



Anxiety in Autistic People who Speak Few or No Words

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A lack of research

Approximately half of autistic people have intellectual disability

Despite this, most studies have excluded people with intellectual disability from research (82% of all studies, IQ>70)



Russell et al., 2019



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Mental Health research for those with the most complex needs



 **Clinical Psychology Review**
Volume 57, November 2017, Pages 32-44

Review

Measurement tools for mental health problems and mental well-being in people with severe or profound intellectual disabilities: A systematic review

Samantha Flynn ^a, Leen Vereenoghe ^b, Richard P. Hastings ^a, Dawn Adams ^c, Sally-Ann Cooper ^d, Nick Gore ^e, Chris Hatton ^f, Kerry Hood ^g, Andrew Jahoda ^d, Peter E. Langdon ^e, Rachel McNamara ^g, Chris Oliver ^h, Ashok Roy ⁱ, Vasiliki Totsika ^a, Jane Waite ^h

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<https://doi.org/10.1016/j.cpr.2017.08.006> [Get rights and content](#)

Open access **Research**

BMJ Open Interventions for mental health problems in children and adults with severe intellectual disabilities: a systematic review

Leen Vereenoghe,¹ Samantha Flynn,² Richard P Hastings,^{2,3} Dawn Adams,⁴ Umesh Chauhan,⁵ Sally-Ann Cooper,⁶ Nick Gore,⁷ Chris Hatton,⁸ Kerry Hood,⁹ Andrew Jahoda,⁶ Peter E Langdon,⁷ Rachel McNamara,⁹ Chris Oliver,¹⁰ Ashok Roy,¹¹ Vasiliki Totsika,^{3,12} Jane Waite¹³



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Impact of mental health difficulties



*"It's (anxiety) restricted his life, you know, he is **no longer able to go to a local school**, he has **harmd himself**, his **hands are all bitten**, he's erm, we **can't go even to see family**. We have to **very carefully plan** what we are going to do by way of holidays and things, we have **separate holidays** now and so yeah we have to plan, and we have to **plan his future as well**, and his future options are foremost in our minds."*

Edwards et al., 2022



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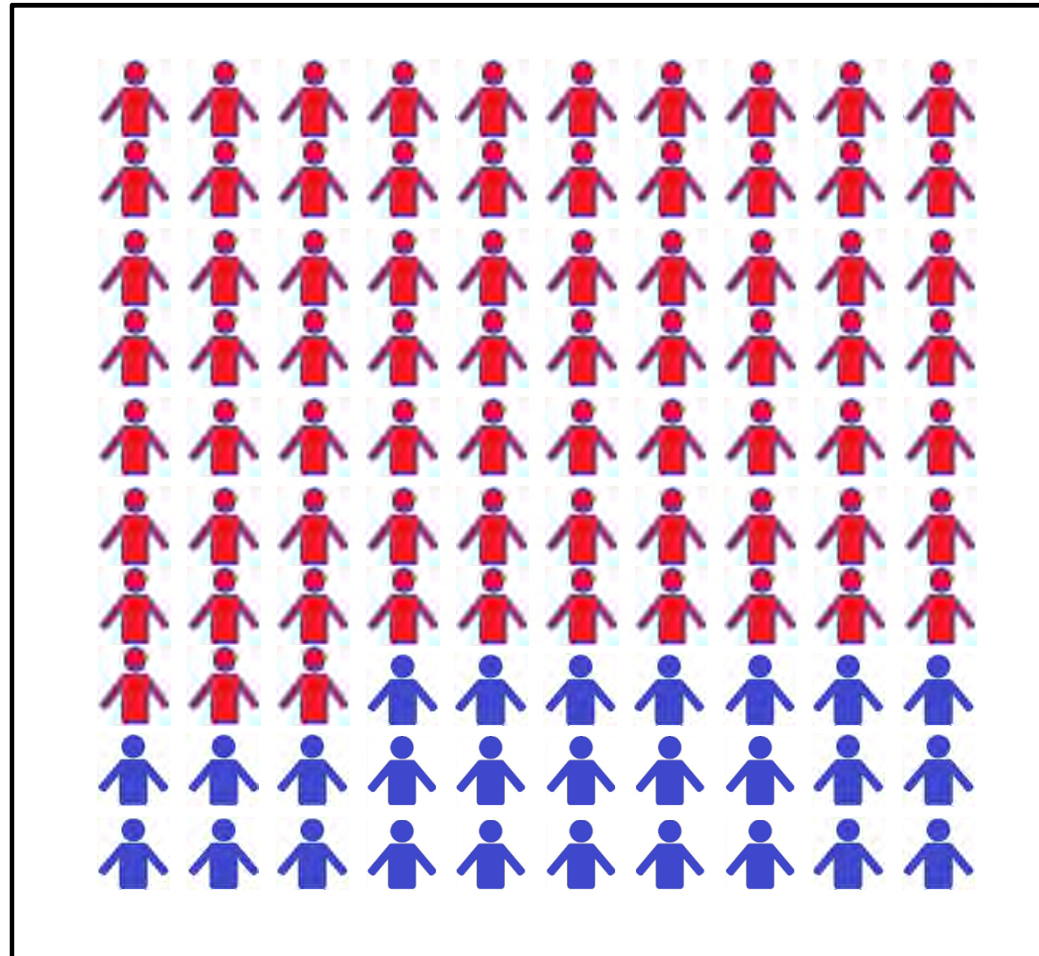
Autistic people often experience anxiety

