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





25 September 2024

Reports

<u>Independent investigation of the NHS in England: Lord Darzi's report on the state of the National Health Service in England</u>

In July 2024, the Secretary of State for Health and Social Care commissioned Lord Darzi to conduct an immediate and independent investigation of the NHS.

Lord Darzi's report provides an expert understanding of the current performance of the NHS across England and the challenges facing the healthcare system. Lord Darzi has considered the available data and intelligence to assess:

- patient access to healthcare
- the quality of healthcare being provided
- the overall performance of the health system

Studies

<u>Post-diagnostic support for adults diagnosed with autism in adulthood in the UK: A systematic review with narrative synthesis</u>

More adults than ever before are seeking an autism diagnosis in adulthood. While receiving a diagnosis may be beneficial, many autistic people struggle to navigate their new diagnosis, and require support. This study conducted a systematic review of previous research on the support available after diagnosis (post-diagnostic support) for autistic adults without intellectual disability who were diagnosed in adulthood in the UK.

The experiences of autistic adults who were previously diagnosed with borderline or emotionally unstable personality disorder: A phenomenological study

An increasing number of studies are investigating the links between autism and borderline personality disorder. Studies report overlapping differences and the challenges in differentiating between these two diagnostic labels. In practice, there are many people, especially autistic women, who feel that they were misdiagnosed with borderline personality disorder. This study aimed to explore the experiences of autistic adults who were previously diagnosed with borderline personality disorder.

Short report: Prison-reported rates of autism in female prisons in England

Research suggests that whilst not more likely to offend, autistic people are overrepresented within the Criminal Justice System. To date, prevalence estimates are available only for male autistic offenders. Thus, this research aimed to provide the prison-reported rate of autistic female prisoners currently residing in the female prison estate in England.

<u>Insistence on sameness, repetitive negative thinking and mental health in autistic and non-</u>autistic adults

Autistic people are more likely to have mental health problems than non-autistic people. We know that having repetitive and negative thoughts can contribute to multiple mental health problems such as depression and obsessive-compulsive disorder. Autistic people often do the same behaviours repetitively, and they may also have more repetitive thinking styles. This could contribute to higher rates of mental health problems in autistic people. In this research, we wanted to find out if higher rates of repetitive behaviours contributed to depression and anxiety, and whether this relationship was because of repetitive negative thinking.











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Barriers to healthcare predict reduced health-related quality of life in autistic adults without intellectual disability

Autistic adults frequently show increased physical or mental health conditions and impairments in social, occupational, and other life domains. Accordingly, they often report reduced healthrelated quality of life. Yet, numerous barriers prevent effective healthcare for autistic adults. To date, the impact of healthcare barriers on health-related quality of life in autism has not been investigated. We, thus, sought to investigate the health-related quality of life of autistic adults without intellectual disability in Germany and analyze previously reported and novel predictors of health-related quality of life including healthcare barriers using multiple linear regression.

Learning for life, friendships and relationships from the perspective of children and young people with intellectual disabilities: findings from a UK wide qualitative study

Relationships and sexuality education (RSE) programmes are widely taught in schools, however for children and young people with intellectual disabilities, these programmes appear to be limited regarding information on relationships, informed choices and decision making. The purpose of this study was to seek the views and understanding of children and young people with intellectual disabilities, and those involved in their care and education, to identify best practice and approaches to the delivery on relationships and sexuality education.

Awareness of down syndrome screening among educated Muslim women is associated with a favorable attitude toward testina

There is a general assumption that Muslim women refuse Down syndrome screening, and therefore, many health practitioners do not offer it or briefly discuss it with their participants. This study aims to objectively assess women's awareness, knowledge, and attitudes toward Down Syndrome screening (D.S.S) in a Muslim-majority population.

Comparing eating and mealtime experiences in families of children with autism, attention deficit hyperactivity disorder and dual diagnosis

Children with neurodevelopmental conditions like autism and attention deficit hyperactivity disorder may experience eating difficulties and related health issues later in life. Sharing family meals can help prevent these issues developing, but most studies have looked at families with neurotypical children. Our goal was to learn more about how families of children with autism, attention deficit hyperactivity disorder and both conditions (autism + attention deficit hyperactivity disorder) experience mealtimes.

