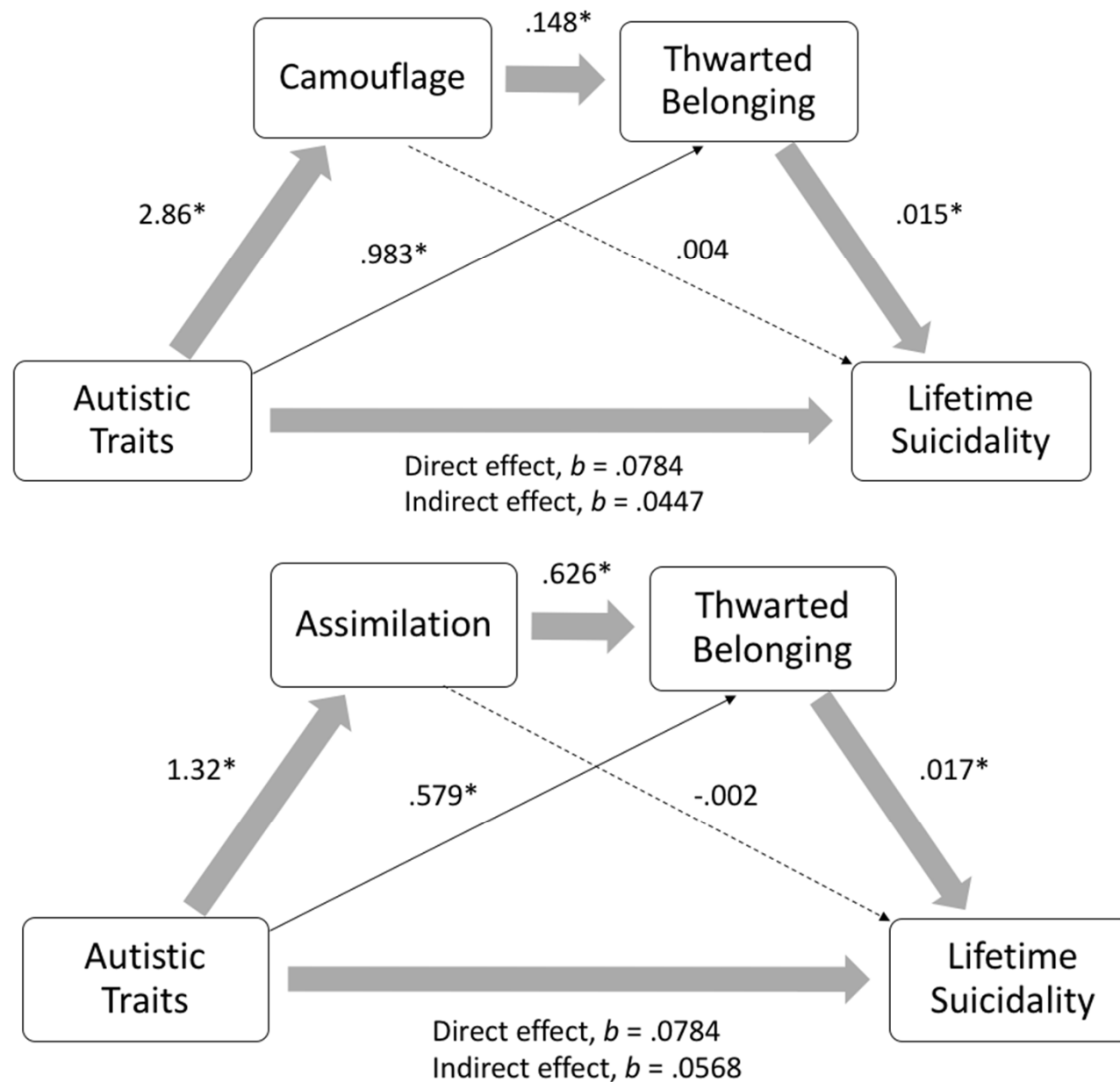
Autistic adults:

1. 'Camouflaging' (3.5%)
2. Unmet support needs (3.1%)
3. NSSI (4%)



Camouflaging, autistic traits and IPTS

- 160 undergraduate students (86.9% female)
- CAT-Q (Hull et al, 2019):
 - Compensation (for autism-related difficulties in social situations)
 - Assimilation (to fit in with others/not stand out from the crowd)
- Associated with poor mental health (Hull et al, 2019).
- **Do people with high autistic traits try to camouflage these traits to try and fit in, leading to feelings of thwarted belonging, and suicidality?**





The double empathy problem, camouflage, and the value of expertise from experience