Neurotypical
children

Children with an
intellectual
disability

Autistic children

Also highly prevalent in people with
genetic syndromes associated with
autistic characteristics (e.g. fragile-X
or Cornelia de Lange syndromes)



Mattila et al, 2010;
Simonoff et al, 2008;
Edwards et al., 2021



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Risk factors for mental health difficulties



Broad risk factors around the person

- Chronic poverty
- Boredom
- Loneliness
- Lack of opportunity to exert control over own life and the future
- Lack of meaningful friendships and relationships
- Stressful family circumstances
- Unemployment
- Debt
- Stigmatisation and bullying
- Being asked to complete tasks that are too difficult, leading to opportunities being removed



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Risk factors for mental health difficulties

49 research studies examining
cognitive ability (IQ)

18,430 autistic children

Higher anxiety scores in children
associated with higher IQ scores;
irrespective of design

However, only a relatively small
portion of variance in anxiety scores
was explained by IQ

There was a significant threat to validity. Measurement tools may not be fit for purpose with individuals with a diagnosis of severe to profound intellectual disability or who speak few or no words.

Mingins et al., 2020



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Risk factors for mental health difficulties



Person characteristics that increase risk

- Executive Functions differences (memory, flexibility, problem-solving, planning, predicting the future)
- Intolerance of uncertainty
- Sensory difference
- Health difficulties
- Poor sleep

Many of these
differences are
commonly
experienced by
autistic people

Hout et al., 2009; Jenkinson et al., 2020 ; Taylor & Knapp, 2003; Wigham et al., 2015; Zimmerman et al., 2017



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Risk factors for mental health difficulties

- N = 165 individuals (heterogeneous aetiology; including ASD, FXS, CdLS, AS)

Model
explained 62%
of the variance
in anxiety
scores

- **Health problems**
- **Intolerance of uncertainty**
- Auditory sensory processing differences

Consistent across three anxiety measurement tools



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Edwards, 2022

Historical beliefs: barriers to support



Autistic people with complex needs don't experience mental health difficulties

Mental health difficulties are just 'part of autism'

That sign/symptom/behaviour is not due to a mental health issue

There is nothing that can be done



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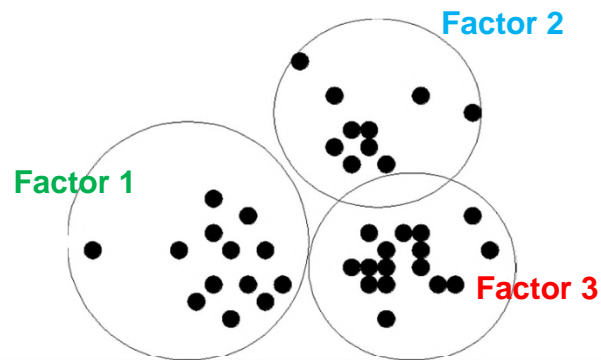
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Historical beliefs: barriers to support

Do anxiety and autism go hand in hand?