Community views of neurodiversity, models of disability and autism intervention: Mixed methods reveal shared goals and key tensions

Controversies regarding the neurodiversity movement may be exacerbated by confusion over its meaning. For example, some suggest neurodiversity entails acceptance of the social model, whereas others describe it as more nuanced.

Contracted functional connectivity profiles in autism

Autism spectrum disorder (ASD) is a neurodevelopmental condition that is associated with atypical brain network organization, with prior work suggesting differential connectivity alterations with respect to functional connection length. Here, we tested whether functional connectopathy in ASD specifically relates to disruptions in long-relative to short-range functional connections. Our approach combined functional connectomics with geodesic distance mapping, and we studied associations to macroscale networks, microarchitectural patterns, as well as socio-demographic and clinical phenotypes.











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Alzheimer Dementia Among Individuals With Down Syndrome

With the advancement in administrative data as a research tool and the reliance on public health insurance for individuals with Down syndrome, population-level trends in Alzheimer dementia in this population are beginning to be understood.

The relationship between interpersonal distance preference and estimation accuracy in autism People naturally seek an interpersonal distance that feels comfortable, striking a balance between not being too close or too far from others until reaching a state of equilibrium. Previous studies on interpersonal distance preferences among autistic individuals have yielded

<u>Prenatal environmental risk factors for autism spectrum disorder and their potential mechanisms</u> Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is globally increasing in prevalence. The rise of ASD can be partially attributed to diagnostic expansion and advocacy efforts; however, the interplay between genetic predisposition and modern environmental exposures is likely driving a true increase in incidence. A range of evidence indicates that prenatal exposures are critical. Infection during pregnancy, gestational diabetes, and maternal obesity are established risk factors for ASD. Emerging areas of research include the effects of maternal use of selective serotonin reuptake inhibitors, antibiotics, and exposure to toxicants during pregnancy on brain development and subsequent ASD. The underlying pathways of these risk factors remain uncertain, with varying levels of evidence implicating immune dysregulation, mitochondrial dysfunction, oxidative stress, gut microbiome alterations, and hormonal disruptions.

The development, feasibility and acceptability of Empower-Autism: A new psychoeducational and psychotherapeutic programme for caregivers of children recently diagnosed with autism Caregivers can experience significant challenges following their child's autism diagnosis and often seek informational, relational and emotional support. Post-diagnostic support for caregivers has received relatively little research attention and represents a significant gap in the international evidence base.

Exploring Adaptive Virtual Reality Systems Used in Interventions for Children With Autism Spectrum Disorder: Systematic Review

Adaptive systems serve to personalize interventions or training based on the user's needs and performance. The adaptation techniques rely on an underlying engine responsible for processing incoming data and generating tailored responses. Adaptive virtual reality (VR) systems have proven to be efficient in data monitoring and manipulation, as well as in their ability to transfer learning outcomes to the real world. In recent years, there has been significant interest in applying these systems to improve deficits associated with autism spectrum disorder (ASD). This is driven by the heterogeneity of symptoms among the population affected, highlighting the need for early customized interventions that target each individual's specific symptom configuration.

News

Midwives lack specialist training for women with learning disabilities

Midwives feel inadequately prepared to support women with learning disabilities because they lack specialist training and require additional support in health education and communication skills, according to new research.











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Children with SEN five times more likely to be permanently excluded from school

Children with school-identified special educational needs (SEN) are five times more likely to be permanently excluded from school than their peers without SEN, new analysis has found.

Two in five parents of children with SEND forced to give up work

Two in five parents of children with special education needs and disabilities (SEND) are being forced to give up their jobs due to a lack of support, according to new research from the charity Support SEND Kids.

Helping to create autism-inclusive workplaces

Our charity has launched a new award to help organisations create more inclusive, understanding and supportive workplaces for autistic employees. The Autism Inclusive Employer Award aims to increase autism understanding, support the needs of autistic staff and enable more autistic people to feel comfortable at work.

Budget 2024: submission from national autism organisations

The Autism Alliance UK, National Autistic Society, Autistica and Ambitious about Autism have made a submission to the 2024 Budget process led by the Treasury.

NHS England and DanceSyndrome collaborate to promote learning disability nurses

DanceSyndrome, an inclusive dance charity based in Lancashire, and NHS England have partnered up to launch a new film series encouraging people to consider a career in learning disability nursing.

Autism is more heritable in boys than in girls

If boys have greater inherited liability for autism, the female protective effect may not fully explain the sex difference in prevalence.









