# Learning Disabilities and Autism Asperger Syndrome quality of life challenging behaviour research mental capacity health information intellectual disabilities research mental capacity health information carers



**15 November 2022** 

## **Studies**

### Predictability modulates neural response to eye contact in ASD

Deficits in establishing and maintaining eye-contact are early and persistent vulnerabilities of autism spectrum disorder (ASD), and the neural bases of these deficits remain elusive. A promising hypothesis is that social features of autism may reflect difficulties in making predictions about the social world under conditions of uncertainty. However, no research in ASD has examined how predictability impacts the neural processing of eye-contact in naturalistic interpersonal interactions.

## A study on prescriptions contributing to the risk of high anticholinergic burden in adults with intellectual disabilities: retrospective record linkage study

People with intellectual disabilities may face a disproportionate risk of experiencing high anticholinergic burden, and its negative sequalae, from a range of medications, and at younger ages than the general population, but there has been little previous study. Our aim was to determine the source of anticholinergic burden from prescribed medication.

## Thinking, fast and slow on the autism spectrum

The Dual Process Theory of Autism proposes that autistic individuals demonstrate greater deliberative (slower) processing alongside reduced (faster) intuitive processing. This study manipulated the reasoning time available to investigate the extent to which deliberative and intuitive processing are sensitive to time context in autism. A total of 74 young autistic people and 132 control participants completed the Cognitive Reflection Test to measure intuition and deliberation, with responses being either speeded (fast condition) or delayed (slow condition). The autistic group produced more deliberative and less intuitive responses than controls overall. Both groups showed more intuitive responses in the fast condition and more deliberative responses in the slow condition, demonstrating the reasoning style in autism is sensitive to context.

## A qualitative exploration of autistic mothers' experiences I: Pregnancy experiences

Pregnancy may pose a number of physical and healthcare-related challenges for autistic people, who experience differences in sensory processing and can face barriers to accessing healthcare. However, little research has explored autistic pregnancy experiences. Semi-structured interviews were conducted with 24 autistic and 21 non-autistic women during the third trimester of pregnancy.

#### Portrayals of autism in the British press: A corpus-based study

Press representations of autism and autistic people both reflect and help shape public attitudes towards autism and neurodiversity and may establish critical barriers to social integration for autistic individuals. This study examined such representations in UK newspapers in the period 2011–2020 using a corpus-based approach. It also considered how press representations changed over time and differed with regard to reporting style (tabloids vs broadsheets) and political orientation (left- vs right-leaning).

#### Sleep in Children with Autism Spectrum Disorder: A Narrative Review and Systematic Update

Sleep problems are a common comorbidity for children with autism spectrum disorder (ASD), and research in this area has a relatively long history. Within this review, we first outline historic patterns in the field of sleep and ASD. Second, we conducted a systematic update and coded these studies based on their alignment with historic patterns.

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## There and Back Again: Neuro-Diverse Employees, Liminality and Negative Capability

The workplace challenges faced by neuro-diverse employees are currently under-researched. This article considers how such employees experience the world of work, focusing on the demands they face to conform to established expectations around self-presentation and performance and how they utilise spatial resources in order to transcend them. Drawing on data generated from a series of in-depth interviews, it explores both their everyday experiences of frustration alongside how the mobilisation of liminal spaces can assist them in transitioning to and from the demands of the 'neuro-typical' workplace. The article seeks to contribute to an understanding of the lived experiences of neuro-diverse employees and how the design and practices of the workplace can contribute to feelings of marginalisation and even exclusion.

## <u>Sleep Problems Before and During the COVID-19 Pandemic in Children with Autism Spectrum</u> Disorder, Down Syndrome, and Typical Development

Sleep problems are common in children and adolescents, particularly those with Neurodevelopmental Disorders. With the changes in daily habits resulting from the COVID-19 pandemic, we have analyzed sleep characteristics, during social isolation, in Brazilian children and adolescents aged between 4 and 12 years with Autism Spectrum Disorder (N = 267), Down Syndrome (N = 74), and typical development (N = 312). The ASD group presented with worse indicators of sleep habits in the Children's Sleep Habits Questionnaire (CSHQ-BR) and fell asleep later during the pandemic. The entire group started fall asleep and waking up later during the pandemic - as well as waking up more often during the night. These results may contribute to parental guidance and sleep habit-related interventions during and after the COVID-19 pandemic.