Evidence that anxiety can be differentiated from autism characteristics (Renno & Wood, 2013)

Anxiety symptom expression is different



“The difficulty with assessing anxious behaviour in children with autism....is that it may not even be clear to parents, teachers, clinicians, or researchers which specific behaviours are indicative of anxiety...the context becomes critical in evaluation of the function of the behaviour” (Moskowitz et al., 2013)



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Identifying signs of anxiety



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Identifying signs of anxiety

- Behavioural indicators of physical health difficulties (pain) overlapping with indicators of anxiety
- Aggression and self-injury could be learnt patterns of behavior to avoid or escape (but not intentional!)
- Specific phobias with a unique focus
- Anxiety linked to changes in routine
- Social anxiety in the absence of concern related to perceived scrutiny or negative evaluation by others



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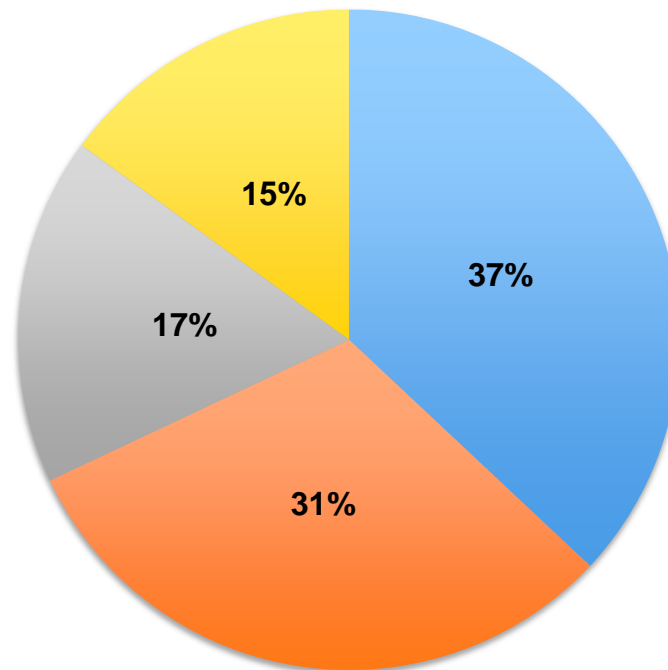


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Identifying signs of anxiety

Rates of autistic children with atypical vs. traditional anxiety diagnoses (Kerns et al., 2014)



■ No Anxiety ■ Traditional and atypical ■ Traditional ■ Atypical



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Identifying signs of anxiety

Interviews with 49 caregivers of children and adults with CdLS to identify prevalence of **subthreshold** symptomatology



91.8% showed symptomatology for one anxiety disorder
81.6% showed symptomatology for two anxiety disorders

Groves et al.
Journal of Neurodevelopmental Disorders (2022) 14:54
<https://doi.org/10.1186/s11689-022-09462-w>

Journal of
Neurodevelopmental Disorders

RESEARCH

Open Access



Divergent presentation of anxiety in high-risk groups within the intellectual disability population

Syndrome specific profiles of anxiety



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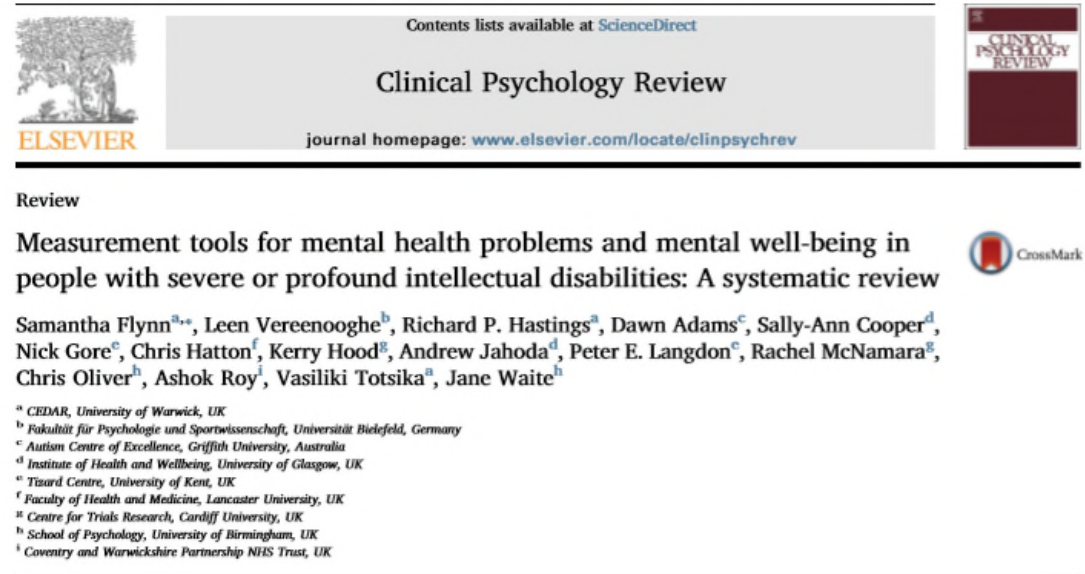
Identifying signs of psychological distress