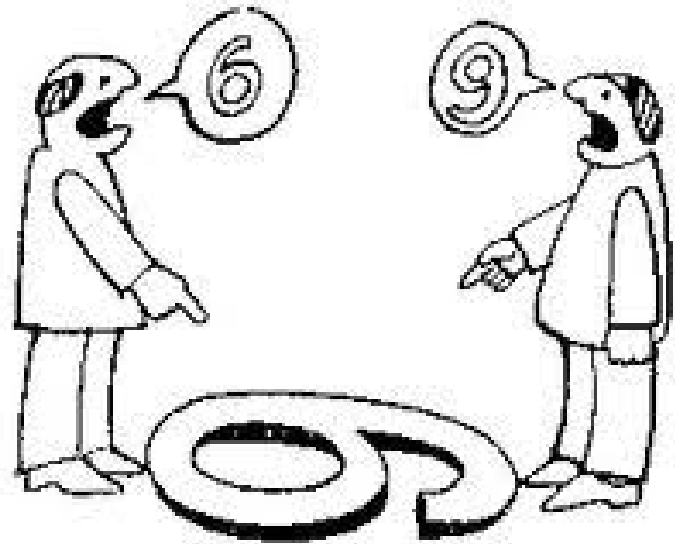
Peter Mitchell ^(a1), Sarah Cassidy ^(a1) and Elizabeth Sheppard ^(a1) 

DOI: <https://doi.org/10.1017/S0140525X18002212> Published online by Cambridge University Press: 23 July 2019

In response to: [Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism](#)

[Related commentaries \(32\)](#) [Author response](#)

- IPTS could have relevance to autism and autistic traits in explaining increased risk of suicidality in this group
- Important not to inadvertently encourage camouflaging autistic traits





Implications for Prevention

“What works, not what’s on offer”

‘People like me don’t get support’: Autistic adults’ experiences of support and treatment for mental health difficulties, self-injury and suicidality

Louise Camm-Crosbie¹, Louise Bradley¹, Rebecca Shaw²,
 Simon Baron-Cohen^{3,4} and Sarah Cassidy^{1,3,5} 

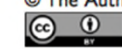

Autism
 1–11
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Table 4. Thematic table showing the overarching theme, three themes and eight sub-themes.

Tailored support is beneficial and desirable

‘People like me don’t get support’			Lack of understanding and knowledge			Well-being	
Dismissed for treatment or support because seen as ‘coping’	Support geared towards children	Long waiting lists and lack of funding	Obstacles to accessing and receiving treatment and support	Not believed or listened to	Not suited to my needs	Negative impacts	Positive and enabling



42%

**not understood,
listened to or
taken seriously
by practitioners**

"They ALWAYS treat me like I'm just a bit stressed [...] I was suicidal."

52%

**had negative
experiences**



26%

**denied mental
health services
as a direct result
of being autistic**

"As soon as my autism diagnosis was confirmed, I was kicked off the mental health waiting list."

40%

**believe there is
nothing out
there to help
them**



30%

**had problems
with inaccessible
services**

36%

**said practitioners
had inadequate
autism knowledge**

"I'm told that depression and anxiety is normal for me."

AMASE

Autistic Mutual Aid Society Edinburgh

**Helping autistic people
to help each other.**



Implications for prevention

- **Timely access to support – Autistic pathway needed**
- **Training developed in partnership with autistic people – otherwise unhelpful stereotypes can be reinforced**
- **Continuity of care, more sessions**
- **Sensory environments (quiet, natural light)**
- **Alternative access (other than phone, e.g. online, text or web based support)**
- **Adapted therapies in partnership with autistic people**



Overall Summary

- **Suicidal thoughts and behaviours in autism significantly higher than psychiatric groups**
- **Late diagnosed / undiagnosed adults without ID appear most at risk**
- **Increased vulnerability to known risk factors:**
 - Reduced sense of belonging, isolation
 - Difficulty accessing support and treatment for mental health conditions and suicidality
- **Suicidality in autism beyond co-morbidities:**
 - Camouflaging, social support?

**Access to appropriate treatment and support live saving,
but difficult to access ...**

Mental Health Autism: Dr. Louise Bradley, Dr. Rebecca Shaw, Heather Cogger-Ward, Autistic Steering Group.

Newcastle University: Dr. Jacqui Rodgers, Dr. Sarah Wigham, Dr. Magdalena Glod.

ARC and CLASS clinic: Prof. Simon Baron-Cohen, Dr. Carrie Allison, Dr. Paul Bradley, Dr. Janine Robinson, Meghan McHugh, Dr. Gareth Richards, Dr. Rebecca Kenny.

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