## challenging behaviour Asperger Syndrome mental capacity intellectual disabilities





23 October 2024

## **Studies**

quality of life

A Longitudinal Study of Aggression in People with Autism and Other Neurodevelopmental **Disabilities** 

Aggression is common in autism and neurodevelopmental disorders, but longitudinal research on aggression is lacking. We longitudinally tracked aggression in 254 individuals from toddlerhood to emerging adulthood.

Reflections on an Evidence Review Process to Inform the Co-Design of a Toolkit for Supporting End-of-Life Care Planning With People With Intellectual Disabilities

There is growing recognition that healthcare inequalities faced by people with intellectual disabilities extend to their experiences at the end of life, resulting in calls for more inclusive research to help address these inequities. Our study aimed to address this through the codesign of a toolkit for supporting end-of-life care planning with people with intellectual disabilities.

The Suicide Assessment Kit-Modified Interview: Development and preliminary validation of a modified clinical interview for the assessment of suicidal thoughts and behavior in autistic adults People with a diagnosis of autism are at increased risk of death by suicide. There is a need for clinical instruments that are adapted to the needs of autistic people. In this study, we modified and evaluated a clinical suicide interview (Suicide Assessment Kit-Modified Interview) for use with autistic people who do not have an intellectual disability. Autistic people helped us to modify the original version of the instrument by improving the questions, providing explanations for difficult terms or concepts, and recommending that we use different rating scales.

Unmet need for autism-aware care for gynaecological, menstrual and sexual wellbeing Autism can make menstruation and menopause and other aspects of reproductive and sexual health (RSH) more difficult. However, healthcare professionals (HCPs) often fail to provide autism-aware care, and often lack the skills or confidence to discuss RSH with patients. This study explored whether autistic people experience particular difficulties and have unmet needs when seeking RSH care.

A thin line between consent and abuse - Reflections on sexual experiences among Swedish young adults with intellectual disabilities

Research shows that young adults with intellectual disabilities struggle to understand the social codes embedded in sexual situations. This may lead to an incomprehension of sexual consent, or when consenting to sex may lead to abuse. This qualitative study aimed to gain an in-depth understanding of sexual experiences and perceptions about sexual consent among Swedish young adults with intellectual disabilities.

Effects of Mozart-Orff parent-child music therapy among mothers and their preschool children with autism spectrum disorder: A mixed-methods randomised controlled trial

Autism spectrum disorder (ASD) negatively impacts mental health, particularly in mothers of autistic children who experience heightened stress. Applied behaviour analysis (ABA) and music therapy are recognised interventions for improving ASD symptoms. However, the specific benefits of parent-child music therapy and ABA for autistic children and their mothers remain uncertain. This study evaluated the effects of parent-child music therapy on preschool autistic children and their mothers.











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# <u>Successful strategies for preventing and controlling violence against people with intellectual disabilities: a scoping review</u>

Violence against people with intellectual disabilities is unfortunately a reality all over the world, as they are one of the populations most vulnerable to various forms of aggression. Assertive prevention and control measures are crucial to tackle and reduce this problem. The aim of this study was to map and summarize the main measures for preventing and controlling domestic violence against people with intellectual disabilities.

#### How can we do authentic co-construction with autistic secondary pupils?

Co-constructed digital storytelling methods have the potential to provide authentic children's perspectives for planning health and education support. The Our Stories project investigated how this method can be applied with autistic children and young people (CYP).

# <u>The effectiveness of applied behavior analysis program training on enhancing autistic children's</u> emotional-social skills

This study focuses on the potential of Applied Behavior Analysis (ABA) to improve emotional and social skills in children with autism spectrum disorder. ABA is a well-established therapeutic approach that uses behavior modification techniques to encourage positive behaviors and reduce challenging ones. Despite its widespread use, further research is needed to better understand its specific impact on emotional and social development in autistic children.

#### Patterns of Brain Maturation in Autism and Their Molecular Associations

In the neurotypical brain, regions develop in coordinated patterns, providing a fundamental scaffold for brain function and behavior. Whether altered patterns contribute to clinical profiles in neurodevelopmental conditions, including autism, remains unclear.

# **Study Summaries**

Adolescents with disabilities at higher risk of self-harm, but intersectionality also a vital consideration

Self-harm is a global public health problem (Hawton et al., 2003). In England, approximately 200,000 adolescents aged 12 to 17 engage in self-harming behaviour every year without receiving clinical support and additionally, around 21,000 adolescents seek medical treatment following self-harm incidents (Geulayov, et al., 2018; Morgan et al., 2017; Patalay & Gage, 2019).