Items from the SCARED

6. My child is scared when s(he) has to take a test..

4. My child complains of feeling

17. My child can't seem to get bad or silly thoughts out of his / her head



Parents are less likely to endorse items which require a child to verbally express anxiety (e.g. 'worries' or 'complains'; Hallett et al., 2013)



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Identifying signs of psychological distress

Understand presentation



Box 1: Signs of anxiety and fear

Changes to the body	Changes to thoughts/ thinking patterns	Changes to emotions	Changes to behaviour
<ul style="list-style-type: none">● fast and irregular heartbeat● sweating● tiredness● muscle tension● dizziness● trembling● pale complexion● stomach aches● nausea● difficulty falling asleep or staying asleep● startles more easily	<ul style="list-style-type: none">● inability to concentrate● repetitive thoughts about perceived threat● concerns about losing control● inability to relax	<ul style="list-style-type: none">● irritability● feeling worried● distress● crying/negative vocalisations	<ul style="list-style-type: none">● avoiding or hiding from objects or situations● fidgeting/moving more than usual/restlessness● fixed or 'frozen' to the spot● increased preference for routine● pacing● on the look out for danger

Identifying signs of psychological distress

Avoidance

“We don’t do that, sort of put him in a situation, because you just have to know that’s not going to be safe, so you know, you withdraw, you just don’t escalate these things. (Mother of 18-year-old male)”



Avoidance
due to
anxiety

Avoidance due to
sensory
processing
difference

“We’ve learnt our lesson now, when you go somewhere new for the first time, the second time you go, you try it on a different route, or you do something different. Because you’re almost setting yourself up to have problems in the future if you try to keep things the same. That’s one of the things I’ve learnt across the years. (Mother of 11-year-old male)”

Tarver et al., 2020; Edwards et al., 2022

Challenges during anxiety assessment: symptom overlap



“There’s rocking, a calm rocking, and then there’s a distressed rocking”

Parent of young autistic adult who uses few or no words



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Historical beliefs: barriers to support



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Identification



Support

Pain and discomfort

Sensory impairment or sensitivity

Anxiety and low mood

Sleep problems

Impulsivity and insistence on sameness

Social behaviour

Learned function

Communication

**Influence on
behaviour**

**Can be changed or
accommodated**

**Often missed or
neglected**

**Used by
parents/carers AND
clinicians**

The Be-Well Checklist

Helping parents, carers and professionals to reduce challenging behaviour and improve the wellbeing of people with severe learning disability and complex needs



Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., Pearson, E., Richards, C., Waite, J., Welham, A., Wilde, L., and Woodcock, K.

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Identification



On the horizon: A tool kit of support

Clinical Anxiety Screen for people with Severe to Profound Intellectual Disability (CIASP-ID)

34 item scale
Anxiety, low/withdrawn and pain

Launch Event

12. avoid (or try to avoid) certain objects or places?						
Almost never	Once a month	Less than once a week	Once or twice a week	At least 3-4 times per week	Every day	More than once a day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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What can we do to improve mental health?