## <u>Jugaling between caregiving and self-actualization: Older parents' lifelong experience of caring</u> for an adult child with developmental disabilities

Recently, the number of adults with Developmental Disabilities (DD) who live with their parents has increased. This study aims to explore how parents report retrospectively and interpret their experience in the context of self-actualization in the long-term care of a child with a developmental disability. Four forms of parents' experiences emerged from the analysis: "This child is my whole world"—Total devotion; "I Can Do Both"—Actualizing personal and familial goals as well as caregiving issues; "It's a mission, it's a calling, it's a full-time job"—Self-actualization through caregiving; and "Disability will not stop me"—Emphasizing self-actualization. While prior studies have created a distinct separation between caregiving and self-actualization, the current study focuses on the complex dynamics of lifelong parental caregiving for a child with DD, illustrating the parents' ways of actualizing their life goals in the context of caregiving over the years.

## Assessment of Chewing in Children With Down Syndrome

In the present study a comprehensive protocol to assess chewing in four children with Down syndrome is provided and described. One baseline and four assessment meals were conducted across four textures of foods to investigate the presence or absence of components of chewing (bite down, chew and tongue lateralization), as well as movements associated with the development of chewing. Results showed that at baseline all participants ate their typical diet (i.e., pureed food) but no chewing components or movements were observed.

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**15 November 2022** 

## **Reports**

Who I Am Matters - Experiences of being in hospital for people with a learning disability and autistic people

This report looks what people with a learning disability and autistic people experience when they need physical health care and treatment in hospital.

## Legislation

Mental Capacity Act 2005 at a glance

This at a glance summary presents an overview of the Mental Capacity Act (MCA) 2005, which is important to health and social care practice.

## Framework

<u>National framework for NHS continuing healthcare and NHS-funded nursing care (easy read)</u>
Easy read version of the national framework for NHS continuing healthcare and NHS-funded nursing care.

## Guidance

New care home guidance to better support people with a learning disability and dementia

The Care Inspectorate and Healthcare Improvement Scotland (HIS) has developed new guidance to ensure care homes provide the right support for people with a learning disability and dementia.

The guidance, which is thought to be the first of its kind, focuses on people with a learning disability and advancing dementia who can no longer be cared for in their own home due to increased needs.

Learning Disability and Autism Community Discharge Grant 2020 to 2023

Information for local authorities in England about the Community Discharge Grant, to help address double running costs in 2020 to 2023.

## Strategy

Read the Allied Health Professions strategy for England: AHPs Deliver – Easy read version

This new strategy is for the whole Allied Health Profession (AHP) community: support workers, assistant practitioners, registered professionals, pre-registration apprentices and students. It is inclusive and reflects how AHPs work in multidisciplinary teams, so that those who identify as part of the AHP community working in a variety of health and care sectors can use it to continually improve and redesign services.

## News

Employment and contribution

People have told us that employment and contribution are one of the most important things that help them to be able to lead a good life.

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### The Oliver McGowan Mandatory Training on Learning Disability and Autism

In July the Health and Care Act 2022 introduced a requirement that regulated service providers ensure their staff receive training on learning disability and autism which is appropriate to the person's role.

The Oliver McGowan Mandatory Training on Learning Disability and Autism is the standardised training that was developed for this purpose and is the government's preferred training for health and social care staff to undertake. It is named after Oliver McGowan, whose death shone a light on the need for health and social care staff to have better training. It is the only training with permission to include Paula McGowan OBE, telling Oliver's story and explaining why the training is taking place.

