## challenging behaviour Asperger Syndrome mental capacity intellectual disabilities





8 May 2024

### **Studies**

quality of life

Trajectory of depressive symptoms over adolescence in autistic and neurotypical youth

Adolescence coincides with a dramatic rise in the onset of psychiatric conditions including depression. Depression symptoms may be particularly prevalent and impairing for youth with autism spectrum disorder (ASD). While prior research suggests adolescence is associated with worsening depression symptoms for typically developing (TD) and autistic youth, it is unclear if they follow a similar course.

The effect of individual and paired Brailletonik exercises on balance and reaction time in children with intellectual disability

Children with Intellectual Disabilities (ID) are less proficient in motor skills compared to normally developing children, which means they need more time for learning skills. In this context, the purpose of this research is to investigate the effect of the Brailletonik physical activity program (BPAM) on the balance and reaction time of children with ID.

#### Adapting the EQ-5D-3L for adults with mild to moderate learning disabilities

Approximately 1.5 million adults in the UK have a learning disability. The difference between age at death for this group and the general population is 26 years for females and 22 years for males. The NHS Long Term Plan (January 2019) recognises learning disabilities as a clinical priority area. People with a learning disability are often excluded from research by design or lack of reasonable adjustments, and self-reported health status/health-related quality of life questionnaires such as the EQ-5D are often not appropriate for this population. Here, we systematically examine the EQ-5D-3L (its wording, content, and format) using qualitative methods to inform the adaption of the measure for use with adults with mild to moderate learning disabilities.

Trainee advocacy for medical education on the care of people with intellectual and/or developmental disabilities: a sequential mixed methods analysis

Medical trainees (medical students, residents, and fellows) are playing an active role in the development of new curricular initiatives; however, examinations of their advocacy efforts are rarely reported. The purpose of this study was to understand the experiences of trainees advocating for improved medical education on the care of people with intellectual and/or developmental disabilities.

Research methods at the intersection of gender diversity and autism: A scoping review

Research has increasingly focused on the intersection between gender diversity and autism. Understanding the foci, methods, and rigor of recent studies could help guide and maximize impact in this accelerating research area. We conducted a scoping review of peer-reviewed literature on this topic published between 2018 and 2023.

<u>Identifying autistic children: Priorities for research arising from a systematic review of parents'</u> experiences of the assessment process

Our goal was to systematically identify, appraise and synthesise the qualitative research on parents' experiences of the autism assessment process. The empirical studies were quality appraised using the Critical Appraisal Skills Programme tool. We synthesised the data using a meta-synthesis approach. Parents' experiences were categorised into four phases namely: the pre-identification phase, the identification process, emotional reactions to the identification of the children as autistic and the post-identification phase.











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<u>Comparison of the efficacy of parent-mediated NDBIs on developmental skills in children with</u>
ASD and fidelity in parents: a systematic review and network meta-analysis

Recently, studies on behavioral interventions for autism have gained popularity. Naturalistic Developmental Behavior Interventions (NDBIs) are among the most effective, evidence-based, and widely used behavior interventions for autism. However, no research has been conducted on which of the several NDBI methods is most effective for parents and children with autism spectrum disorders. Therefore, we conducted a network meta-analysis to compare the specific effects of each type of parental-mediated NDBI on children's developmental skills and parent fidelity.

# **Study Summaries**

A triple empathy problem? Exploring barriers to accessing healthcare for autistic adults

Autism is a lifelong developmental disability which affects how people communicate and interact with the world (National Autistic Society, n.d.). Having autism is also associated with adverse health outcomes (Doherty et al., 2022), with the UK government finding a 16-year mean life expectancy reduction in autistic people (HM Government, 2021). A suggested reason for these adverse outcomes is barriers to healthcare for autistic people. Doherty et al. (2022) found that a third of autistic people reported not seeking medical treatment for a potentially life-threatening condition.

#### News

Missed target to reduce number of autistic people detained in mental health hospitals

The Government has failed to meet its own promise to reduce the number of autistic people and people with learning disabilities held in mental health hospitals, failing to address a major human rights crisis.

#### **Empowering Autistic Travel**

We are very excited to begin work on a year-long project, Empowering Autistic Travel, researching autistic people's experiences of travel and transport. We have ambitious plans to gain an in-depth understanding of the barriers that autistic people face, as well as exploring solutions for more comfortable and enjoyable journeys.

#### Consultation on changes to Personal Independence Payments (PIP)

The Government has released its consultation on changes to Personal Independence Payment (PIP) alongside a Green Paper setting out proposals for reform. Many autistic people depend on PIP to live full and dignified lives. The current system is not suitable for autistic people and needs reform, but a simple cost-cutting exercise will simply mean autistic people are let down.

#### "Horrifying" abuse uncovered at special school in Walthamstow

Staff caught on CCTV abusing children at a special school in Walthamstow have not been sacked, according to an investigation by BBC File on 4. Thirty-nine pupils were abused in so called 'calming rooms' by staff at one of the largest special schools in the UK between 2014 and 2017. Memory sticks storing the CCTV footage were discovered by new leadership at Whitefield school in 2021, prompting a police investigation.











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#### Relationships and sex: what does good support look like?

People with learning disabilities and autistic people want to have relationships and relationships are an important part of everyone's lives. However, institutional and attitudinal barriers may prevent them from exercising and enjoying this fundamental human right. In this article, Clinical Psychologists Dr Kelly Asagba and Dr Sophie Doswell discuss the factors that can help people with learning disabilities and autistic people develop positive relationships.

Netflix urged to take down "deeply irresponsible" documentary linking autism and gut health. The National Autistic Society has described a new Netflix documentary which links autism with gut health as "deeply irresponsible" and "offensive". Hack Your Health: The Secrets of Your Gut explores the link between the gut microbiome and your overall health and wellbeing, as well as how the gut and the brain are linked.

<u>'Things have gone backwards for parents with learning disabilities', says BASW officer</u>
Denise Monks's passion for social justice is evident not only in her work now as a professional officer at the British Association of Social Workers, but also her beginnings in the sector. While working at Stockport Council in 2002, just a few years after qualifying, she noticed a gap in support for parents with learning disabilities. So she created a specialist team to bridge it.

#### <u>Autism Alliance brings forward solutions for next Government</u>

Our new campaign, Doing the Right Thing, launched in April 2024 and looks ahead at what a new government could do now to improve the lives of autistic people and their families.

A Rep Body Statement on the Prime Minister's speech about PIP and 'Sick Note Culture' Last week Prime Minister Rishi Sunak said in a speech that the government will change the rules about who will decide if people cannot work because they are ill or disabled. He also said the government will look at how Personal Independence Payments work.

### Crowdsourcing to curb aggression in autism: Q&A with Matthew Goodwin

To accelerate the development of real-time behavioral prediction technology, a research team is sharing data and seeking new collaborators.

North West England train stations install information panels with Makaton symbols Information panels with Makaton symbols that promote walks, trails, cycle routes, nature reserves, and heritage attractions have been installed at six train stations across Cumbria in North West England.