Support

Psychological support is not just 'talking therapy'

Skills development (ways of coping a difficult situation)

Relaxation techniques

Graded exposure

Although Cognitive Behaviour Therapy may be appropriate for some people with ID



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Identification

Clinical Interviews and observations

Utilising Interview Methodology to Inform the Development of New Clinical Assessment Tools for Anxiety in Autistic Individuals Who Speak Few or no Words

[Georgina Edwards](#) , [Joanne Tarver](#), [Lauren Shelley](#), [Megan Bird](#), [Jessica Hughes](#), [Hayley Crawford](#) & [Jane Waite](#)



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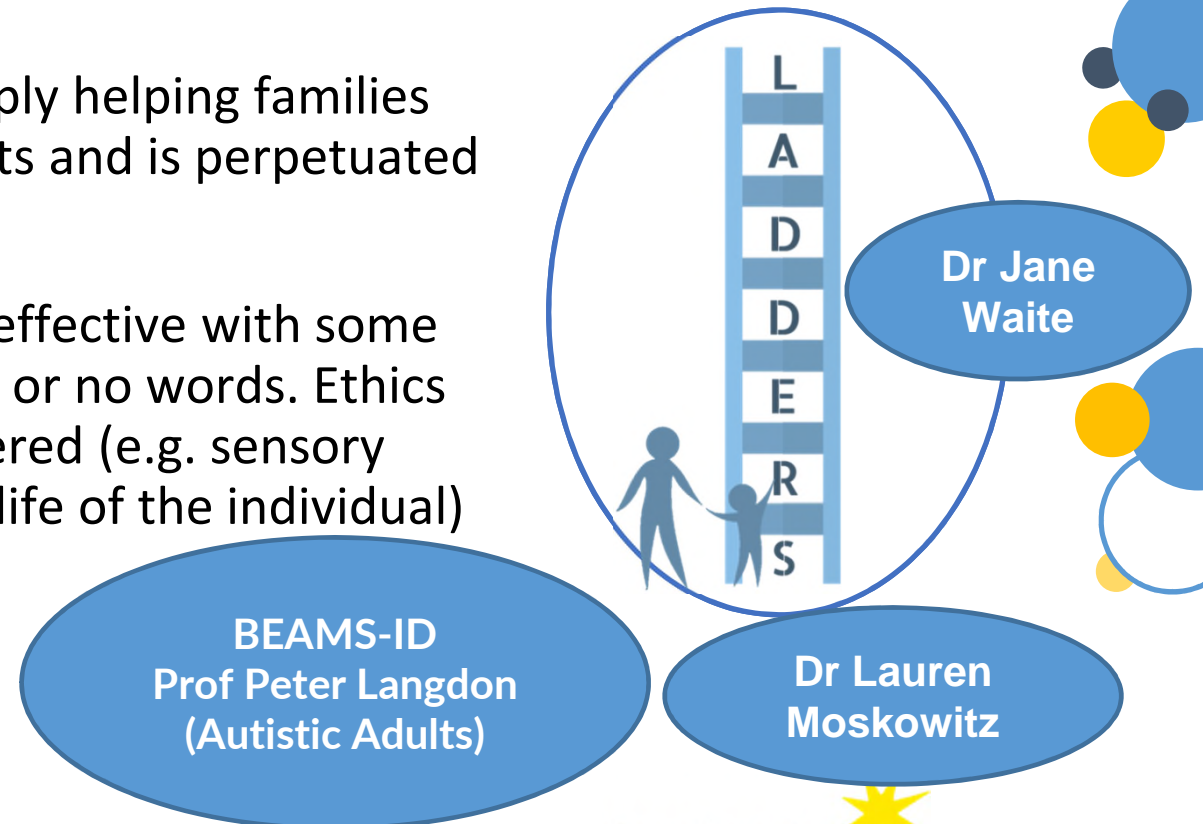
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What can we do to improve mental health?

Working with families is key – simply helping families understand how anxiety manifests and is perpetuated

Behavioural intervention appears effective with some autistic children who speak few or no words. Ethics needs to be carefully considered (e.g. sensory processing issues and quality of life of the individual)



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What can we do to improve mental health?



Increase controllability and choice!

Focus on communication

Give a choice

Choice Board

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What can we do to improve mental health?



Increasing certainty!

- Predictable routines
- Visual timetables
- Using a cue card when change occurs

All anxiety has an avoidance component. There is a balance between reducing anxiety and avoidance

Increasing tolerance to uncertainty (building skills!)

- Scheduling something unpredictable
- Introducing subtle changes
- Skills to cope with stress

What can we do to improve mental health?



Ensure that a person's sensory processing and health are considered.



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What can we do to improve mental health?

Support

Challenging behaviour can be an indicator of a mental health problem. Should people be turned away from mental health assessments because they are only present with 'behaviour'?

Coping well? Avoidance of anxiety provoking situations and triggers may not be a long term solution



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THANK YOU!

Any
Questions?



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