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20 May 2025

Studies

quality of life

Approaches used to prevent and reduce the use of restrictive practices on adults with learning disabilities: a realist review

This study aimed to understand how, why, for whom, and under what circumstances approaches used by healthcare staff to prevent and reduce the use of restrictive practices on adults with learning disability or autism work (or do not work).

Nonfatal injury emergency department visits and inpatient hospitalizations among persons under age 65 with an intellectual and developmental disability or deaf or hard of hearing disability

Vulnerable populations at risk of injury include persons with intellectual and developmental disabilities (IDD), and persons who are deaf or hard of hearing (DHH). The purpose of this study was to describe and compare emergency department and inpatient hospitalization (ED + IP) injury rates and rate ratios by injury type among persons under age 65 with IDD or with DHH to those without IDD or DHH.

Disease and mortality trajectories of cognitively able autistic individuals in mid- and later adulthood

An increasing number of autistic adults have entered their later life, but little is known about the disease trajectory in mid- and later adulthood. We aimed to examine the patterns of comorbidity progression in adults with autism spectrum disorder (ASD) that may affect their mortality.

Allyship in Healthcare for People With Learning Disabilities as a Praxis of Respect, Attention and Collaborative Action

There is a dearth of literature focusing on how allyship in health may be enacted in relation to people with learning disabilities (LD). This is concerning, because people with LD are vulnerable to health inequalities and forms of medical dehumanisation including do-not-resuscitate orders, diagnostic overshadowing and overprescription of psychotropic drugs. Deploying critical disability studies as a lens through which to understand disability, this paper reviews models of disability allyship developed in healthcare, research and theatre. In doing so it advocates transformative allyship as a model that can both animate action in support of people with learning disabilities and accommodate the involvement of others, including clinicians, carers and relatives, without compromising the all-important commitment to supporting disability cultures.

Choroidal and retinal vascular changes in adults with Down syndrome: Insights into the Alzheimer's disease continuum

Retinal and choroidal vascular changes have been proposed as a non-invasive central nervous system (CNS) proxy for clinical trials in Alzheimer's disease (AD). However, their role in Down syndrome (DS), the largest genetically predisposed group for AD, remains unclear.

Narrative identity differences in autism

Autism is characterized by a modification of the sense of self, particularly self-continuity. While former studies focused on the recollection and narrative of single past events, the present study aimed to explore autistic individuals' narrative identity by assessing for the first time their life story, described as the most integrated form of personal narrative and the closest to the self.











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The Alzheimer's Biomarker Consortium–Down Syndrome (ABC-DS): A 10-year report

Virtually all adults with Down syndrome (DS) will accumulate the neuropathologies associated with Alzheimer's disease (AD) by age 40, with the majority having a clinical dementia diagnosis by their middle 50s.

Visual feedback and motor memory contributions to sustained motor control deficits in autism spectrum disorder across childhood and into adulthood

Autistic individuals show deficits in sustained fine motor control which are associated with an over-reliance on visual feedback. Motor memory deficits also have been reported during sustained fine motor control in autism spectrum disorders (ASD). The development of motor memory and visuomotor feedback processes contributing to sustained motor control issues in ASD are not known.

Impact of ASD and ADHD on pediatric asthma exacerbations: a retrospective analysis of the Nationwide Inpatient Sample 2005–2020

Background: To explore the impact of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) on in-hospital outcomes in children hospitalized for asthma exacerbations.

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A cross-cultural examination of bi-directional mentalising in autistic and non-autistic adults

So-called 'mismatch accounts' propose that, rather than arising from a socio-cognitive deficit present in autistic people, mentalising difficulties are the product of a mismatch in neurotype between interaction partners. Although this idea has grown in popularity over recent years, there is currently only limited empirical evidence to support mismatch theories. Moreover, the social model of disability such theories are grounded in demands a culturally situated view of social interaction, yet research on mentalising and/or autism is largely biased towards Western countries, with little knowledge on how successful mentalising is defined differently, and how tools to assess socio-cognitive ability compare, across cultures.

Brain Morphometry in Infants Later Diagnosed With Autism is Related to Later Language Skills Autism spectrum disorder (ASD) presents early in life with distinct social and language differences. This study explores the association between infant brain morphometry and language abilities using an infant-sibling design.