## Special report: The new history of autism

The history of science has long overlooked contributions from underrepresented groups — and the history of autism research is no exception. For 40 years, virtually every story about the field's origins has starred Leo Kanner and Hans Asperger, who are credited with writing, in 1943 and 1944, respectively, the earliest accounts of autism as a distinct diagnosis.

More recently, however, historians have begun to excavate the work of several women and Jewish clinicians that enabled, and in at least one case, predated, Kanner and Asperger's famous descriptions. In "The new history of autism" — broken into three parts here and published sequentially on Monday, Wednesday and Friday this week — journalist David Dobbs tells the stories of these forgotten scientists in detail.

#### Community Newsletter: A profound discussion on autism labels

Every so often, discussion of a controversial topic dominates our feed. For this week's Community Newsletter, we focus on the discourse around an opinion piece Spectrum published last week: It's time to embrace 'profound autism' by Alison Singer, president of Autism Science Foundation (ASF).

### Psychiatric conditions hospitalize almost one in three autistic women by age 25

EDITOR'S NOTE: This article was originally published in May 2022 as a conference report from the International Society for Autism Research annual meeting. We have updated the article to reflect new data published in JAMA Psychiatry in October 2022.

About 32 percent of autistic women are hospitalized for a psychiatric condition by age 25, a fraction six times higher than for women without autism and nearly twice that of autistic men.

## NICE and health inequalities

Health inequalities are differences in health across the population, and between different groups in society, that are systematic, unfair and avoidable. They are caused by the conditions in which we are born, live, work and grow. These conditions influence our opportunities for good mental and physical health.

#### Lags in genetic testing, variant reporting hinder autism research

Only about a quarter of autistic people undergo genetic testing — even though such testing can guide medical care and multiple organizations encourage it. The reasons why, an unpublished survey finds, include insurance issues, parental concerns about stigma, and health-care providers' own misconceptions about genetic testing, along with their fears of long waitlists.

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### A mix of common and rare variants shapes autism inheritance patterns

Autism's heritability in families stems from a combination of both common and rare inherited variants that team up to hit a threshold in some people, according to an unpublished study.

## Support providers for people with a learning disability at financial 'tipping point'

People with learning disabilities and autism are being denied their right to decent, fulfilling, and stable care, according to a new report from learning disability and autism social care providers. The financial impact report, commissioned by a group of providers of services for adults with a learning disability and autistic people, revealed that organisations are reaching a financial tipping point.

## New collaborative in Leicestershire aims to address health inequalities for people with a learning disability

A collaborative approach to address health inequalities and transform the lives of people with learning disabilities and/or autism across Leicestershire has been formally agreed.

The LDA Collaborative, led by Leicestershire Partnership NHS Trust (LPT) with Leicester, Leicestershire and Rutland Integrated Care Board (ICB), will combine the work of local authorities, NHS providers and commissioners into one virtual team.

## Just over half of people receiving care had review of support plan in past year, shows official data

Just over half of people receiving council-arranged long-term care had a review of their support plans in 2021-22, official figures have shown. NHS Digital said 55.2% per cent of people who had been receiving long-term support for more than a year were reviewed in 2021-22, down from 58.4% in 2020-21.

## Joint Committee investigates impact of draft Mental Health Bill on children and young people, and people with learning disabilities or autism

The Joint Committee continues its scrutiny of the draft Mental Health Bill, which proposes removing learning disabilities and autism as conditions which can justify long term civil detention in inpatient care (if the person is suffering no concurrent mental health conditions.) On Wednesday 9 November, the committee will question clinicians and experts on whether this is likely to improve the treatment of people with autism and learning disabilities.

## Now I Know

Autistic women and non-binary people are everywhere. Many go through life without knowing they are autistic. In this campaign, we hear six of their stories, in their words.

The Now I Know campaign features powerful photography and films of both autistic women and non-binary people from across the country, who share their experiences of late diagnosis of autism. The campaign was inspired by the words of Dawn Mills, who was diagnosed at the age of 56 and features in the campaign. She said: "I always knew who I was, now I know why I am."