### **Webinars**

### <u>Upcoming webinar - Constipation: Unblocking the problem</u>

Constipation can be a major issue for people with learning disabilities, leading to further health complications and premature death. In this webinar we will hear from Tracy Pouard, a Learning Disability Nurse who has worked in this area for over 13 years, along with Mark Bowden and Shaun Harvey – two experts with lived experience – who have been working with Tracy to raise awareness and develop solutions for combatting constipation.

#### Upcoming webinar – UK PBS Alliance: How do we measure quality of life?

Quality of life improvements are the most important outcome of positive behaviour support (PBS), with 87% of respondents to a recent UK PBS Alliance survey saying that this was a key focus of their work. However, just 51% of respondents were measuring these improvements.











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### **News**

<u>Waiting times for assessment and support for autism, ADHD and other neurodevelopmental</u> conditions

In 2024, we would never imagine that children in this country are being told they cannot access their education because there is no suitable school for them. We would not expect that some children are non-verbal and wearing nappies well into the primary school years, because they haven't been able to get the help they needed sooner. It is unthinkable for parents to be told the only option for them is to sedate their distressed 3-year-old autistic child in hospital. In 2024, situations like these are happening every day in England.

<u>Thousands of children with neurodevelopmental conditions left without support due to long NHS</u> waits

New research shows that thousands of children with suspected neurodevelopmental conditions (such as ADHD, autism, cerebral palsy and learning disability) are waiting for years for an appointment following a referral, with some waiting for over four years for a diagnosis.

#### Number of autistic people in mental health hospitals: latest data

The latest monthly Assuring Transformation NHS Digital data shows that in September 2024:

- In total 2,020 autistic people and people with learning disabilities are in inpatient mental health hospitals in England
- 1,385 (69%) of these people are autistic
- There are 200 under 18s in inpatient units that are autistic or have a learning disability. Of these, 98% are autistic.

Law on disabled children's social care is outdated and unfair, Law Commission says

The Law Commission has launched a consultation on disabled children's social care law to ensure that it is fair, simple and meets the needs of disabled children and their families.

<u>Engagement report – for sight testing and dispensing of spectacles to SEND children and young people in a special educational setting across England</u>

NHS England undertook a period of engagement with patients, parents and carers, schools and the optical profession between 30 August 2023 and 16 October 2023 and the outputs of this engagement were published on the 30 August 2023. The report summarises the feedback received along with actions we will undertake. An easy read version of this document will be available shortly.

The National Autistic Society has responded to Kemi Badenoch's views on autism, as seen in the 'Conservatism in Crisis' pamphlet.

Mel Merritt, Head of Policy and Campaigns at the National Autistic Society, said: "Kemi Badenoch's comments and the statements in the 'Conservatism in Crisis' document are not only offensive to autistic people but detached from reality and demonstrate a fundamental lack of understanding of autism and disability."

Aspiration and specialist support are key to young disabled people thriving in the workplace

The Public Services Committee has published its report, 'Think Work First: the transition from education to work for young disabled people'. The report concludes that young disabled people yearn to work and to thrive in their careers but far too many are written off and told that 'people like them' can never succeed.











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#### Siblings of autistic children seven times more likely to be diagnosed with autism

Siblings of autistic children are seven times more likely to be autistic as well, which is 20% higher than the rate in infants with no autistic siblings, according to the findings of a recent large study.

#### Coroners' warnings must carry the force of law

Christine and Francis Saunders cannot know if improvements suggested by the coroner's inquest into the death of their daughter have been implemented.

#### Government launches national conversation to inform new 10 Year Health Plan

Today, the government announced the beginning of the biggest national conversation about the future of the NHS since its birth. The general public, NHS staff and experts are being invited to share their experiences, views and ideas for fixing the NHS with the responses used to shape the government's new 10 Year Health Plan, published in Spring 2025.

'Music, friendship, opportunity, freedom': the rise in clubs and gigs for neurodivergent people Autistic people and those with ADHD can feel stressed at regular gigs, prompting a wave of carefully tailored new events. But can they cater to incredibly diverse needs?

#### "I am proud to be black and I am proud to have a learning disability"

Aisha reflects on why diversity in the media is needed, some of the barriers she has had to overcome in her life and why she thinks Black History Month is so important...

#### "We are better together. We are stronger together"

In September, Jack and Kumudu visited Inclusion Europe in Brussels, Belgium. Here they talk about how it went...