Guidance

Care workforce pathway for adult social care (easy read)

The first booklet on this page tells you what people working in care need so they can do this important work. The next 8 booklets tell you about each of the job groups in adult social care.











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20 May 2025

Reports

Review into the operational effectiveness of the Care Quality Commission (easy read) Easy read of the final findings and recommendations of the review into the operational effectiveness of the Care Quality Commission.

News

Autism assessment waiting times

As of December 2024, 224,382 people were waiting for an autism assessment in England, latest NHS data has revealed.

Social ability stereotypes about autistic people challenged in new study

The stereotype that autistic people lack social ability has been challenged in a new study from the University of Edinburgh, which found no significant difference in the effectiveness of how autistic and non-autistic people communicate.

Everyone isn't 'a little bit autistic' – here's why this notion is harmful

I recently had a medical appointment and explained that I'm autistic. It affects how I communicate and understand information, and sometimes I'm misinterpreted as being rude. The person nodded and replied: "Well, everyone's a little bit autistic." They then shared something they struggle with, sometimes, when they haven't had enough sleep.

Mental Health Bill reforms welcome but should go further – JCHR finds

In a report published today following legislative scrutiny, the Joint Committee on Human Rights proposed amendments to the Mental Health Bill.

Our response to the Work and Pensions Committee report calling for greater protections for vulnerable benefit claimants

Tim Nicholls, Assistant Director of Policy, Research and Strategy at the National Autistic Society, said: "We welcome the Work and Pensions Committee Report's recommendations to make the department safer, more transparent, and more accountable. But there is a very long way to go.

'In our Words' - Celebrating our charity's sixty years and the story of autism in the UK

We are delighted to announce that the National Autistic Society's new online archive, <u>In our Words</u> is officially published. It is the culmination of a two-year project to gather, curate, and archive the rich history of our charity, and to reflect the changing attitudes and public perspectives of autism over the last 60 years.

Inside Our ADHD Minds review - Chris Packham's revelatory show couldn't be more crucial

Packham refutes harmful anti-woke ideas about the overdiagnosis of neurodiversity by meeting people like Henry, who finds day-to-day life a severe struggle, and Jo, who has spent years constantly being told she's 'too much'.

How pragmatism and passion drive Fred Volkmar—even after retirement

Whether looking back at his career highlights or forward to his latest projects, the psychiatrist is committed to supporting autistic people at every age.











Learning Disabilities and Autism Asperger Syndrome quality of life research mental capacity intellectual disabilities research mental capacity intellectual disabilities



20 May 2025

MPs attend Understanding Autism Sessions for World Autism Acceptance Month

On the 24th April and 1st May, the National Autistic Society hosted Understanding Autism sessions for Members of Parliament as part of our World Autism Acceptance Month campaign, It's How You Show Up. Over two sessions, nine MPs received an introduction to autism, the challenges autistic people face, and how to show up for their autistic constituents.

The Down Syndrome Act – Update from member representatives

The Down Syndrome Act became law in 2022 – you can more about the act and watch some films made by the Down Syndrome Association here.

The Independent Commission into Social Care led by Baroness Casey

At the beginning of May, the government announced how the Social Care Commission will work – they shared the Terms of Reference. These say what the commission will work on and the deadlines for doing its work.

The reassuringly expensive burden of regulation.

Tim Keilty, one of the elected member representatives talks about his experience of monitoring working in a support provider organisation.

RFK Jr's autism comments place blame and shift research responsibility to parents, critics say

Robert F Kennedy Jr, the US health secretary, has intimated that parents are to blame for their children's autism, and that they are responsible for researching every aspect of their children's lives that could affect their development.

<u>Documentary or reality TV? Love on the Spectrum stars say show's shift means cast should be</u>

Ruth and Thomas Wyndham did not want payment for appearing in a TV doco – but now it's an international hit, they question how well participants are being supported.

Chris Gathercole obituary

My father, Chris Gathercole, who has died aged 87, was a pioneering clinical psychologist. He was an advocate for people with learning disabilities being involved in decisions about themselves and for them to be independent.









